The Pathway Research for Eye Care in Stroke (PRECiS) Study

IMPROVING VISUAL REHABILITATION FOR STROKE SURVIVORS

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Thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy

Discipline of Orthoptics
Graduate School of Health
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CERTIFICATE OF ORIGINAL AUTHORSHIP

I, Shanelle Sorbello, declare that this thesis is submitted in fulfilment of the requirements for the award of Doctor of Philosophy, in the Graduate School of Health at the University of Technology Sydney.

This thesis is wholly my own work unless otherwise referenced or acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

This document has not been submitted for qualifications at any other academic institution.

This research is supported by the Australian Government Research Training Program.

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THESIS FORMAT & OVERVIEW

This is a thesis by compilation, whereby the contents are a combination of both conventional thesis chapters and manuscripts that have been published or are intended for publication. An overview of the thesis chapters and their contents is provided below.

Chapter 1 – Introduction: Post-stroke vision impairment and provision of care in Australia

Chapter One provides an introduction to the topic of post-stroke vision care in the context of Australian healthcare. It provides an overview of the relevant information pertaining to stroke care within Australia, the complexities involved in vision care provision for Australian stroke survivors, and the unique setting in which this research has taken place. Chapter One also outlines why this is an important area of research in relation to the impact of vision impairment on stroke survivors and the broader community.

Chapter 2 – Stroke related visual conditions: A narrative review

Chapter Two is a comprehensive overview of the various vision and eye conditions that can result as a consequence of stroke, as well as those likely to be present in older Australians who are most at risk of stroke. This information is necessary in understanding the breadth and complexity of visual disorders occurring within this population, and hence the challenges involved in their identification and management. In doing so, this chapter provides the necessary context for understanding the chosen research methods and results.

Chapter 3 – Meeting the need for post-stroke vision care: A scoping narrative review of current practice

A scoping review of the available evidence was conducted to identify and describe the evidence available pertaining to post-stroke vision care provision in Australia and countries with similar healthcare systems. This was necessary to provide a foundation for this research by outlining post-stroke vision care practices and pathways currently in use, as well as identifying potential barriers and unmet care needs within this are of care provision. This chapter relates to the 'screening' phase described in Vanhaecht's method for care pathway development, as it confirmed the presence of a large gap in this area of stroke care and hence the need for a change in practice relating to post-stroke vision care in Australia.

Chapter 4 – Determining current post-stroke vision care pathways & practices in NSW: Methodology for Stage One

This chapter outlines the methodology used in the first stage of the PRECiS study, whereby quantitative and qualitative methods were employed in a exploratory study of post-stroke vision care practices and pathways in NSW. An explanation and justification of study design and data collection tools is provided in the context of Vanhaecht's seven phase method for care pathway development that was used to inform this research.

Chapter 5 – Determining post-stroke vision care pathways & practices in NSW: A feasibility study of two surveys

This chapter describes the methodology and results of a small feasibility study conducted after the initial development of the Stroke Survivor Survey and the Health Professional Survey intended for use in stage one of the PRECiS Study. A feasibility study was deemed necessary to ensure that the surveys were designed in such a way that all relevant data could be collected, while ensuring the surveys were accessible to the target populations and the burden of participation was minimised.

Chapter 6 – Describing existing post-stroke vision care in NSW: Survey Results

This chapter outlines the results of the quantitative component of stage one, being the Stroke Survivor Survey and Health Professional Survey. The results provide an overview of the current vision care practices and pathways from the perspectives of stroke health professionals and stroke survivors in NSW. Discussion of these results in relation to the existing evidence base and the implications for care pathway development is also provided. These results, together with the results outlined in chapter seven, relate to the 'diagnostic and objectification' phase of Vanhaecht's method whereby key stakeholders were engaged in the evaluation of current care practices.

Chapter 7 – The experience of vision impairment among stroke survivors in NSW: Interview Results

Chapter seven relates to the results of the qualitative aspect of stage one, being the stroke survivor interviews. These results provide greater insight into the experience and challenges of Australian stroke survivors with vision impairment during their stroke recovery journey. Discussion of these results in relation to the results of the surveys, and the existing evidence base collectively, is also provided.

Chapter 8 – Development of a post-stroke vision care framework for use in NSW (Stage Two): Methodology

This chapter outlines the methodology used in stage two of the PRECiS Study, relating to Vanhaecht's 'development' phase. The RAND/UCLA Appropriateness Method was modified and utilised to develop and form consensus on a Post-stroke Vision Care Framework. The initial framework development was informed by the results of stage one, as well as the existing evidence base. The methodology described explains how this evidence was combined with the clinical expertise of vision and stroke health professionals to produce a final framework that addresses the barriers and unmet care needs previously identified in stage one.

Chapter 9 – Development of a NSW post-stroke vision care framework: Results

Chapter nine describes the results of stage two, whereby the NSW Post-stroke Vision Care Framework was developed and finalised through several rounds of evaluation. The final framework is comprised of a set of best practice statements and a care pathway that address the pitfalls of current post-stroke vision care provision and were deemed appropriate for use in NSW. Discussion of these results in relation to the existing evidence base and overall context of Australian stroke care is also provided.

Chapter 10 – Summary and conclusions

This chapter provides a summary of the findings of the PRECiS Study across both stages, the strengths and limitations of this study as well as potential directions for future research in this area of stroke and vision care. Discussion of the study results and outputs in relation to relevant literature both in an Australian and global context is also provided.

STATEMENT OF CONTRIBUTION

Statement of Contribution for Thesis by Compilation

Contributor	Statement of contribution
Shanelle Sorbello	Wrote thesis manuscript. ***PRECiS: Stage One*** – literature reviews (Chapters 1, 2 and 3), survey design (stroke survivor survey, health professional survey, REDCap build), interview schedule design, participant recruitment, conducted feasibility study, conducted interviews, transcription of interviews, and data analysis (qualitative and quantitative). ***PRECiS: Stage Two*** – experimental design, design of surveys and REDCap build (including development of original best practice statements and care pathway), conducted panel meeting (focus group), conducted interviews, transcribed panel meeting and interviews, and data analysis (qualitative and quantitative).
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Date	26/07/23
Prof. Kathryn Rose	Aided experimental design, thesis manuscript refinement and editing.
Dr Amanda French	Aided experimental design, PRECiS: Stage One survey data analysis, PRECiS: Stage One interview data coding review (first five interviews), PRECiS: Stage Two panel meeting support and minutes, thesis manuscript refinement.
Prof. Fiona Rowe	Aided experimental design, thesis manuscript refinement.
Sonia Lau	Secondary review of abstracts for inclusion in Chapter 3 literature review.

Principal Supervisor Confirmation

I have sighted email or other correspondence from all contributors and/or co-authors confirming their contribution.

Professor Kathryn Rose	Production Note: Signature removed prior to publication.	21/08/2023
Name	Signature	Date

STATEMENT ON THE IMPACT OF COVID-19 ON THIS PROJECT

The onset of the COVID-19 pandemic caused significant disruption to recruitment and data collection during this project. The initial onset of the pandemic affecting NSW in early 2020, occurred during recruitment and data collection of Stage One of the PRECiS Study. The resultant physical distancing and 'stay at home' public health orders, reduced accessibility to the target populations (stroke survivors and stroke health professionals), as face-to-face recruitment opportunities such as hospital visits, stroke support groups and conferences were cancelled or restricted. Recruitment strategies were altered to utilise online mediums and platforms (online forums, social media, virtual meetings and conferences) to access these populations. However, due to the increased time and psychological burden on health professionals during this period, and the increased stress experienced by at-risk-populations, such as the elderly and those with chronic illness, those within our target populations were less likely to participate in research studies, and hence we were unable to meet our initial recruitment targets for this stage.

In a similar way, Stage Two of the PRECiS Study was impacted by the spread of the Delta-variant in NSW in 2021 and resultant lockdowns. While we were fortunately able to recruit the desired number of health professionals for this stage, data collection methods had to be planned to facilitate participation from home e.g. online survey rounds and video-conference meetings/ interviews. As data collection occurred over several rounds in Stage Two, we experienced a significant drop-out rate when moving through each round. It is likely to be attributable in part, to the increased pressure and time demands placed on healthcare professionals working in hospitals and other care facilities at this time. It should also be noted that the onset of the pandemic resulted in many changes to healthcare practices within all types of care facilities, and hence changed the way in which elements of the NSW Post-stroke vision care framework were reviewed and discussed in Stage Two. For example, healthcare facilities in NSW during this time often had significant staff shortages, reduced patient capacity, and restrictions on external visitors into facilities (including visiting allied health and support services). There was also a significant increase in the use of telehealth and online healthcare delivery modes during this time. The resultant framework was developed in consideration of these changes and is representative of a new healthcare guideline/ pathway created in a post-coronavirus context.

PUBLICATIONS, PRESENTATIONS, AWARDS AND HONOURS

Publications

Sorbello S, Quang Do V, Palagyi A, Keay L. Poorer Visual Acuity is Independently Associated With Impaired Balance and Step Length But Not Overall Physical Performance in Older Adults. *Journal of aging and physical activity*. 2020:1-9

Sorbello S, Rose K, French A, Rowe F and Lau S (2023) Meeting the need for post-stroke vision care in Australia: a scoping narrative review of current practice, Disability and Rehabilitation, DOI: 10.1080/09638288.2023.2214743

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Sorbello S, French A, Rose K. (2018) Current post-stroke vision care and meeting the need: A systematic review. *75th Orthoptics Australia Annual Scientific Conference*, Adelaide, Australia.

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Sorbello S, French A, Rowe F, Rose K. (2019) Post-stroke vision care in Australia: are we meeting the need? *A Focus on Orthoptics in Neurology Symposium,* Sydney, Australia.

Sorbello S (2019) Vision loss after stroke. *Stroke Recovery Association's Annual Stroke Awareness Week Forum*, Sydney, Australia.

Sorbello S (2020) Apps and adaptation strategies for vision loss after stroke. *Stroke Recovery Association's Topical Thursday*, virtual.

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Table 9.4 Median panel score of NSW Post-stroke Vision Care Pathway sections presented with measures of agreement. 266

LIST OF ABBREVIATIONS

WHO	World Health Organisation
ICD	International Classification of Diseases
TIA	Transient Ischemic Attack
ASA	American Stroke Association
CNS	Central Nervous System
FIM	Functional Independence Measure
CT	Coherence Tomography
NASSA	National Acute Stroke Services Audit
RSSF	Rehabilitation Stroke Services Framework
NSW	New South Wales
ADLs	Activities Of Daily Living
OT	Occupational Therapist
VA	Visual Acuity
COTNAB	Chessington Occupational Therapist Neurological Assessment Battery
LOTCA	Lowenstein Occupational Therapist Cognitive Assessment
RPAB	Rivermead Perceptual Assessment Battery
VISA	Vision Screening Assessment Tool
SVDST	Stroke & Vision Defect Screening Tool
VFE	Visual Fields Easy
HVFA	Humphrey Visual Field Analyser
NIHSS	National Institutes of Health Stroke Scale
OKP	Oculokinetic Perimetry
SVOP	Saccadic Vector Optokinetic Perimeter
PBCT	Prism Bar Cover Test
HETI	Health Education and Training Institute
CVA	Cerebrovascular Accident
MMSE	Mini Mental State Evaluation
MoCA	Montreal Cognitive Assessment
OSC	Oxford Cognitive Screen
MCQ	Multiple Choice Question
OT-APST	Occupational Therapy Perceptual Screening Test
L-POST	Leuven Perceptual Organisation Screening Test
TVPS-3	Test Of Visual Perceptual Skills – 3rd Edition
BIT	Rivermead Behavioural Inattention Test
V-DISTRO	Virtual Reality Diagnostic Test
SNAP	Sunnybrook Neglect Assessment
OCT	Optical Coherence Tomography
ON	Optic Nerve

CRAO	Central Retinal Artery Occlusion
VEGF	Vascular Endothelial Growth Factor
NAION	Non-Arteritic Ischemic Optic Neuropathy
POAG	Primary Open Angle Glaucoma
ALT	Argon Laser Trabeculoplasty
SLT	Selective Laser Trabeculoplasty
AMD	Age-Related Macular Degeneration
CNV	Choroidal Neovascularisation
UK	United Kingdom
NDIS	National Disability Insurance Scheme
PTO	Area of convergence of the Parietal, Temporal and Occipital Lobes
PEF	Parietal Eye Fields
FEF	Frontal Eye Fields
V1	Primary Visual Cortex
CRA	Central Retinal Artery
RAPD	Relative Afferent Pupillary Defect
GCA	Giant Cell Arteritis
ICP	Intracranial Pressure
ICA	Internal Carotid Artery
LGN	Lateral Geniculate Body
LPS	Levator Palpebral Superioris
MLF	Medial Longitudinal Fasiculus
SR	Superior Rectus Muscle
IO	Inferior Oblique Muscle
INO	Internuclear Ophthalmoplegia
PPRF	Pontine Paramedian Reticular Formation
BSG	Brainstem Generator Area
NPH	Nucleus Prepositus Hypoglossi
riMLF	Rostral Interstitial Nucleus of the MLF
INC	Interstitial Nucleus of Cajal
PC	Posterior Comissure
DLPN	Dorsolateral Pontine Nucleus
DMPN	Dorsomedial Pontine Nucleus
NRTP	Nucleus Reticularis Tegmenti Pontis
VOR	Vestibulo-Ocular Reflex
LR	Lateral Rectus Muscle
MR	Medial Rectus Muscle
WEBINO	Wall-Eyed Bilateral Internuclear Ophthalmoplegia
MVN	Medial Vestibular Nucleus
SVN	Superior Vestibular Nucleus

OTR	Ocular Tilt Reaction
OKN	Optokinetic Nystagmus
PAN	Periodic Alternating Nystagmus
EWN	Edinger Westphal Nucleus
VRT	Visual Restoration Therapy
MESH	Medical Subject Headings
VIS	Vision In Stroke Study
IVIS	Impact Of Vision Impairment After Stroke Study
NHS	National Health Service
ED	Emergency Department
PRECiS	Pathway Research for Eye Care In Stroke Study
SSS	Stroke Survivor Survey
HPS	Health Professional Survey
REDCap	Research Electronic Data Capture
UCSD	University Of California San Diego
UBACC	UCSD Brief Assessment of Cognitive Capacity
NGO	Non-Government Organisation
MDT	Multidisciplinary Team
LOV	Loss Of Vision
VFD	Visual Field Defect
GP	General Practitioner
ECHP	Eye-Care Health Professional
NECHP	Non-Eye-Care Health Professional
BIVAB	Brain Injury Visual Assessment Battery for Adults
MFVP	Motor Free Visual Perception Test
OM	Ocular Motility
Rx	Treatment
RAM	RAND/UCLA Appropriateness Method
BPS	Best Practice Statement
NHMRC	National Health and Medical Research Council
IPR	Inter-Percentile Range
IPRAS	Inter-Percentile Range Adjusted for Asymmetry
AI	Asymmetry Index
CFA	Correction Factor for Asymmetry
MEP	Multidisciplinary Expert Panel
PSVCP	Post-Stroke Vision Care Pathway
PSVCF	Post-Stroke Vision Care Framework

GLOSSARY OF TERMS

Strabismus	Misalignment of the eyes caused by extra-ocular muscle imbalance, or an 'eye turn'.
Hypotropia	When the affected eye in a strabismus is lower than the non-affected eye.
Hypertropia	When the affected eye in a strabismus is higher than the non-affected eye.
Esotropia	When the affected eye in a strabismus is positioned more medially/is more convergent/more adducted, than the non-affected eye.
Exotropia	When the affected eye in a strabismus is positioned more laterally/ or is more divergent/more abducted, than the non-affected eye.
Torsion	The twisting or rotating movement of the eye around it's front-back axis.
Excyclotorsion	An outward torsional movement of the eye.
Incyclotorsion	An inward torsional movement of the eye.
Adduction	The inward/medial movement of the eye.
Abduction	The outward/ lateral movement of the eye.
Apraxia	Inability to perform learned or familiar movements despite having the physical capability to do so.
Agnosia	Inability to recognise familiar objects, faces or sounds.
Figure ground discrimination	The ability to distinguish an object or figure from the background on which it appears.
Contrast sensitivity	A measure of ability to distinguish differences in shadings or patterns of varied contrast levels. Contrast sensitivity is typically measured using sinusoidal patterns whereby patterns (alternating black and white lines) of a specified spatial frequency are presented in differing levels of contrast, and a threshold level (lowest contrast level detected) for each spatial frequency is recorded.
Oculokinetic perimetry	A visual field test which allows for self-assessment using a paper test chart. Termed 'oculokinetic' because it is the patient's eye that moves during the test, rather than the target.
Optokinetic nystagmus	A physiological, tracking, reflex movement of the eyes instigated by movement of the visual field. This is seen when an individual tracks a moving object (slow phase movement), and once the

	object moves out of the field of vision, the eyes move back to the point where they first saw the object (fast phase movement).
Prism bar cover test	The use of a prism bar (prisms of increasing strength stacked and attached to one another vertically) to measure a difference in alignment between the eyes.
Bielchowsky head tilt test	A test involving a prism bar cover test performed with: 1) the patients head straight and eyes looking directly ahead (primary position), 2) eyes in right and left gaze, 3) patient's head tilting to the left and right. Used to determine which extra-ocular muscle is affected in a vertical strabismus.
Vestibulo-ocular reflex	A 'gaze stabilising reflex' which uses sensory input from the vestibular system regarding head position to instigate compensatory movements of the eyes in the opposite direction. This allows stable fixation on an object during head movements.
Saccades	A rapid, conjugate eye movement that shifts fixation from one object to another. They can be reflexive or voluntary in nature.
Smooth pursuits	A slow, conjugate, tracking movement of the eyes.
Acalculia	Inability to recognise numbers and/or perform basic calculations.
Visual extinction	Inability to perceive or recognise a visual stimulus or object in the affected area of the visual field when there is a competing visual stimulus present in the unaffected area of the visual field. When there is no competing visual stimulus in the unaffected visual field, the object or stimulus in the affected area will be recognised.
Ptosis	Pathological drooping eyelid. Can occur to differing severities where the field of vision may or may not be obscured.
Keratitis	Inflammation of the cornea.
Keratopathy	Damage or degradation of corneal tissue.
Hemianopia	Loss of sight in one half of the visual field.
Quandrantanopia	Loss of sight in one quadrant of the visual field.
Binocular single vision	The ability to use both eyes simultaneously to view an object with perceived depth. Each eye views an object from a slightly different angle due to physiological position of the eyes within the head. This causes 'disparity' between the two images seen by each eye. When the two disparate images are fused to perceive one single image, this gives the perception of depth in the image, which can be maintained during eye movements.
Diplopia	Double vision.
Asthenopia	Collective term used for symptoms of ocular fatigue or strain, headaches and/or lacrimation.

Papilledema	Swelling of the optic disc.
Tarsorrhaphy	A surgical procedure in which part or all of the upper and lower lids of an eye are joined together. Used to aid in eye closure and prevent damage from corneal exposure.
Trabeculoplasty	A procedure performed where a laser is applied to the trabecular meshwork of the eye to promote fluid drainage within the eye and lower intraocular pressure.
Trabeculectomy	A surgical procedure performed on the trabecular meshwork of the eye to create or open a pathway for fluid drainage and hence lower intraocular pressure.
Vitrectomy	A surgical procedure in which some or all of the vitreous humor (gel-like substance in the eye) is removed. Typically performed to allow access to the retina for repair of retinal tears/ detachments/ holes.
Presbyopia	The gradual, age-related, loss of the eye's ability to focus on object viewed up close caused by stiffening of the crystalline lens.
Hyperopia	A type of refractive error where the object of fixation theoretically comes to focus behind the retina, causing difficulty in viewing objects up close. Also termed 'farsightedness'.
Myopia	A type of refractive error where the object of fixation theoretically comes to focus before the retina, causing difficulty in viewing objects at a distance. Also termed 'near-sightedness'.
Astigmatism	A type of refractive error caused by imperfections in the curvature of the cornea, i.e., the cornea is not perfectly spherical in shape, but rather is more curved along one axis than is along the other.
Conjugate eye movements	Ocular movements where the eyes move in the same direction to maintain binocular fixation (e.g., both eyes move to the left or right).
Disjugate eye movements	Ocular movements where the eyes move in opposite directions in order to view an object at different distances (e.g., convergence of the eyes to view at near, divergence of the eyes to view at distance).
Synkinesis	Unintentional contractions of some facial muscles during the attempted movement of other muscles (e.g., forceful eye closure on attempted smile), typically a result of trauma to the facial nerve.
Accommodation	The act of changing the shape of the crystalline lens through contraction of the ciliary muscles to alter its refractive power and bring objects viewed at near into focus.

Scotoma	A distinct area of blindness within the visual field.
Cotton wool spots	Areas of retinal ischemia within the nerve fibre layer presenting is white spots with blurred edges when viewing the retina through fundoscopy or retinal photographs.
Optic disc cupping	The head of the optic nerve at the back of the eye, when viewed through the pupil has a cup-like shape with slightly raised edges (where the nerve fibres travel from the retina into the optic nerve) and a central depression. When retinal nerve fibres are lost or damaged through high intraocular pressure, the raised edges appear thinner and the inner 'cup' increases in size, referred to as 'cupping'.
Homonymous (visual field defect)	A visual field defect where the area of visual field loss occurs in the same half of the visual field in both eyes, e.g., loss of the left side of the visual field in both eyes.
Congruous	Used to describe a visual field defect that is identical in both eyes, e.g., the same shape and size.
Sectoranopia	Loss of sight in a sector of the visual field, usually wedge shaped.
Ophthalmoplegia	Paralysis of the extraocular muscles that control eye movement.
Adaptive head posture	An alternative head posture (e.g., head is titled or turned to one side) which is adopted in some cases of strabismus in order to alter the position of the eyes and bring them into alignment and hence alleviate the symptom of double vision.
Gaze palsy	Inability to bring the eyes into a particular gaze (e.g., inability to look up or down = vertical gaze palsy).
Ectropion	Outward drooping of the eyelid or drooping of the eyelid where the eyelid sags or folds away from the eye.
Entropion	Inward drooping of the eyelid or drooping of the eyelid where the eyelid sags or folds towards the eye.
Dissociated nystagmus	When both eyes have nystagmus occurring in the same direction but with different amplitudes.
Skew deviation	Vertical strabismus that occurs as a result of supranuclear lesions.
Collier's sign	Lid retraction that occurs when attempting a particular gaze position.
Ocular tilt reaction	Physiological reaction of the eyes in response to head tilt (vestibular input), whereby the eye on the side of the tilt moves downwards and is incyclotorted, while the eye contralateral to the head tilt is elevated and excyclotorted.
Bells Phenomenon	A reflexive upward and slightly outward rotation of the eyes occurring upon forceful eyelid closure.

Pendular nystagmus	Nystagmus that occurs in a sinusoidal oscillation. Typically slow, multidimensional movements of the eyes with an equal velocity in each direction.
Periodic alternating nystagmus	Horizontal nystagmus that cyclically reverses its direction
Achromatopsia	Partial or total absence of colour vision, also termed 'colour blindness'.
Photophobia	Sensitivity to light.
Photopsia	Flash-like visual disturbances.
Anisocoria	Unequal pupil sizes.
Corectopia	Abnormally shaped pupil (typically more oval shaped).
Enophthalmos	Posterior displacement of the globe.
Pupil-gaze dyskinesis	Abnormal constriction of the pupil in a particular gaze position (typically down gaze or adduction) caused by aberrant regeneration of nerve fibres following compressive lesions of the oculomotor nerve.
Miosis	Pupil constriction.
Epiphoria	Tearing of the eyes.
Blepharospasm	Spasms of the eyelid.
Null point	The position of gaze in which the velocity and amplitude of nystagmus is most reduced and hence visual acuity is best.
Fresnel prisms	A prismatic lens made from light plastic which can be temporarily fitted onto a pair of glasses, typically used to correct strabismus.

ABSTRACT

At present in Australia, stroke remains as the leading cause of cardiovascular death. Visual consequences of stroke are common and often devastating in their impact on stroke survivors' recovery, both in the acute and long-term stages. Despite this, visual rehabilitation is typically absent or only mentioned briefly, in both national and state-based Australian stroke guidelines. The lack of guidance in this area of stroke care suggests a potential lapse in post-stroke vision care provision that can potentially have devastating consequences for stroke survivors and their loved ones, but also for already strained community health and support services. There is little evidence available regarding the current post-stroke vision care practices and pathways specific to the Australian healthcare system and population. This gap in knowledge makes it difficult to determine if the approximately 60% of Australian stroke survivors with vision problems, are in fact having their vision care needs met as part of their overall stroke recovery.

The PRECiS Study aimed to address this gap in knowledge by firstly describing current post-stroke vision care pathways and practices with NSW and secondly, identifying potential barriers to successful vision care as well as unmet care needs for stroke survivors (Stage One). Using a mixed methods approach, stroke health professionals and stroke survivors in NSW were surveyed on their experience of post-stroke vision care. In addition, semi-structured interviews were carried out with stroke survivors and their carers. The results of the survey indicated that the vast majority of health professionals working with stroke patients are attempting to provide vision care without any clear guidelines or protocols as to how they should be implementing such care. Consequently, post-stroke vision care in NSW is unstandardized and extremely variable between different hospitals and care facilities. For stroke survivors, this means that they may have a vision assessment almost immediately on admission or not at all, depending on where they are receiving diagnosis and treatment. Even if vision problems are identified, our data would indicate that the majority of stroke survivors are still not receiving appropriate information, management or referrals in response to a diagnosis of an eye condition. While a lack of available protocols may be a large contributor to this, health professionals also identified a lack of specialist staff specific to vision in stroke care, as well as a lack of resources and appropriate training, as major contributing factors.

Using the information available in existing literature and the data collected from Stage One, Stage Two of the PRECiS Study aimed to develop a post-stroke vision care framework that

addressed the identified unmet care needs and was suitable for use within the context of the Australian healthcare system. The RAND/UCLA Appropriateness Method was adapted and used to develop and validate a set of 43 best practice statements (BPS) and a care pathway, which together will compose a NSW post-stroke vision care framework. The developed BPS for post-stroke vision care and the proposed NSW Post-stroke Vision Care Pathway are evidence-based and expert-endorsed. The combined guidelines address the gap in current post-stroke vision care provision in NSW, by providing clear recommendations for best practice, and that are suitable for implementation in NSW. The development of the NSW Post-stroke Vision Care Framework is a foundational step for a state-wide and potentially national implementation of timely and effective vision care for stroke survivors.

1 INTRODUCTION: POST-STROKE VISION IMPAIRMENT AND PROVISION OF CARE IN AUSTRALIA

1.1 STROKE

The term 'stroke' was first recorded in the 16th century, whereby the sudden onset of physical and/or cognitive deficits was attributed to a 'stroke of God's hande'.[2] Current definitions of stroke continue to evolve, however there is a broadly accepted understanding that stroke can be either ischemic or haemorrhagic in nature. The World Health Organisation (WHO) most recently defines stroke in the International Classification of Diseases (ICD) 11[3] under the following categories:

i) ***Cerebral ischemic stroke*** – acute neurological dysfunction caused by focal infarction at single or multiple sites of the brain or retina. Evidence of acute infarction may come either from a) symptom duration lasting more than 24 hours; or b) neuroimaging or other technique in the clinically relevant area of the brain

ii) ***Stroke caused by intracerebral haemorrhage*** – acute neurological dysfunction caused by haemorrhage within the brain parenchyma or in the ventricular system

iii) ***Stroke caused by subarachnoid haemorrhage*** – acute neurological dysfunction caused by subarachnoid haemorrhage

Similar cerebrovascular conditions that are not formally categorised as stroke by WHO include:

i) ***Transient ischemic attack (TIA)*** – a transient episode of focal neurological dysfunction caused by focal brain or retinal ischemia without acute infarction in the clinically relevant area of the brain or retina. Symptoms should resolve completely within 24 hours

ii) ***Cerebrovascular disease with no acute cerebral symptom*** – silent cerebral infarct (defined as an infarct demonstrated on neuroimaging or at autopsy that has not caused acute dysfunction of the brain); silent cerebral microbleed; or silent white matter abnormalities associated with vascular disease

The ICD definitions of stroke are the most widely used for reporting health statistics and determining eligibility for financial support and healthcare schemes, particularly by WHO member countries including Australia. While historically there was disagreement between the definition of stroke proposed by WHO and the American Stroke Association (ASA),[4] the most recent ICD-11 definitions now align more closely with the ASA definitions.[5]

1.2 Stroke in Australia

In Australia, stroke is still the second leading cause of cardiovascular death.[6] The median age of people who have a stroke in Australia is reported to be 73.2 years with a slightly higher proportion being male (56.4%).[7] Over 25% of people who experience stroke are still of working age (under 65 years).[8] The average length of stay in hospital for stroke patients in 2020 was 27 days, with the majority being discharged to the community (83.4%) and the remaining discharged to inpatient rehabilitation facilities.[7] While the proportion of stroke events has declined between 2001 and 2017,[9] the actual number of stroke events has increased as a result of the aging population.[10] The number of deaths related to stroke has also been declining, with a 25% decrease between 1981 and 2018.[6] However, disability is a common consequence of stroke and in 2009, it was estimated that one third of stroke survivors had a disability that impacted their daily activities.[11] Despite this, less than half of stroke survivors access further rehabilitation after discharge from acute services.[12] Of those included in the 2020 Rehabilitation Stroke Services Audit, approximately half had a Functional Independence Measure (FIM) score of 100 or more (out of 126) upon discharge, while 25% had a total FIM remaining below 79 indicating a lower functional independence level.[13] As numbers of stroke survivors increase, the burden of disease, which is already substantial,[11] is also likely to increase. In 2015, stroke accounted for 2.5% of the total burden of disease in Australia and is estimated to have a financial cost of $5 billion per year.[14]

1.2.1 Stroke Care in the Australian Health System

The Australian public health system provides free emergency and public hospital services for all Australian and New Zealand citizens, permanent residents, and people from countries with reciprocal agreements.[15] The Australian, state and territory, and local governments share responsibility for running this health system. Medicare forms the basis of the Australian healthcare system and has been the universal healthcare scheme in the country since 1984.[15] It covers all costs of public hospital services as well as some, or all, costs of other health services such as those provided by general practitioners, medical specialists and select allied health professionals. The first Australian framework to guide the establishment and evaluation of stroke services to support equitable delivery of best practice care, was developed in 2002 by the Stroke Foundation in collaboration with the Australian Government Department of Health and Ageing. Since then, the framework has undergone iterative updates, with the most recent update published in 2019. The Acute Stroke Services Framework 2019 describes 20 recommended elements for a comprehensive stroke care centre (Table 1.1).[16]

Table 1.1 The 20 recommended elements for a comprehensive stroke care centre as stated in the Stroke Foundation 2019 Acute Stroke Services Framework.

Acute Stroke Services Framework (2019):

Recommended elements for a comprehensive stroke care centre

1	Receive pre-notification of a potential stroke patient
2	Coordinated emergence department systems
3	Stroke unit
4	Rapid access to onsite CT brain (24/7)
5	On-site endovascular thrombectomy (24/7)
6	On-site neurosurgical services
7	Delivery of thrombolysis
8	Ability to provide acute monitoring for at least 72 hours
9	Acute stroke team
10	Dedicated stroke coordinator position
11	Dedicated medical lead
12	Access to HDI/ICU for complex patients
13	Rapid TIA assessment clinics/ services
14	Provision of telehealth services
15	Coordination with rehabilitation service providers
16	Standardised processes for rehabilitation assessment
17	Involvement of patients and carers in rehabilitation
18	Routine use of guidelines, care plans and protocols
19	Regular data collection and QI activities
20	Access and collaboration with other specialist services

In the 2021 National Acute Stroke Services Audit (NASSA), 93 Australian hospitals reported having stroke units, with access to stroke care units improving to 73% from 67% in 2019.[12] Despite this, only 12 hospitals in Australia met all 20 elements of a comprehensive stroke care centre, and these are all located in major cities.[12] The inequality in stroke care between major cities and regional areas within Australia is clearly demonstrated within this report; hospitals in major cities were found to on average meet 17 of the 20 recommended elements, and inner regional hospitals met an average of 15, while outer regional hospitals averaging only 12.[12] The NASSA also found that only 37% of Australian stroke patients reach hospital within the critical 4.5 hour window for effective thrombolysis treatment. While availability of thrombolysis has

increased (88%), the use of this therapy remains low at only 11%.[12] Currently, speed of thrombolysis delivery remains below the standard achieved in other developed countries, such as the UK and US, with fewer than one in three patients receiving treatment within 60 minutes of arrival in an Australian hospital. Provision of thrombolysis treatment is again lower in inner regional (11%) and outer regional (6%) hospitals compared to those in major cities (13%).[12]

As with acute stroke services, a Rehabilitation Stroke Services Framework (RSSF) has been developed, with the most recent update in 2013. The framework defines ten essential elements of stroke rehabilitation services[17] (Table 1.2).

Table 1.2 The 10 essential elements for stroke rehabilitation services as stated in the Stroke Foundation 2013 Rehabilitation Stroke Services Framework.

Rehabilitation Stroke Services Framework (2013): Essential elements for stroke rehabilitation services	
1	Effective links with acute service providers
2	Specialised interdisciplinary stroke (or neurorehabilitation) team with access to staff education and professional development specific to stroke
3	Co-located beds within a geographically defined unit
4	Standardised and early assessment for neurorehabilitation
5	Written rehabilitation goal setting process
6	Routine use of evidence-based guidelines to inform evidence-based therapy
7	Best practice and evidence-based intensity of therapy for the goal related activity
8	Systems for transfer of care, follow-up and re-entry (to formal service provision)
9	Support for the person with stroke and carer to maximise community participation and long-term recovery
10	Systems that support quality improvement

Among the 111 rehabilitation services that participated in the NASSA in 2020, only four services were found to meet all RSSF ten elements.[13] The national average for elements met was six, which was also the average for inner and outer regional areas, while remote stroke rehabilitation services met an average of only two elements.[13] The RSSF also places emphasis on the importance of the interdisciplinary team to provide coordinated rehabilitation. Results

from the recent NASSA report indicate that this is typically led by a rehabilitation physician (70%) and consists of members such as a physiotherapist, occupational therapist and speech pathologist (100%) as well as a dietician (99%), social worker (97%).[13] A small proportion of rehabilitation services also provide access to recreational therapists (13%) and diversional therapists (15%).[13] Access to an eye care specialist such as an orthoptist, optometrist or ophthalmologist is not discussed in the report.[13]

NASSA found that most services reported providing access to continuing education for staff relating to stroke management (70%), with staff at larger service providers being more likely to have this opportunity (89%).[13] Only half of these services were found to have standardised early assessment for rehabilitation while the majority (75%) did not provide the recommended amount of therapy per day.[13] The Stroke Foundation's clinical guidelines for stroke management covers a range of topics relating to life after stroke for the patient and carer. These include return to driving, return to work, leisure activities, sexuality, and accessing support for the patient and their carer. There were discrepancies in the data in regards to the provision of tailored information about stroke rehabilitation; with 97% of services claiming to provide this, while only 63% of patients stated that they received such information according to audit data.[13] Carers are often provided training on stroke recovery (84%), however, only 55% of carers were offered information about support services for themselves.[13]

The COVID-19 pandemic has caused significant change within the hospital system and stroke care services. The pandemic is likely to have created an additional barrier to providing best-practice stroke care, as dedicated stroke services have been redistributed within the health system. Some onsite services were suspended or reduced in their capacity and many stroke patients discharged early.[13] While this has resulted in a decline in participation in quality improvement activities, it has also caused an increase in the delivery of telehealth rehabilitation services. While telehealth services may not always be the preferred form of care provision, it is likely to be the best way forward in bridging the gap in access to specialist stroke care and rehabilitation services between metropolitan and rural regions of Australia.

This gap is most evident in NSW, despite being the state with the highest and most dense population in Australia.[18] There are approximately 220 public hospitals in NSW, of which 37 are known to have stroke units.[12,19] The vast majority of public hospitals in NSW with specialised stroke units are located in major cities.[19] The Royal Flying Doctor's Service provides 24-hour emergency medical flights in most regions of NSW. For some Australians living in remote areas of NSW, this may be the only opportunity to access time-critical stroke care. This inequality in

service increases when considering stroke survivors with vision impairment in NSW. Only 13 public hospitals in NSW have an ophthalmology clinic or service available within them, of which 11 are located in metropolitan Sydney.[20] With a lack of onsite specialist eye care and an undocumented presence of eye-care specialists within stroke care teams, it seems probable that post-stroke vision care provision remains absent or sub-optimal within many NSW stroke care facilities. This is a key question addressed in this thesis.

1.3 Prevalence and recovery of stroke related vision problems

It is unsurprising that up to 60% of stroke survivors have some form of resultant new visual impairment.[21] In Australia, current statistics indicate that there are more than 100 stroke events every day.[8] NASSA data indicates that approximately 30% of Australian stroke patients have a visual deficit upon admission.[12] As the protocol for vision screening of stroke survivors in Australia is largely undefined, it is likely that this is a significant underestimation of the proportion of stroke survivors with vision problems. As stated, findings from other countries with similar health systems indicate that more than half of stroke events will result in some form of visual dysfunction, which is a common finding in both acute and long-term stages of recovery.[21-23] Visual impairments resulting from stroke vary widely[21,22] and include central vision impairment,: visual field loss, often homonymous hemianopia (missing half of the visual field), dry eye resulting from facial palsy, ocular cranial nerve palsies resulting in strabismus (eye turn) and diplopia (double vision) and eye movement abnormalities including problems with convergence (both eyes moving in a coordinated way to look at near objects), nystagmus (rapid, involuntary oscillations of the eyes), and gaze palsy (inability to look in a certain direction). Visual field loss is a common consequence of stroke, affecting up to 50% of stroke survivors.[23,24] Eye movement abnormalities and strabismus are more common, affecting up to 70% of patients following stroke.[24-26] Visual inattention or hemispatial neglect and other visual processing disorders are also common, affecting 15-30% of survivors,[13,24] especially in the case of right hemisphere stroke.

Recovery of stroke-related visual impairment is variable depending on the type of deficit. Only an estimated 7-17% of visual field loss recovers completely over the first 3 months,[23,27] while, 34% of visual perceptual disorders show some recovery.[27] Eye movement abnormalities, including cranial nerve palsies and gaze related defects, occur frequently in brainstem and cerebellum strokes.[25,26] Most gaze defects only partially recover (66%) or do not recover at all (30%), over a 6 month period post-stroke.[26] For patients with ocular cranial nerve palsies,

some recovery over a period of 6-12 months after onset is expected, although recovery is most often partial (43%) with less than a quarter recovering completely.[25]

In addition, as stroke occurs most often in the elderly, with 71% of stroke affected individuals aged over 65,[8] there is also a high prevalence of pre-existing eye conditions in this age group.[24,28,29] Such conditions include: refractive error and age-related presbyopia (loss of accommodative ability) requiring optical correction, as well as other pathological conditions causing visual impairment, such as macular degeneration, cataract, and glaucoma. Many of these conditions require ongoing management by ophthalmologists to prevent further degeneration of vision. This complicates the ocular care of stroke survivors, which requires the detection of both pre-existing and newly acquired visual impairments for appropriate long-term care.

The impact of visual impairment in the community is known to be substantial. As well as significant direct and indirect costs,[30] visual impairment has a major impact on activities of daily living (ADLs) and is a barrier to patient independence in the community, increasing reliance on community support services and carers[31-33], as well as increasing likelihood of nursing home admission.[34] A recent systematic review reported that visual impairment in stroke survivors substantially reduces quality of life (QoL), with a combination of central vision impairment and visual field loss reducing QoL more so than visual field loss alone.[35] A study conducted in the UK interviewing 35 stroke survivors with visual impairment, found that patients reported a number of barriers to reintegration into the community resulting from their visual impairment, including inability to return to work, pursue hobbies or drive.[36] In addition to this, visual impairment is known to negatively impact balance and gait,[37] as well as increase depression[32] and overall morbidity,[34,38] and hence is an additional barrier to successful rehabilitation of stroke survivors.

1.4 DETECTION OF VISION DISORDERS IN STROKE SURVIVORS

Given the extensive range of visual conditions that can be caused by stroke, the frequency with which they occur, and the impact they have on an individual's functionality and quality of life, it would seem imperative that all stroke survivors undergo a vision assessment. While there are well established techniques and tools used in current ophthalmic/orthoptic practice to detect many of these conditions within a healthy population, detection in stroke survivors presents additional challenges. The multiplicity of cognitive[39,40] and physical[41-43] deficits caused by stroke often render standard or 'gold standard' detection methods unviable within an acute stroke population. Techniques and tools employed in the detection of vision impairment

among stroke survivors must take into consideration the possibility of patients having a reduced capacity for mobility,[41-43] communication,[44] comprehension,[39,40] memory[40,45] and heightened levels of fatigue.[46] In addition, many stroke survivors within the acute stage of recovery are often bed bound, and so assessment may only be conducted at bedside within their acute care facility. This raises additional considerations for the mobility of required equipment for assessment, as well as availability of the specialised health professionals required to conduct an accurate vision assessment.

The current collective evidence-base suggests that an orthoptic assessment in a stroke population is a viable and accurate means of screening for visual conditions.[21,47,48] However, studies report that stroke services often don't include formal vision assessment[12,13] and in those that do, there are major inconsistencies in how this is conducted.[49-51] Internationally, there is limited evidence on varied approaches to vision assessment for stroke survivors, with the majority of research on this topic conducted in the UK (see Chapter 3). However, where post-stroke vision screening tools or assessment protocols were implemented, this typically increases the number of visual conditions detected and the number of vision referrals provided.[28,47,48,61] Little research is currently available on the inclusion of vision assessment in stroke services within Australia. The Clinical Guidelines for Stroke Management 2017 indicate that stroke survivors should have visual acuity and visual field assessment, but little is specified regarding how this should be performed or by whom.[52] Assessment for other stroke-related visual conditions are not included in the guidelines. Review of the current care practices for post-stroke visual conditions within Australia is provided in Chapter 3.

1.4.1 Screening tools for vision impairment in stroke survivors

In order to address the difficulties in assessing visual function of stroke survivors in stroke care settings where there is often limited access to specialist eye care staff, a number of vision screening tools have been developed. Each of these tools assess vision in varied detail and are suited to different levels of deficits across the spectrum of stroke severity. The tools also vary in the types of vision impairment assessed, their sensitivity and specificity to these impairments[53] as well as accuracy when administered by non-eye care professionals compared to eye care specialists.[28,54] Table 1.3 outlines the range of vision screening tools developed for use in stroke survivors that have been published in English to date. The literature review conducted by Hanna et al. (2017) was updated by searching the same electronic bibliographic databases for relevant screening tools published between 2017 and 2022.

Table 1.3 Screening tools for vision impairment in stroke survivors (adapted from Hanna et al. 2017)[53]

Screening Tool	Visual Impairment(s) Assessed	Accuracy of Tool	Considerations for Use
Hemispheric Stroke Scale[55]	- Neglect - Visual Perception - Gaze/ eye movements - Visual Field	High sensitivity due to correlation with Barthel index 90% of aphasic patients able to undergo screening	Duration: 30min Does not screen for full range of potential visual deficits Requires patient to understand questioning and communicate with examiner
Chessington OT Neurological Assessment Battery (COTNAB)[56,57]	- Visual Perception - Constructional ability - Sensory motor ability - Ability to follow instructions	Not stated	Duration: 60-80 min Does not screen for full range of potential visual deficits Sensitivity and specificity within stroke populations unknown
Lowenstein OT Cognitive Assessment (LOTCA)[56]	- Orientation - Visual perception - Spatial perception - Praxis - Visuomotor organisation - Thinking operations	Not stated	Duration: 45min The geriatric version includes memory testing instead of spatial perception Does not screen for full range of potential visual deficits Sensitivity and specificity within stroke populations unknown

Screening Tool	Visual Impairment(s) Assessed	Accuracy of Tool	Considerations for Use
Ontario's Society of OT's Perceptual evaluation[56,58]	- Sensation - Scanning - Apraxia - Body awareness - Spatial relations - Visual agnosia	Limited validity documentation	Duration not stated Limited visual functions examined, excluding those most commonly found after stroke (e.g. visual field loss, eye movement abnormalities)
The Functional Impairment Battery[59]	- Near VA - Neglect	70% sensitivity for VA assessment 52% sensitivity for star cancellation test (neglect)	Duration: <60min Limited visual functions examined excluding those most commonly found after stroke (e.g. visual field loss, eye movement abnormalities)

Screening Tool	Visual Impairment(s) Assessed	Accuracy of Tool	Considerations for Use
Rivermead Perceptual Assessment Battery (RPAB)[56,60]	- Colour - Sequencing - Object completion - Figure ground discrimination - Body image - Inattention - Spatial awareness	Limited validity documentation	Duration: 60-120min Length of tool reduces feasibility within acute stroke population due to increased fatigue Shortened RPAB - 81% sensitivity and 100% specificity - 19% patients with impairment missed compared to full version - Duration: 30-35min Does not screen for full range of potential visual deficits Reduced cognition and concentration can hinder reliability
The Checklist for Vision Problems Post-Stroke[61]	- VA - Visual field - Neglect - Ocular motility	69% sensitivity when administered by an Orthoptist 17% sensitivity when administered by a non-orthoptist	Duration not stated Requires patient to understand questioning and communicate with examiner
VIS Standardised Screening Form[62]	- VA - Visual field - Neglect - Ocular motility	92% sensitivity Sensitivity reduced to 42% and specificity 52% without patient reported symptoms	Duration not stated Requires patient to understand questioning and communicate with examiner

Screening Tool	Visual Impairment(s) Assessed	Accuracy of Tool	Considerations for Use
Vision Screening Assessment tool (VISA)[47]	- Near VA - Distance VA - Neglect - Visual Field - Ocular Motility - Colour - Contrast sensitivity - Visual perception	98% sensitivity and 67% specificity for print version 88% sensitivity and 87% specificity for app version Sensitivity of 98% and specificity of 60% for patients needing onward vision referral	Duration: 23.5min 21 of 221 patients unable to complete all aspects of the tool due to cognitive impairment or fatigue.
Stroke &Vision Defect Screening Tool (SVDST)[28]	- Binocular Near VA - Binocular Distance VA - Visual field - Neglect - Ocular motility	88.5% sensitivity; 93.3% specificity for pre-existing conditions when administered by a non-eye care health professional[63] 91.1% sensitivity; 92.6% specificity for new conditions when administered by a non-eye care health professional.[63]	Duration not stated. Requires patient/carer to understand questioning and communicate with examiner.

Screening Tool	Visual Impairment(s) Assessed	Accuracy of Tool	Considerations for Use
The Stroke Vision App[64]	- Visual acuity (Tumbling E at 33cm) - Visual field Confrontation Formal perimetry - Visual inattention (Line bisection, face cancellation)	71% sensitivity; 83% specificity 79% sensitivity; 88% specificity 67% sensitivity; 98% specificity	Total test time: 420s Visual acuity: duration not provided Visual field: 300s Inattention battery: 120s Some participants experienced difficulty understanding instructions. Test administered by trained health professionals. Provides quantitative measures for visual defects.
Visual Fields Easy (VFE) app[65]	- Visual fields (static)	88% sensitivity and 76% specificity	Higher proportion of false negatives when compared to HVF. 40% agreement with HFV in stroke cohort.
V-FAST[66]	- Visual symptoms - Reading - Eye position and movements - Visual fields (confrontation) - Visual inattention/ extinction	86% sensitivity and 42% specificity	Designed for use by paramedics attending suspected stroke patients. Overall accuracy 54%.

1.4.1.1 Visual field loss

The monocular visual field typically spans 60 degrees medially, 100 degrees laterally, 60 degrees upward and 75 degrees downward from the central point of fixation (with some physiological variations as a result of differences in face and eye shape).[67] The most effective

and accurate form of assessment to detect visual field loss is through quantitative perimetry.[67] Ideally, the entire visual field would be tested to allow for detection of peripheral visual field loss as well as loss within the central field (30 degree radius from fixation). Traditionally, assessment of the full visual field was performed on a Goldmann perimeter that is manually controlled by a trained operator and allowed for presentation of both static and kinetic targets.[67] The Goldmann perimeter, manufactured by Haag-Streit, had been considered the gold standard for assessment of visual fields for many years.[68] However, issues regarding examiner reaction time, requirement of a skilled perimetrist and lack of reproducibility, has led to a reduction of its use and ultimately the cessation of production in 2007.[68] Since then, it has been replaced by an automated perimeter, also manufactured by Haag-Streit, called the Octopus 900. The Octopus examines the full visual field in a similar way to the Goldmann perimeter using automated software controlled by the operator rather than manual presentation of targets. This eliminates many of the previous limitations of the Goldmann, such as operator reaction time and a limited range of targets that may have reduced quantitative assessment of visual field sensitivity as well as overall accuracy.[69] However, a drawback of the Octopus 900 is the noise made by the machine when moving and presenting the target that can unintentionally provide an audio que to patients during testing and potentially reduce reliability. The Zeiss Humphrey Visual Field Analyser (HVFA) is more widely used in ophthalmic practice within Australia and overseas.[67] The HVFA is also an automated perimeter that provides quantitative assessment, although kinetic testing is only available in some models.[70] While highly effective at detecting glaucomatous visual field loss, central scotomas and widespread loss such as hemianopia or quadrantanopia, the HVFA only allows limited testing of peripheral field loss occurring beyond the central 30 degrees. As discussed, stroke can cause field loss in a multitude of variations including loss within the peripheral visual field. As such, the Octopus perimeter is a suitable successor to the Goldmann perimeter for the assessment of visual field defects in stroke survivors.[68,71]

Assessment of visual fields using any of the aforementioned equipment requires a relatively well and able-bodied patient. During the assessment the patient must be able to sit upright for a prolonged period of time (average of approximately 5 minutes per eye),[71] understand and remember a complex set of instructions, hold and press a buzzer in one hand and maintain sufficient focus and energy levels for the duration of the test. These perimeters are also large, highly specialised, and expensive pieces of equipment that cannot be readily moved around with ease. Consequently, this type of assessment is not feasible for a large proportion of stroke survivors and not readily accessible or appropriate for those in acute stroke care.

There are a number of alternative assessment techniques and tools available that are more suited to assessment of stroke survivors, with varied sensitivity and specificity.[53] Confrontation-to-visual field is a widely used method of gross qualitative assessment of visual field defects and traditionally utilising the examiner's finger as targets held in the different quadrants of the visual field while the patient fixes their eye on the examiner's. This method is able to detect gross hemianopic and quadrantic field defects with a reasonable level of accuracy but is limited in its capacity to detect other types of visual field defects, and has been shown to have a high risk of bias and low sensitivity.[72,73] The National Institutes of Health Stroke Scale (NIHSS) confrontation method is an adaptation of the traditional confrontation visual field method which involves finger counting. This method reportedly has 20% sensitivity in detecting visual field defects and 98% specificity.[72] In a study comparing the accuracy of this method to automated perimetry assessment, it was found that only two of ten patients with confirmed field defects using the HVF were identified using the confrontation method.[72] There is speculation that use of the traditional confrontation technique using different coloured hatpins or pens as targets might provide a more accurate visual field assessment.[74] These methods can easily be performed at beside and do not require any or very limited equipment (e.g. coloured pens/ targets). They do, however, require the patient to be able to understand basic instructions and communicate the visibility of targets using either verbal or non-verbal methods.

Oculokinetic perimetry (OKP) is described as a variation of confrontational visual field assessment that requires the patient to move their eye following a numbered pattern on a chart then recording the visibility of the central test target in each position of fixation. The test can be self-administered and requires only the test chart, recording sheet and pencil, and hence is portable. However, the test does require the patient to be able to understand and follow verbal or written instructions, communicate and maintain focus for approximately 20 minutes.[75] As a result, very few acute stroke patients in the study described by Cassidy et al. were able to undergo testing using this method.[76] OKP also only tests the central 25 degrees of the visual field, though has been shown to have 94% sensitivity in detecting arcuate, quadratic, hemianopia, altitudinal and nasal step defects.[76] The Saccadic Vector Optokinetic Perimeter (SVOP) uses a similar technique, however, is computerised and utilises infrared eye tracking to assist in assessing patients with cognitive impairment.[77] It has been shown to have reasonably good sensitivity (73%) and specificity (90%), and is faster to administer (104.2 sec) than Goldmann perimetry (203.2 sec).[77] The equipment required to administer SVOP is quite large and difficult to transport, hence may not be appropriate for bedside assessment. Tablet-based

apps have been developed to test visual fields, such as the Visual Fields Easy (VFE) app,[65] the VISA app,[47] and the StrokeVision App.[64] Both the VFE[65] and StrokeVision[64] app utilise static perimetry test strategy, while the VISA app uses a kinetic testing strategy.[47] However, all the aforementioned apps only test the central visual field (~30 degrees). Sensitivity is highest in the VFE and VISA apps,[47,65] while specificity was greatest in the StrokeVision and VISA apps.[47,64]

Various vision and/or stroke screening tools also include assessment of visual fields in varying levels of detail and accuracy (Table 1.3). The hemispheric stroke scale assesses the visual field via confrontation and by asking the patient if they are aware of all of their limbs.[55] The tool has a high correlation with the Barthel index and so is thought to have a high level of sensitivity overall.[55] The Checklist for vision problems post-stroke[61] and the later revised version, the SVDST,[28] assesses visual field deficits by way of patient reported symptoms, as well as by observation of patient behaviour i.e. bumping into things or missing objects to one side. The checklist demonstrated 69% sensitivity when administered by an Orthoptist and much lower sensitivity (17%) when administered by a stroke health professional who was not an Orthoptist.[61] The SVDST demonstrated 90% sensitivity for patient's needing onward vision referral but 50% specificity.[28] The VIS standardised screening form assesses visual field function primarily by patient reported symptoms.[62] In the 2011 study by Rowe et al., the form was administered by the stroke multidisciplinary team at each stroke care facility and showed 92% sensitivity and 52% specificity, however sensitivity was dramatically reduced to 42% without patient reported symptoms.[62]

The VISA paper-based screening tool tests for visual field deficits by asking the patient if they are aware of missing parts of their visual field and also asking the patient's family/ carer if they are aware of the patient missing things on one side or bumping into objects.[47] The tool then asks the health administrator to perform a confrontation visual field by the traditional method and NIHSS method. The VISA tool demonstrated 76% agreement for visual field assessment when compared to formal assessment by an Orthoptist.[47] All of the aforementioned screening tools rely on patient reported symptoms to some extent when assessing visual fields which presents a significant problem in a stroke population where communication deficits are common. It is also of importance to note that of the studies which have compared use of a screening tool conducted by eye care professionals versus non-eye care health professionals, all found greater accuracy in detection of visual conditions and need for onward referral when administered by an eye care professional.[28,54,61] The app-based VISA screening tool differs to the print version only in the assessment of visual fields. The app utilises kinetic testing strategy, whereby the patient is positioned at a test distance of 30cm from the tablet to enable

assessment of the central 40 degrees of the visual field. The fixation target is positioned in one corner of the screen and moves to test all four quadrants sequentially. The VISA app demonstrated higher agreement (85%) than VISA print version for visual field assessment when compared to assessment by an Orthoptist.[47]

1.4.1.2 Eye movement abnormalities

As previously discussed, there are an array of eye movement abnormalities that can occur as a result of stroke, each with varied visual symptoms and presentation. Accurate diagnosis of eye movement abnormalities and localisation of their cause requires highly specialised knowledge of the visual system and skill in assessment techniques. Gold standard assessment for conditions such as cranial nerve palsies and gaze palsies typically include assessment of ocular movement, ocular alignment via cover test, prism bar cover test (PBCT) and further variations of the prism bar cover test (e.g. Bielchowsky Head Tilt Test, PBCT in different gaze positions) as well as assessment of diplopia and/or the vestibulo-ocular reflex.[78] Tests to assess levels of stereopsis, suppression and other binocular functions may also be necessary within the assessment to conclusively diagnose an eye movement abnormality. All of these methods require only small and light weight equipment (e.g. pen torch, prism bars, fixation targets, stereotest booklets) and so are easily performed at bedside if necessary, but do require specialised skill and expertise of the examiner. There are other limitations as these methods of assessment require the patient to have reasonable sitting balance, the ability to communicate and feedback to the examiner for some aspects of testing, have adequate cognitive capacity to understand and remember instructions and maintain focus for a prolonged period of time.

Many of these assessment methods can be modified to make them more feasible for stroke survivors with deficits in cognition or communication, however in order to be accurately administered and interpreted they need to be performed by a trained eye care professional such as an Orthoptist or Ophthalmologist. Alternatively, it is possible to screen for eye movement abnormalities in a stroke care setting and in the absence of an eye care professional if necessary, by utilising a vision screening tool. The hemispheric stroke scale includes a gaze/ eye movement assessment, however, this section only seeks to identify gaze palsies or conjugately deviated gaze and cannot identify impairment across the full spectrum of eye movement abnormalities.[53,55]

The Checklist for Vision problems post-stroke, VIS Screening Form and the SVDST also question symptoms of eye movement abnormality, however, the feasibility and accuracy of this depends on the communication abilities of the patient.[28,61,62] These tools also instruct the

administrator to observe the patient for signs of eye movement abnormality such as eye misalignment (VIS), observe eye movements while tracking an object (Checklist for vision problems post-stroke) or observe binocular fixation and tracking movements (SVDST). In some stroke survivors these abnormalities may present in a way that is easily recognisable to an untrained health professional, however, it is possible that these signs will be missed or misinterpreted if no specialised training is provided. This assumption is supported by the dramatic reduction in sensitivity for detection of eye movement abnormalities by non-orthoptic health professionals in the study by Jolly et al.[61] Developers of the SVDST aimed to address a lack of specialist vision training amongst stroke health professionals by introducing an eLearning module on the NSW Health Education and Training Institute (HETI) website. The module explains recognition techniques and terminology for common stroke-related visual impairments. At present there is no published data available comparing the accuracy of the tool when administered by professionals who have and have not completed the module.

The VISA tool also assesses eye movement abnormality by questioning the patient about double vision, observing any abnormal head posture (face turn), guided observation of eye alignment and guided assessment of vertical, horizontal and convergent eye movements.[54] While the inclusion of multiple screening methods within this tool make it more likely to detect eye movement abnormalities, agreement between the tool and specialist assessment for these conditions was slightly lower (89%). Overall sensitivity (83%) and specificity(81%) of the tool was also reduced when administered by a naïve screener.[54] In a similar way, the V-FAST screening tool for stroke survivors assesses eye movement abnormalities through observation of eye position and eye movements in four positions of gaze.[66] As this screening tool was developed for use by paramedics, an online training module was also developed to supplement the tool and improve accuracy of screening by non-eye care health professionals. The V-FAST was shown to accurately detect overall visual impairment in 76% of FAST-positive and 80% of FAST-negative strokes.[66]

1.4.1.3 Nystagmus

Nystagmus can typically be diagnosed by observation, however, there are latent forms of nystagmus that may only become apparent when one eye is covered or when looking in a certain position of gaze. These latent forms of nystagmus are typically diagnosed during the ocular motility assessment on cover test and/or during assessment of ocular movements. As such, assessment of this eye movement disorder can easily be performed at bedside with easily portable equipment such as an occluder and pen torch. The assessment requires

minimal cooperation from the patient but may in some instances require them to follow basic instructions. Diagnosis does however require the examiner to be aware of the different types of nystagmus and trained in these techniques of assessment and so would be most accurate when performed by an eye care specialist or neurologist. More in-depth assessment of the type of nystagmus and acquisition of details required to inform management plans, such as determining the null point position of gaze, again requires highly specialised knowledge and skill and so would not be an appropriate responsibility to task to a non-eye care health professional. The screening tools described may allow for detection of constant nystagmus through standard observation or gaze evoked nystagmus through observation of eye movements (Checklist for vision problems post-stroke, SVDST, VISA).

1.4.1.4 Visual processing disorders

Visual processing or visual perceptual disorders is an umbrella term used to describe a multitude of conditions that can result from disruptions of the various neural pathways involved in receiving and understanding visual information. Due to the variety and complexity of conditions that can occur and the differences in how they may present between individuals, diagnosis is particularly difficult. There is currently no gold standard form of assessment for these conditions and assessment typically involves careful questioning of symptoms and utilisation of one or more examination tools.[53] Table 1.4 outlines the published screening tools available for detection of visual perceptual disorders in stroke survivors published in English to date. The literature review conducted by Hanna et al. (2017) was updated by searching the same electronic bibliographic databases for relevant screening tools published between 2017 and 2022. Prior evaluation of these tools found a common issue regarding overly long assessment time.[56] This review also excluded the following tools due to missing validation and normative data: Ontario's society of OTs perceptual evaluation, the cerebrovascular accident (CVA) evaluation battery of St Mary's Hospital, Chessington OT neurological assessment battery and Baylor adult visual perceptual assessment.[56]

Table 1.4 Screening tools for the detection of visual processing disorders in stroke survivors (adapted from Hanna et al. 2017)[53]

Screening Tool	Disorders/ Functions examined	Accuracy of Tool	Considerations for Use
Mini Mental State	Post-stroke cognitive screening tool with	This was the only tool identified which was deemed suitable for post-	Duration: 10-15 min

Screening Tool	Disorders/ Functions examined	Accuracy of Tool	Considerations for Use
Examination (MMSE)	domain for visual construction	stroke screening and contained a visual perception domain[79] 0.82 internal consistency[80] 0.85 test-retest[81] 66% sensitivity and 97% specificity[82] MMSE identified 43 patients with impaired cognition compared to 50 identified by MoCA[83]	MMSE unable to screen for complex impairments such as visuospatial defects
Montreal Cognitive Assessment (MoCA)	- Visuospatial/executive functions - Naming - Memory - Attention - Language–sentence repetition - Language–verbal fluency	94% sensitivity and 42% specificity[82] MoCA identified 59 patients with impaired cognition compared to 43 identified by MMSE[83]	Duration not specified Can be performed at bedside
Oxford Cognitive Screen (OSC)[84]	- Picture naming - Semantics - Orientation free - Orientation MCQ - Sentence reading	Sensitivity and specificity values when validated against other tools: Picture naming: 59.32% sensitivity and 72.92% specificity Semantics: 27.59%, 98.31% Orientation free: 68.00%, 87.38% Orientation MCQ: 52.00%, 92.23% Sentence reading 62.97% sensitivity and 81.94%	Duration: 15-20min Primarily screens for post-stroke cognitive impairment and includes some testing of visual perception. Authors noted reasons for subset exclusions for some participants

Screening Tool	Disorders/ Functions examined	Accuracy of Tool	Considerations for Use
		specificity	included problems
	- Number writing	Number writing 52.63% sensitivity and 70.10% specificity	with vision, motor impairment, comprehension,
	- Calculation	Calculation 45.45% sensitivity and 91.14% specificity	fatigue, expressive aphasia and time.
	- Broken hearts	Broken hearts 94.12% sensitivity and 69.01% specificity	
	- Space asymmetry	Space asymmetry 65.63% sensitivity and 75.00% specificity	
	- Object asymmetry	Object asymmetry 46.88% sensitivity and 91.07% specificity	
	- Imitation	Imitation 72.20% sensitivity and 90.70% specificity	
	- Verbal recall	Verbal recall: no cut-offs	
	- Verbal recognition	Verbal recognition: no cut-offs	
	- Episodic Recognition	Episodic Recognition 75.00% sensitivity and 73.53% specificity	
	- Executive task	Executive task 66.67%, 74.19%	
	- Visual field	Visual field: was not compared to other measure for validation Test–retest reliability= 83.3% sensitivity and 93.48% specificity	

Screening Tool	Disorders/ Functions examined	Accuracy of Tool	Considerations for Use
Occupational Therapy Perceptual Screening Test (OT-APST)	- Agnosia - Visuospatial relations including neglect - Body scheme - Constructional skills - Apraxia - Acalculia - Functional skills	Inter-rater reliability= 0.66–1.0[85] Intra-rater reliability= 0.64–1.0[85] Test–retest reliability= 0.76–0.95[85] Intraclass correlation coefficient range= 0.6–1.0[86]	Duration: 20-30min[56,85,86] Requires prior/ separate assessment of visual acuity, tracking, visual fields, and visual history to provide essential information for assessment modification. Also requires adequate hearing, comprehension, and reasonable dexterity of one hand for writing.
The Leuven Perceptual Organisation Screening Test (L-POST)[87]	- Perceptual organisation ability (75 items)	Test-retest reliability = 0.70 (in healthy subjects)[89] Test-retest reliability = 0.77 (in brain injury subjects)[90]	Duration: 20-35min[90] Available online and easily administered at bedside using tablet or laptop. Neglect friendly version available but patient must be pre-diagnosed with visual neglect.

Screening Tool	Disorders/ Functions examined	Accuracy of Tool	Considerations for Use
Shortened L-POST[88]	- Perceptual organisation ability (26 items)	79% sensitivity and 54% specificity	Duration: 7-14 min[88]
The Test of Visual Perceptual Skills – 3rd Edition (TVPS-3)[91]	- Visual discrimination - Visual memory - Spatial relations - Form constancy - Sequential memory - Visual figure-ground - Visual closure	Overall intraclass correlation coefficient= 0.92 Visual discrimination= 0.64 Visual memory= 0.53 Spatial relations= 0.82 Form constancy= 0.55 Sequential memory= 0.66 Visual figure-ground= 0.67 Visual closure= 0.77	Duration: 40 min Enables stroke patients to respond without motor or verbal expression and is suitable for those with reading difficulties (pictures only). Poor test-retest reliability for each subscale may be improved by increasing the size of the pictures and eliminating timing of the memory test.

1.4.1.5 Visual Neglect

Perhaps the most well understood and most thoroughly researched visual processing disorder that occurs following stroke is visual neglect. Visual neglect is more easily detected, however, like other visual processing disorders, there is no widely agreed gold standard method of assessment.[53] Studies have found that using a battery of at least three different neglect tests increased the accuracy of assessment for this condition.[92-95] Tests for neglect typically include line bisection, cancellation and/or figure copying tasks, which were traditionally administered using pen and paper. Variations of many of these tests are now also available online for testing via a tablet or computer.[53] Line bisection tests require the patient to draw a line or cross where they perceive the middle of a given horizontal line to be. Horizontal lines of varied lengths

(50mm-200mm) have been used to test for neglect in populations of stroke survivors and it has been found that longer lines (185-200mm) greatly increase the sensitivity of this test.[96]

Cancellation tests require the patient to scan a page of various images and cross out all repetitions of a specified target stimuli within the page. Consistently missed target items within the same side of the page (typically left) indicates neglect of that side. The star cancellation test and shape cancellation test both utilise 'distractor' items amongst the target items on the page.[59,97] Conversely, the Bells test and letter cancellation test contain items that all resemble each other and hence are said to be able to detect visual exploratory deficits more effectively.[98] A study by Ferber and Karnath found both the Bells test and letter cancellation test to be more sensitive than the star cancellation test.[98] The authors suggest that the use of distractor items that are easily discriminated may make it easier for the patient to detect the target items and so reducing the sensitivity of this style of cancellation test. A more recent study offered contradictory findings by demonstrating the shape cancellation test to be the most sensitive of all cancellation tests for detection of visual neglect.[99] Further research is needed to determine the impact of distractor items on the sensitivity of cancellation tests. Studies have also indicated that the patient's spontaneous starting point should be considered (e.g. starting from right to left) as this increases test sensitivity.[95] It is worth noting that the spontaneous starting point should be considered in relation to the first language of the patient, as a 'right to left' pattern may be less significant in patient who has learnt to read and write in a language that follows this pattern.

Figure copying and drawing tasks involve the patient recreating a given image (figure copying) or drawing an image from memory e.g. a clock face. A patient with visual neglect may leave out one side of the image, or parts of the image on that side, or condense the image disproportionately to the side that does not have neglect (e.g. all numbers of the clock face are drawn on the right side). Studies have shown that figure copying is more sensitive in detecting visual neglect when compared to drawing tasks, presumably because figure copying requires more visual input than drawing an image from memory.[100]

There is also notable variability in how these tests are scored between examiners, particularly in relation to the interpretation of minor errors.[85] There is a need for further research and perhaps greater standardisation in the scoring methods for these tests in order to improve sensitivity and specificity. Limitations of line bisection, cancellation, figure copying and drawing tests within a stroke population include the requirement for patients to have reasonable dexterity of at least one hand (preferably their normal writing hand), have sufficient cognitive

capabilities to understand and follow the given instructions, as well as ability to recognise objects and/or recall an object's appearance and of course, have a good near visual acuity. If such requirements do not exclude the patient from assessment, these tests are easy to administer at bedside, relatively inexpensive and have reasonable sensitivity when administered correctly and in combination with each other. The Rivermead Behavioural Inattention Test (BIT) encompasses all variants of the aforementioned screening methods,[101] however, is lengthy to perform and so is difficult for stroke patients to complete at the acute stage of recovery.[53] Shorter alternatives have since been developed that have demonstrated varying levels of accuracy (Table 1.5). The content of this table represents a literature review conducted by Hanna et al. (2017) that was updated by searching the same electronic bibliographic databases for relevant screening tools published between 2017 and 2022.

Table 1.5 Screening tools for the detection of visual neglect in stroke survivors (adapted from Hanna et al. 2017)[53].

Screening Tool	Test Variation	Accuracy of Tool	Considerations for Use
Line Bisection	1 line (200mm)	Argell et al found line bisection to be the most sensitive (55%) compared to star cancellation, figure copying and drawing tasks[94]	Failed to detect 40% of neglect cases in isolation (exact sensitivity unclear)[98] Only line bisection correlated significantly with Catherine Bergego scale[102] Positive correlation found between line bisection and extinction[103]
	4 lines (50mm ,200mm)	19% sensitivity with 5cm line and 38% sensitivity with 20cm line[95]	
	unknown	76% sensitivity[104]	
	3 lines (200mm)	33% sensitivity and 100% specificity[93]	
	3 lines (20.4mm)	38% sensitivity and 100% specificity[96]	
	12 lines (63mm, 123mm, 185mm)	48% sensitivity and 100% specificity[96]	
Cancellation Tests	Star cancellation	46% sensitivity[94]	Random shape cancellation, star cancellation and complex
		40% omissions detected[98]	
		54% sensitivity and 96% specificity[93]	

Screening Tool	Test Variation	Accuracy of Tool	Considerations for Use
		41% sensitivity and 90% specificity[96]	line bisection = 88% sensitivity No significant correlation with Catherine Bergego scale
	Bells test	50.5% sensitivity[95]	
		61% omissions detected[98]	
	Shape cancellation	41% sensitivity[95]	
		70% sensitivity[99]	
	Letter cancellation	62% omissions detected[98]	
		32% sensitivity[96]	
Figure Copying		27%-43% sensitivity[94-96,99] 99% specificity[99] No significant correlation to Catherine Bergego scale[102]	Dexterity Vision
Drawing task	Clock drawing Unspecified drawing task Representational drawing	42%[94]; 28%[95]; 6%[96] sensitivity 99% specificity[99]	Drawing from memory may be inappropriate for stroke survivors with cognitive deficits in memory or association processes
Rivermead Behavioural Inattention Test (BIT)	Battery includes: - line crossing - letter cancellation - star cancellation - figure and shape copying - line bisection - representational drawing - picture scanning - telephone dialling - menu reading	Test re-test stability coefficient= 0.89 for conventional tests and 0.97 for behavioural tests (P<0.001) Inter-rater reliability = 0.99 for conventional and behavioural tests (P<0.001)[101] Sensitivity and specificity not stated	

Screening Tool	Test Variation	Accuracy of Tool	Considerations for Use
	- article reading - telling and setting time - coin sorting - address and sentence copying - map navigation - card sorting		
Virtual Reality Diagnostic Test (V-DiSTRO)[93]	Battery includes: - line bisection - star cancellation - visual extinction - baking tray test	100% sensitivity and 82% specificity Visual extinction: 100% sensitivity and 95% specificity Baking tray task: 100% sensitivity and 86% specificity	Duration = 15min; 3x faster than BIT (reported as 50min duration)
The Sunnybrook Neglect Assessment (SNAP)[99]	Battery includes: - spontaneous drawing of clock and daisy - line cancellation - line bisection (15cm and 20cm) - copying of clock and daisy - shape cancellation	68% sensitivity and 76% specificity overall Shape cancellation most sensitive (70%) and drawing/copying most specific (99%)	Duration not specified but authors claim speed of administration is a strength of the tool.
The French Test Battery for Unilateral Neglect[97]	Battery includes: - line bisection - bells test - text reading - figure copying - clock drawing - overlapping	86% sensitivity for whole battery; individual sensitivity of tests ~50% and below combination of shape cancellation, complex line bisection and star cancellation = 88% sensitivity	Duration not specified

Screening Tool	Test Variation	Accuracy of Tool	Considerations for Use
	figures - writing	Adding two-part picture, articles reading and object finding = 100% sensitivity	

1.4.1.6 Pupil defects

Pupil defects can typically be detected through simple observation of the eyes and pupil reactions in varied lighting. A complete pupil assessment should include measurement of pupil size in standard room illumination as well as in dim light, checking direct and consensual response to light and the near response. The equipment necessary to carry out a pupil assessment is lightweight and inexpensive (e.g. pen torch, ruler, near fixation target) and so the assessment can be easily conducted at bedside. Assessment of pupil function does not require verbal communication from the patient, and only involves minimal instruction. As such, pupil assessment can be carried out on all stroke survivors and is feasible to conduct in the acute stages of stroke recovery provided the patient is conscious. While the procedures for pupil assessment are simple, detection of abnormalities and interpretation of the pupillary responses requires expert training, particularly when subtle defects are present. Consequently, pupil assessment should be carried out by a health care professional with appropriate training such as an eye care professional or neurologist.

1.4.1.7 Intra-ocular defects

A vitreous or retinal haemorrhage will cause a rapid reduction of central vision in the affected eye that may not resolve without intervention.[105] Patient or carer reported symptoms of reduced monocular vision or poor best-corrected visual acuity in one eye may allude to the presence of a haemorrhage, however conclusive diagnosis requires more detailed assessment. In clinical practice, vitreous or retinal haemorrhages are diagnosed during a dilated fundus examination using a slit lamp, ophthalmoscope, fundus camera and/or optical coherence tomography (OCT).[105] Examination of this kind does not require the patient to be responsive or communicate. Ophthalmoscopes are small, portable pieces of equipment, and portable slit lamps and fundus cameras are available. With the exception of ophthalmoscopes, this equipment is highly specialised and expensive, and are not widely used in hospitals.

Table mounted machinery such as fundus cameras and OCT are typically used in eye clinics, and so may be available in hospitals with an ophthalmology service. Assessment on table mounted machinery would require the patient to be well enough to travel to the eye clinic (either within the treating hospital or to an external eye clinic) as well as have good sitting

balance, reasonably steady fixation and the ability to follow basic instructions on eye positioning. This makes diagnosis of posterior eye conditions such as haemorrhages difficult in an acute stroke population. While haemorrhages at the posterior of the eye are not uncommon in stroke patients,[22,106] screening tools for this population do not typically test for retinal pathologies, with the exception of questioning previously diagnosed conditions.

1.4.1.8 Lid/ Tear dysfunction

Lid and tear dysfunction are often associated with each other and should be considered collectively when screening for abnormalities. Lid dysfunction such as the inability to completely open or close one eye, can be easily detected through observation. More detailed assessment may involve various measurements such as the width of the palpebral fissure, extent of levator function, and margin reflex distances. The measurements are simple to obtain and only require a ruler and pen torch. However, accurate acquisition of these measures does require appropriate training and knowledge of the ocular and facial muscles involved in lid function. Inability to completely close one or both eyes can lead to break down of the tear film, dryness and exposure of the cornea.[107] This will often cause symptoms of discomfort, and eye pain of the ocular surface if nerve function in this area is intact. Prolonged exposure of the cornea can lead to corneal erosion and scarring, which can permanently reduce vision.[105] It should hence be assumed that if lid dysfunction prevents complete closure of the eye, there is consequent tear film disruption.

As discussed previously, some cranial nerve palsies can also affect tear film production. This may result in disruption of the tear film and dry eye with or without the presence of lid abnormalities. Again, patient reported symptoms of ocular discomfort, pain and/or blurred vision in the affected eye(s) can indicate an issue with the tear film.[105] More conclusive diagnosis of the cause and severity of the tear dysfunction requires a more in-depth assessment. This is typically performed on a slit lamp, sometimes with the use of topical fluorescein dye to highlight areas of irregularity of the ocular surface.[105] Assessment of tear film integrity, tear break up time and corneal abnormalities should be performed. Other tests to investigate tear irregularities include the Schirmer's test and tear osmolarity.[105] All of the aforementioned assessment methods require cooperation from the patient with regard to communication, understanding and following instructions as well as ability to maintain a stable seated position and gaze. Without communication from the patient, detection of tear dysfunction and/or dry eye may be difficult in an acute stroke population but remains extremely important to prevent patient discomfort and potential vision loss if left untreated.

1.4.1.9 Pre-existing eye conditions

Pre-existing eye conditions are found in approximately 14% of stroke survivors.[108] Ideally, these conditions would be determined by requesting the patient's records from their treating eye care provider. This would provide accurate and comprehensive details of their ocular health without recall bias or the need for extensive questioning of the stroke survivor or family. However, this would require the stroke survivor or their carer to provide the details of their treating eye care provider(s) which may not always be possible due to issues with memory and/or communication. This method also does not account for those who have not previously sought formal eye care and so do not have a medical history of these conditions available. Various vision screening tools for use in stroke survivors also question previous ocular conditions as part of the assessment (see Table 1.3). While this has been shown to be a valuable and often effective means of identifying pre-existing eye conditions, it again requires good communicative ability, cognitive function and reasonably accurate memory from the patient. Where the stroke survivor is unable to provide their own visual history, this may be asked of their family or carer. However, it should be considered that not all patients will have a family member or carer present, or that this person may not be aware of their full visual history. A comprehensive ophthalmological assessment can often determine and differentiate pre-existing and newly acquired eye conditions. This would involve a lengthy assessment by an ophthalmologist utilising many, if not all of the specialised techniques and equipment previously discussed in order to investigate conditions that may be age-related, familial, idiopathic or caused by the stroke.

1.5 MANAGEMENT OF STROKE RELATED VISION DISORDERS: ACUTE

As stroke can cause a variety of eye conditions, depending on the location and extent of the stroke, a stroke survivor may acquire one or more vision/eye disorders as a consequence. They may also have pre-existing eye conditions that are compounded by stroke related vision loss, and are likely to have other concurrent sensory, cognitive, and physical deficits. In a large English study of acute stroke patients, 20% of stroke survivors within an acute stage of two weeks post-stroke could not undergo vision assessment or intervention.[108] Over 50% of those unable to participate in vision care were a result of early discharge, other reasons included being medically unwell, unconscious or on an 'end of life pathway'.[108] As such, the management of post-stroke visual conditions can be complicated and may not always be feasible to address immediately in the context of acute stroke.

However, there are a variety of short-term management options that can be easily provided to stroke survivors during the acute stages of recovery that may ease the burden of their vision problems, at least in part, until more formal management can be provided. Of course, the plausibility of treatment provision is dependent on prior vision screening to determine what the vision problem is. For almost all visual conditions, the first form of management should be the provision of information about the condition: what it is, if and how it can be treated, what the expected recovery is, what the functional implications are and what further management and support services are available.[109,110] Stroke survivors in the UK have reported that provision of this information early in their post-stroke recovery and throughout helped to reduce feelings of anxiety and uncertainty about their vision problems.[36,111] Beyond this, the management strategies utilised should be specific to the condition as well as the symptoms and needs of the patient.

1.5.1 Visual field loss

Recovery of visual field loss, if it occurs, typically takes place in the first 6 months post-stroke but is often incomplete,[23] hence short-term management strategies should be employed where possible, to mitigate the impact of the visual field loss on rehabilitation. The impact of visual field defects can vary according to location, size and density of the loss. These details should be provided to the stroke survivor and/or their family where possible. This may aid understanding of their condition and hence improve awareness and help develop compensation strategies.[112] Advice can also be provided with regard to how to maximise use of their remaining visual field by the stroke survivor strategically positioning themselves in different circumstances. For example, a patient with right hemifield loss should position themselves so that the object of fixation (a person in conversation, the TV, their dinner plate) is to their left. In addition, the patient should also be encouraged to make eye movements towards the area of loss, to better identify potential hazards or necessary items.[23,113] This visual scanning can be continued as more formalised training under the supervision of an appropriately trained health professional and/or incidentally as part of other rehabilitation activities. Visual scanning training may not always be appropriate in the acute stages of recovery and should be considered on a case-by-case basis. Visual scanning techniques will be discussed in further detail as a long-term management strategy (Section 1.6). Peli prisms may also be used to promote awareness of objects and 'expand' the visual field, by placing segments of Fresnel prisms on the patient's glasses above and/or below the pupil margins.[114] Prisms of an appropriate power and correctly fitted with the prism base towards the affected side, can shift images from the area of visual field loss into the seeing field and hence may help

to compensate for the visual field loss during rehabilitation. However, prisms may be poorly tolerated and potentially exacerbate confusion in stroke survivors with cognitive deficits and existing evidence in favour of Peli prism use may be biased by a period effect of the study design.[115]

1.5.2 Eye movement abnormalities

Recovery from eye movement abnormalities can be rapid in some cases and complete recovery is possible, depending on the condition and cause.[26] Health professionals providing care should deliver information on recovery that is specific to the individual's condition. For example, a microvascular cranial nerve palsy may recover in full within three to six months. However, a brainstem lesion causing a gaze palsy, is unlikely to completely recover and improvement occurs slowly over a period of 6-12 months. The primary complaint of patients with eye movement abnormalities is often diplopia,[26] which can be disorientating and extremely uncomfortable. It can make simple everyday tasks very difficult and hence is likely to be a hindrance during stroke recovery, in both the acute and long-term stages. Effective short-term relief of diplopia can be achieved through monocular occlusion, using an eye patch.[25] Typically, if vision is unequal between the eyes, the eye with poorer vision is covered so that the patient still has a functional level of vision.[78] If vision is equal in both eyes then alternate occlusion may be appropriate.

Fresnel prisms are also an effective means of treating diplopia caused by misalignment of the eyes. The strength of the prisms should be determined based on the prism bar cover test results performed at the required distance (measures may differ for near and distance fixation). The prism(s) are then fit to the patient's glasses in the appropriate orientation over the affected eye (or sometimes over both) to shift the image onto a different part of the retina. When the image falls on corresponding retinal points in both eyes, it can then be fused and seen as a single image. The use of Fresnel prisms can cause some reduction in visual acuity,[116,117] and prismatic aberrations in certain lighting,[118] which may be poorly tolerated by some patients, or if worn for prolonged periods.[78] Alternative use of occlusion and Fresnel prisms may help patients find a balance between improved comfort and functional vision during acute rehabilitation. Fresnel prisms fit onto progressive spectacle lenses can be problematic[119] as this lens type can often generate a prismatic effect of its own[120] and so may reduce the effectiveness and tolerability of the Fresnel prisms.

Occlusion is the most commonly used treatment method in the acute stages of eye movement disorders, as recovery can be quite rapid in some cases of ocular motility defect. If prisms were

used it would require changing the power of fitted Fresnel prisms often.[109] However, use of occlusion rather than prisms, renders the patient monocular and can have significant implications on mobility. In some cases of eye movement abnormalities, adopting an alternative head posture can keep the eyes in a position that avoids the gaze where diplopia is present or helps to minimise the diplopia.[25,26] This method can sometimes be used to also reduce nystagmus by utilising the 'null point'. If a null point, or position of gaze where nystagmus is least apparent, has been identified, then adopting a head posture to keep the eyes in this position, may improve the quality of vision.[112] Similarly, Fresnel prisms may also be used to manage nystagmus by fitting them in such a way (yoked) that the eyes are kept in the null point position.[112]

1.5.3 Visual processing disorders

As visual processing disorders can cause more obscure, sometimes confusing symptoms, they can be particularly concerning to patients who may not understand what they are experiencing or why. It has been reported that due to the nature of visual processing disorders causing 'unusual' or poorly understood symptoms, they are less frequently reported than other stroke-related visual conditions.[111,121] Having such conditions diagnosed, recognised and explained, may offer some reassurance to stroke survivors and promote better understanding amongst their friends and family.[111] Feelings of anxiety and depression are common following stroke and so the provision of information in the case of less recognised conditions, such as visual processing disorders, is an important form of management to minimise their burden. Advice on coping strategies and information about treatment options and/or support services available, may also be appropriate, depending on the exact nature of the condition and the readiness of the patient to accept the condition. In the case of visual neglect, additional short-term management may include promoting awareness of the neglected side.[109] This may be done through repeated encouragement to scan and acknowledge items in the area of neglect and the incorporation of visual scanning into other rehabilitation activities, where appropriate.

1.5.4 Pupil defects

Pupil abnormalities can cause blurred vision at a certain distances and difficulty seeing in low light or sensitivity to light (photophobia).[105] Ensuring that the patient has glasses that are appropriate for their refractive error will not eliminate the difficulty caused by the pupil defect, but will allow the stroke survivor to have the best vision possible until treatment can be provided. In the case of fixed dilated pupils, dimmer lighting or use of tinted lenses may reduce photophobia and improve comfort.[122] Conversely, stroke survivors with miosed pupil(s) may

benefit from a well-lit environment and direct lighting when eating meals, reading, and performing other detailed close activities.

1.5.5 Intra-ocular conditions

Haemorrhages in the posterior eye generally require surgical intervention and can be treated quite successfully. While it may not be appropriate for a stroke survivor in the acute stages of recovery to undergo this type of treatment, providing them with information about their condition, and the treatment options available with a likely positive prognosis, can ease their concerns about their vision loss. The disruption to central vision caused by haemorrhages can cause difficulty in conducting tasks when viewing with both eyes. Occlusion of the affected eye may prevent disrupted images from this eye and improve the functionality of the patient's vision until treatment can be obtained.

1.5.6 Lid/ Tear dysfunction

As discussed, the inability to completely close one or both eyes due to lid dysfunction can lead to drying of the eye and eventuate to corneal exposure. To relieve the symptoms of dry eye and protect the cornea, ocular lubricants should be administered to the affected eye hourly.[105] A thick lubricating ointment should also be administered to the affected eye and the eye lids taped shut before the patient goes to sleep.[105] Care should be taken to use a tape that is gentle on the skin and accounts for any allergies the patient might have. Bandage contact lenses may also be used if signs of corneal exposure start to occur.[105] Depending on the patient's physical condition, contact lenses may have to be inserted and maintained by their treating health professionals. If the patient is able to insert contact lenses themselves, proper education on how to insert and remove the contact lens and proper hygiene practices should be provided.

1.6 MANAGEMENT OF STROKE RELATED VISION DISORDERS: LONG-TERM

Little is known about current care practices in Australia for treatment of vision loss following stroke and no treatment methods are discussed in the Clinical Guidelines for Stroke Management.[52] The guidelines do indicate that for those at high risk of falls, a comprehensive home assessment for falls management should be undertaken and modifications made where necessary. It is known that vision impairment increases the likelihood of falls in older people[37,123] and so it is advisable that this recommendation is followed for stroke survivors with resultant vision impairment.

1.6.1 Visual field loss

There is still limited evidence available on all current treatment methods for visual field loss following stroke and so it is not possible to make conclusive comment on the effectiveness of

these methods.[113] Studies conducted in the UK suggest that advice and information provision are the most commonly utilised treatment methods by eye care professionals in the early stages for post-stroke visual field loss.[23,124] Other methods of treatment can be classified as restitutive, compensatory and substitutive. Compensatory treatments refer to visual scanning and search training methods that aim to teach the patient to compensate for their field loss by improving the speed and accuracy of eye movements to the affected side. There are mixed results published regarding the effectiveness of compensatory treatment methods.[109] However, a Cochrane review on interventions for visual field loss, recommended that these methods are more beneficial than placebo or control at improving specific tasks but not at assisting recovery of the visual field loss.[113] Reports of expansion of the visual field of 1-48 degrees following compensatory treatment have been made,[125] however these improvements may be the result of natural recovery within the 12 months following stroke. Specific improvements in speed and accuracy of eye movements to the affected side, increased reaction times,[126-130] and increased number of saccades[131] after visual scanning training have also been reported.

Stroke survivors have also reported subjective improvements in activities of daily living such as reading speed and accuracy.[126,127,130] A study by Nelles et al. found that this training is associated with increased activity in the affected cortex and is believed to be task specific.[132] That is to say, those that underwent visual search training demonstrated improvement in scanning to the affected side but little to no improvement in reading tasks while those who had reading training showed improved reading ability but little improvement on visual search tasks.[129,133] Consequently, a combined training strategy appears favourable and has since been proven to cause improvement in both tasks.[126] Other compensatory interventions utilise typoscopes, rulers, and vertical reading. While typoscopes are reportedly commonly used as a method of treatment by health professionals in the UK, their effectiveness has not been thoroughly investigated.[109]

Peli prisms are a form of substitutive treatment that can also be used as a long-term management strategy for visual field loss. The premise of shifting the images from the area of loss into the 'seeing' part of a visual field, is designed to cue the patient to shift the centre of their gaze towards the affected side and hence improve awareness of objects on the side of their hemianopia and assist scanning.[114] A study of participants with visual field loss found that the majority (74%) reported a positive difference after six weeks of use, of which 93% continued using the Peli prisms for up to three months and 42% maintained use at the 'long term follow-up'.[115] Another group of participants reported that they wished to continue using

Peli prisms, because they assisted with walking.[134] When Peli prisms were trialled in the traditional horizontal position and an oblique position, there was no difference in the number of participants who wished to continue use, for either orientation of the prisms.[134]

Visual restoration therapy utilises light stimuli presented at the border of the area of visual field loss for a prescribed amount of time,[113] with prescribed training time varying significantly between studies.[135-139] A number of studies reported expansion of the visual field by 1-11.3 degrees following treatment,[137,140,141] however, eye movement recordings were not performed and so improvement in visual scanning cannot be excluded. In those studies that did record eye movements using a scanning laser ophthalmoscope, little to no change in the visual field loss dimensions was noted.[138,142,143] The majority of studies recruited patients with chronic homonymous hemianopia (longer than 6 months) as a means of excluding natural recovery. Despite the lack of objective improvement, participants reported an improvement in quality of life and activities of daily living such as mobility and reading.[135,144,145] It is possible that these subjective improvements may be due to adaptation to the visual field loss over time rather than a result of the therapy.

1.6.2 Nystagmus

Much of the evidence available regarding eye movement abnormalities have been investigated in populations with mixed aetiology, as such abnormalities can occur as a result of several neurological conditions in addition to stroke.[109] Pharmacological interventions are often the first line of treatment used for nystagmus, however, there is limited evidence available regarding the treatment of nystagmus specifically in stroke populations.[146] Neurologists most commonly report prescription of Gabapentin and Baclofen for nystagmus management.[147] Trihexyphenidyl has been shown to have no effect on the velocity of nystagmus, while 3,4-diaminopyridine did have a significant effect but was not replicated when assessed in a sub-group of stroke patients.[146] Botulinum toxin has also been trialled for treatment of nystagmus, however, this requires repeat injection into the extraocular muscles every 3-6 months, which proved to be a barrier for many patients as a long-term treatment method.[148]

1.6.3 Eye movement abnormalities

Botulinum toxin is also widely used for treatment of strabismus,[149] particularly when planning for more permanent treatment such as ocular muscle surgery or when such surgery is not possible. The use of Fresnel prisms or permanent prisms ground into spectacles is also widely employed for treatment of strabismus and eye movement abnormalities, such as cranial nerve and gaze palsies.[109] In patients that have the potential for binocular single vision, prisms are

used to compensate for eye misalignment by shifting the image from the deviated eye so that it overlaps with that in the other eye and the two images can be fused. Alternatively, prisms can be used to shift the image from one eye into a pre-existing area of suppression or simply further away from the central field of view, so it is more easily ignored. However, prisms are limited in their use for large ocular deviations and in the case of torsional diplopia (tilted images), with most existing trials excluding deviations above 30 prism dioptres in size.[150,151] In such circumstances, the use of occlusion or an alternative head posture may be more appropriate. Occlusion for the treatment of diplopia may involve complete occlusion of one eye or partial occlusion if the diplopia is only present in one direction of gaze.

In some cases of eye movement abnormalities, such as vergence disorders, conservative treatment with orthoptic exercises may be appropriate. Convergence insufficiency has been reported in up to one third of stroke survivors and can cause difficulty reading, as well as symptoms of diplopia and asthenopia.[22] Treatment with vergence exercises to improve convergence capability can eliminate these symptoms when looking at near objects and particularly when reading.[152] If vergence training is unsuccessful or deemed inappropriate for the patient, surgical intervention may be required. It has been postulated that despite the lack of evidence for these treatments in stroke populations, the treatment benefits should be similar to other cohorts with acquired eye movement abnormalities.[109] The clear benefits of these treatment methods through practical application over the many years, likely reduces the need for clinical trials to be conducted, and their continued successful use in clinical practice is indicative of their ability to alleviate symptoms.[112]

1.6.4 Visual processing disorders

There is currently a lack of high quality evidence regarding interventions for visual perceptual disorders, with very few treatment options discussed in the literature.[109] Spontaneous recovery of visual processing disorders may occur, however, it is recommended that diagnosis, explanation of the condition and advice on coping strategies are of benefit to stroke survivors with this type of deficit.[36,111] Published interventions for visual perceptual disorders include functional training, sensory stimulation, strategy training, and repetition.[153] Functional training involves the repeated practice of daily activities that aims to improve patient independence, rather than treat the cause of the problem. Sensory stimulation utilised procedures target visuo-perceptual processes such as colour matching, shape recognition, and judgement of line length. The rationale for this training is that when patients carry out these perceptual tasks, they will show improvement on other non-trained tasks that utilise similar perceptual elements.[153] Strategy training might be viewed as a form of compensatory treatment, whereby

the patient learns a rule or technique that can be used when they encounter activities that require perceptual processing. Finally, repetition therapy requires the patient to repeat particular tasks until their performance improves. It differs from the aforementioned strategies, in that there is no practice of everyday activities, no focus on basic sensory processing and no teaching of explicit strategies.

All of the available trials exploring these treatment options for stroke survivors, utilise sensory stimulation, sometimes in combination with another strategy.[153] No trials provide data on long term improvement in ADL scores and in those that had a control group, no significant difference in ADL scores was detected.[153] Cross-modal word recognition training has been investigated in patients with alexia where single words were presented visually and via audio simultaneously.[154] Patients recognised words from the training program faster than untrained words, but this improvement was not maintained at follow up.

A survey of occupational therapists in Canada revealed that the most commonly reported treatment methods for visual neglect were perceptual retraining (33.2%) and visual scanning training (16.2%). However no details on how these interventions were performed was provided.[155] A similar survey of Orthoptists in Scotland indicated that advice and/or explanation regarding visual neglect was the most widely used management strategy (72%) among others, such as typoscopes, reading aids, and non-computerised scanning therapy.[49] A trial by Machner et al investigated the effect of hemifield eye patching of the non-neglect side of the visual field and optokinetic stimulation on the side of the neglect.[156] Both the control group and the treatment group had equal improvement in neglect-related functional disability. A 2013 Cochrane meta-analysis review showed cognitive rehabilitation to have a significant immediate effect on standardised assessments, however, when only high quality trials were included in the meta-analysis, this effect was not maintained.[157] Similar ambiguity remains regarding visual scanning training for treatment of visual neglect, as published studies are too dissimilar to make comparisons and so further high-quality evidence is needed in order to support or refute this as a treatment strategy.[109] There is some evidence to support the use of smooth pursuit training over standard scanning therapy, as greater improvement has been shown in both auditory and visual outcomes.[158] This improvement was maintained at a two week follow-up for both mild and severe cases of neglect.

1.6.5 Pupil defects

Pupil defects are difficult to treat in isolation and need to be addressed in relation to the systemic cause of the defect if no spontaneous recovery occurs. Formal assessment and

management by an ophthalmologist and/or neurologist should be undertaken to ensure cause of the pupil abnormality (typically neurological) is addressed.[105] It is possible to address unequal pupil size, particularly where this causes impaired depth of focus or glare, e.g. miotics for a dilated pupil.[159]

1.6.6 Intra-ocular conditions

As previously discussed, retinal artery or vein occlusion is a form of stroke in itself, as the optic nerve (ON) and retina are considered an extension of the central nervous system. Central retinal artery occlusion (CRAO) can cause irreversible ischemia of the retina within four hours of onset.[160] Where cases are presented to medical services within this timeframe, intravenous or intra-arterial thrombolysis may be performed to dissolve the arterial occlusion.[160] Hyperbaric oxygen has also recently been shown to have benefit in CRAO treatment by increasing oxygenation to the inner retinal layer.[161] However, this treatment is most effective in patients who present to medical services within 24 hours of onset.[160] In patients with acute CRAO who are aged over 50, it is important to rule out giant cell arteritis by pathology testing, as they may require urgent steroid treatment to prevent extensive vision loss.[160] Commonly in older patients, the cause of ischemia is atherosclerosis and emboli, which warrants urgent referral to a stroke centre for investigation and treatment. In cases of non-arteritic CRAO, other approaches such as ocular digital massage and anterior chamber paracentesis have been proposed to dislodge the blockage and support arterial reperfusion.[105] These interventions have not been evaluated in randomised clinical trials.[160]

Retinal vein occlusion is generally not treated with anticoagulation therapy as this has not been demonstrated to be effective and may worsen the visual condition of patients.[161] Similarly, systemic thrombolytic therapy has been shown to be ineffective or too risky for treatment of this condition.[161]

Treatment for retinal vein occlusion primarily aims to: reduce macula oedema that has a significant impact on visual acuity, increase oxygenation of the retina and prevent further neovascularisation.[105] Such treatment methods include intravitreal injections and implants of corticosteroids, intravitreal injection of anti-VEGF drugs, hyperbaric oxygenation, pars plana vitrectomy and laser photocoagulation.[161] Corticosteroids aim to downregulate the expression of cytokines and chemokines as a means of re-establishing the blood-retina barrier and preventing ‘leaking’ of the blood vessels.[161] Anti-VEGF drugs work to block a particular cytokine, VEGF, which in turn leads to vasoconstriction and reduced macula oedema.[161] This is now commonly used as the first line of treatment for macula oedema due to proven

immediate and long-term improvements in visual acuity.[160] This form of treatment, however, does require intravitreal injections repeated every four weeks initially and as such can be burdensome and invasive. Vitrectomy will typically be performed if vitreomacular traction and/or vitreous haemorrhage occurs as a result of retinal vein occlusion, but is also proposed to remove the scaffold for growth of new abnormal vessels and increase retinal oxygenation.[161] Similarly, laser photocoagulation has also been found to increase retinal oxygenation and constrict retinal and collateral veins within the treated area.[162] Typically, laser treatment is reserved for those cases with persistent leakage from focal aneurysms or for treatment of major ischemic branch retinal vein occlusions.[160] There is potential for retinal vein occlusions to resolve without intervention, however treatment should address any systemic and ocular risk factors such as hypertension or primary open-angle glaucoma, in order to reduce the chance of recurrence and involvement of the fellow eye.[105]

The primary treatment methods for other pre-chiasmal stroke related visual conditions such as non-arteritic anterior ischemic optic neuropathy (NAION) and papilledema are based on management of the systemic risk factors.[105] While there are currently no effective treatments for NAION in isolation, aspirin is often prescribed prophylactically to reduce risk of TIA or stroke.[163] Management of arteriosclerotic risk factors is still the governing principle in NAION treatment, with particular focus on avoiding over-treatment of hypertension.[163] In the case of papilledema caused by haemorrhagic stroke and resultant increased intracranial pressure (ICP), acute treatment of the haemorrhage is critical and will depend on the systemic wellbeing of the patient. Medical treatment to manage hypertension is advised and is generally accompanied by intravenous administration of activated coagulation factor VII.[164] Intracranial hypertension may be managed with Mannitol and/or Furosemide depending on its severity and the tolerance of the medications by the patient.[164] Surgical interventions include craniotomy for decompression of the brain or surgical clipping of aneurysms.[164]

1.6.7 Lid/ Tear dysfunction

The primary ocular complication from lid and/or tear dysfunction is exposure keratopathy that results from the inability to close one or both eyes completely and an unstable or insufficient tear film.[107] In mild cases, frequent lubrication with preservative free artificial tears is recommended during the day, with a lubricating ointment administered at night with eyelid(s) taped shut.[105] For more severe cases, lubricating ointment may be necessary periodically during the day in combination with artificial tears.[105] Punctal occlusion, to block drainage of tears, may also assist in the treatment of persistent dry eye, however, this treatment alone may not be sufficient to prevent exposure keratitis if lid closure is not possible. The lateral

portion of the eye lid may also be taped shut during the day to prevent exposure while avoiding obstruction of the visual axis. Bandage contact lenses are also commonly used in addition to ocular lubricants for patients with exposure keratitis as a means of protecting the cornea and improving comfort.[165,166] If the issue persists without any spontaneous recovery of lid function, surgical intervention may be required.[107] Partial tarsorrhaphy or implantation of platinum or gold weights into the upper eyelid are utilised in chronic cases of facial nerve palsy to aid lid closure.[105] If severe corneal decompensation occurs within the visual axis, a corneal graft may be considered in an attempt to restore some visual function to the affected eye.[105]

1.6.8 Vision support services

In some cases of vision problems following stroke, the condition may persist in the absence of effective treatment, leaving the stroke survivor with permanent and debilitating vision impairment. While the lack of treatment options available is undoubtedly disheartening for many in this situation, the option to access low vision aids, assistive technology, and strategies to regain independence may offer physical and psychological benefits. Vision support services such as Vision Australia and Guide Dogs NSW provide a variety of helpful services, including access to low vision aids and services, orientation and mobility training, workplace support, occupational therapy and orthoptic services, as well as providing access to community support groups. The use of low vision aids for patients who have persistent reduced central vision even after glasses correction, has been shown to have benefit.[167] There is also information available on home modifications and use of lighting to aid visually impaired people, however, these methods are yet to be validated for use in stroke survivors with vision impairment.[109] Despite this, there is some indication that such services improve functional ability[168] and stroke survivors have indicated a preference to be provided with the information about these services prior to discharge.[36,111] Other vision support services available within Australia include the Macular Disease Foundation Australia, Retina Australia, Glaucoma Australia, Blind Citizens Australia, Next Sense, Centre for Eye Health and Royal Society for the Blind.

1.7 AGE - RELATED EYE CONDITIONS

The Australian Institute for Health and Wellbeing reports that 93% of Australians aged 65 and over are affected by long-term vision disorders.[29] The most common causes of vision loss reported within the Australian population are refractive error, cataracts, macular degeneration, glaucoma, diabetic retinopathy.[29,169] Symptomatic dry eye is also estimated to be prevalent in over 50% of older Australians.[170] Pre-existing eye conditions occur in up to 40% of stroke survivors[171] with refractive error, glaucoma, age-related macular degeneration,

cataract and diabetic retinopathy found to be the most common eye conditions in populations of stroke survivors in Australia and the UK.[24,29]

1.7.1 Refractive error

Refractive error is inclusive of hyperopia (long-sightedness), myopia (short-sightedness), presbyopia (age-related reduced elasticity of the lens causing loss of ability to focus on close objects) and astigmatism (irregular corneal curvature). Refractive error can be effectively treated with glasses or contact lenses. Despite this, uncorrected refractive error is still reported to be the leading cause of vision loss in older Australians.[169] It is also a common and addressable condition in stroke survivors.[21,172]

1.7.2 Glaucoma

Glaucoma affects approximately 4% of Australians over the age of 65 years.[29] There are several types of glaucoma that vary in the mechanism of disease, however, all cause progressive vision loss due to damage of the ON and retinal nerve fibres. The most common form of glaucoma in older people is primary open angle glaucoma (POAG).[105] The majority of patients with POAG have elevated intraocular pressure (normal range of 10-21 mmHg)[105] that results in slow but progressive atrophy of the ON. Glaucoma development is largely asymptomatic until its later stages and as a result, diagnosis is often not possible until the disease has progressed to a point where changes to optic disc (located where the ON enters the eye) and/or retinal nerve fibres appearance or vision loss are evident.

Clinical signs of glaucoma include characteristic patterns of visual field loss such as a nasal step, paracentral scotoma, arcuate scotoma, altitudinal defects, constriction and/or generalised depression of the visual field.[105] Other clinical signs may be visible upon assessment of the optic disc and ON through fundoscopy, photography or OCT. The optic disc may show thinning of tissue at its rim that begins inferiorly in most cases.[105] Thinning of the retinal nerve fibre layer may also be evident on OCT and an increased cup to disc ratio (usually >0.6).[105] In some cases of POAG, patients may display clinical signs in the absence of elevated intraocular pressure. This is referred to as normal or low tension glaucoma.[105] Contrary to this, patients may also present with elevated intraocular pressure but no other clinical signs or symptoms, which is considered ocular hypertension.

The first line of treatment for POAG is typically medication in the form of eye drops that aim to reduce intraocular pressure.[105] In most cases, a single drug will be prescribed and may be later changed or used in combination with another drug types to improve effectiveness and/or reduce side effects. Drugs for the treatment of glaucoma include prostaglandin agonists, beta-

blockers, selective a2-receptor agonists, carbonic anhydrase inhibitors and miotics.[105] Depending on the effectiveness of medical intervention, patient compliance and observed side effects, other interventions such as laser or surgery may be required. Argon laser trabeculoplasty (ALT) and selective laser trabeculoplasty (SLT) both aim to improve aqueous flow through the trabecular meshwork and hence lower intraocular pressure.[173] ALT and SLT have proven efficacy at lowering intraocular pressure but have a similar diminishing effect over time.[174] However, ALT is not appropriate for repeat treatments due damage caused by scarring of the trabecular meshwork and surrounding tissue.[175] SLT causes minimal histological damage to the treated area[175] and as a result can be repeated as an adjunctive therapy to medication or in bridging the gap between medical and surgical interventions.

Surgical interventions include trabeculectomy, tube shunt procedures and newer, micro-surgeries, such as the iStent trabecular micro-bypass.[105] The appropriateness of surgical intervention is determined by glaucoma severity, individual patient circumstances affecting compliance and efficacy of prior treatment. There are several other types of glaucoma that are less common but can be equally detrimental to vision such as: angle closure glaucoma, inflammatory glaucoma, pigment-dispersion syndrome (pigmentary glaucoma), pseudo exfoliation syndrome (exfoliative glaucoma) and neovascular glaucoma.[105] The pathophysiology of each of these varies and hence treatment options aim to address the cause of reduced aqueous drainage and resultant elevated intraocular pressure.[105]

1.7.3 Cataracts

Cataracts refers to the opacification of the normally clear crystalline lens in the eye. It usually develops gradually with age as a normal physiological occurrence. Cataracts can cause visual symptoms such as glare, blur, colour desaturation and in some cases, monocular diplopia and myopic shift.[105] The age at which cataracts become symptomatic is generally 65 years or older.[29] This may be accelerated by environmental factors, such as consistent over-exposure to UV light, injury to the eye through accident or surgery, drugs such as steroids and antipsychotics, or by systemic disease such as diabetes.[105] The most common types of cataracts (nuclear, posterior subcapsular, and cortical) refer to the nature and location of the opacity within the crystalline lens and will vary symptoms accordingly.[105] Cataract surgery involves removing the opaque lens and replacing it with an artificial intraocular lens of a specific power suitable for the patient. The necessity of cataract surgery will depend on the extent of visual disruption or the need to treat co-existing ocular conditions (e.g. to allow view of the fundus in the management of retinal disease).

1.7.4 Age-related macular degeneration

In 2017-18 there were approximately 244,000 Australians with age-related macular degeneration (AMD),[29] which has been reported to be the leading cause of blindness in those aged 65 and over.[169] Macular degeneration may be non-exudative (dry) or neovascular/ exudative (wet), with the possibility for dry AMD to progress to wet AMD over time.[105] AMD causes gradual reduction of central vision over time, supposedly as a result of oxidative stress on retinal cells from build-up of lipid and protein deposits (drusen) within the retina, exacerbated by ageing and smoking.[176] Clinical signs of dry AMD include macular drusen, reduced visual acuity, Amsler grid abnormalities and impaired dark adaptation.

Treatment options for dry AMD are still very limited and focus primarily on managing risk factors such as smoking, hypertension and hypercholesterolemia, as well as increasing intake of antioxidants such as Vitamin C, E, lutein, zeaxanthin and zinc to slow progression.[176] Wet AMD involves choroidal neovascularisation (CNV) whereby abnormal blood vessels invade the retinal pigment epithelium and/or retina and cause haemorrhaging and accumulation of blood in the sub-, intra- or preretinal areas.[105] Wet AMD is associated with significant central vision loss, metamorphopsia and central or paracentral scotomas.[105] The primary treatment method for wet AMD involves intravitreal anti-VEGF injections to reduce CNV and the consequent bleeding, which causes the central vision disturbance.[105] Late-stage AMD may involve multiple areas of retinal photoreceptor cells with retinal pigment epithelium atrophy, termed 'geographic atrophy'. The vision loss resulting from geographic atrophy is irreversible, as there are currently no interventions proven to be effective.[176]

1.7.5 Dry eye syndrome

Dry eye is typically caused by abnormality in the production of one or more components of the tear film. Symptoms of dry eye syndrome typically include burning or discomfort of the eye(s), foreign body sensation, mild to moderate reduced vision and excessive tearing.[105] Symptoms are often exacerbated by wind, smoke, excessive heat, low humidity or prolonged use (e.g. driving, computer use, watching TV). Clinical signs may include irregular tear meniscus at the inferior lid margin (<0.5mm height) or reduced tear break-up time (<10 seconds).[105] Other indications may include punctate corneal or conjunctival staining with fluorescein, rose bengal or lissamine green dye; or the presence of corneal filaments in more severe cases. Treatment will include the use of artificial tears (approximately four times per day) in isolation if dry eye is considered mild, or in combination with a lubricating ointment in more severe cases.[105] Punctal occlusion with collagen or silicone plugs may also be appropriate if symptoms persist or worsen. Adjunctive treatment may include oral flaxseed oil, omega-3 fatty acids, topical

vitamin A and/or use of a bandage contact lens.[105] In addition, ocular pathologies can cause dry eye symptoms such as corneal surface irregularities, lid closure problems and palsies of the trigeminal and facial nerves (see Chapter 2, 2.3.5) but these are not included in the diagnosis of dry eye syndrome.[105]

1.8 OTHER CONSIDERATIONS FOR STROKE SURVIVORS WITH VISION LOSS

The multiplicity and complexity of stroke-related visual deficits is apparent and stroke survivors need to be provided healthcare accordingly. The relationship between vision impairment and a range of adverse outcomes, such as increased dependency on support services,[36] increased likelihood of nursing home admission,[34] depression and mortality[34,38] are well established. Similarly, stroke survivors share this increased risk of depression[177], nursing home admission[178] and report feeling a loss of independence.[179] Equally important, but often overlooked by healthcare providers, is the mental and emotional wellbeing of the carer. Evidence suggests that spouses of stroke survivors are more likely to be depressed and display more physical ailments[180] and informal carers experience loss of autonomy and independence[181] following the stroke event.

This demonstrates the importance of a holistic patient care approach in stroke recovery. In the case of stroke survivors with vision impairment, this should include access to counselling and/or psychology services, with ongoing support services that work with patients to help them to meet their individual recovery goals and opportunities to connect with emotional support groups. In addition, a support service to maximise vision and visual comfort are also vital.

The importance of effective communication and collaboration between members of the multidisciplinary stroke team should not be underestimated. As discussed previously, many of the limitations in vision assessment and diagnosis relate to potential communication, cognitive and/or physical deficits of the patient. Where such comorbidities exist, assessment and management efforts are likely to be vastly improved through collaborative care provision between eye care professionals, speech pathologists, physiotherapists and occupational therapists. While there is limited information available regarding the presence of eye care professionals in stroke care teams within Australia, there is evidence to support the benefit of inclusion of orthoptists and optometrists in stroke care settings overseas.[182-184] Effective multidisciplinary collaboration in stroke rehabilitation settings requires ease of access and coordination between specialist services to best meet the care needs of stroke survivors.

Shared experience among peer support groups and community based self-managed programs have clear benefit for stroke survivors long-term recovery.[185,186] In the context of Australian healthcare, the role of social workers in helping to facilitate this care provision should be highlighted. While the Clinical Guidelines for Stroke Management indicate a need for the provision of information regarding available community and specialised support, there is no specific call for social workers in this role. Introduction to a social worker early in the recovery process can assist in patient and carer support and may help to lighten the emotional burden of dealing with multiple diagnoses, aid in providing a patient centred approach to rehabilitation efforts, inform the multidisciplinary team of eligibility requirements for support services and improve communication and collaboration between the team in the absence of a case manager.[187,188]

In addition, the financial burden of stroke for the stroke survivor and potentially their carer and/or dependants is not addressed in current care guidelines within Australia. Stroke survivors in the UK report being unable to return to work as a result of their post-stroke vision impairment.[36] Another qualitative study of stroke survivors in the UK indicated that this inability to work is compounded by greater expenditure on medical appointments and services after suffering stroke.[111] Fortunately in Australia there are currently financial support programs in place for citizens living with disability. The primary financial support programs available for Australians are the National Disability Insurance Scheme (NDIS) for those aged under 65 years, and My Aged Care for those aged 65 and over. Other forms of financial support to aid independence of people with vision impairment also include the NSW spectacles programme, the Vision Impaired Persons Travel Pass, and the Taxi Transport subsidy scheme. Further avenues of financial support that may be accessible to Australians with stroke related vision loss include Centrelink (disability support pension, carer payment/allowance) and the Department of Veteran Affairs for those who previously served in the Australian Defence Force. There are specific eligibility requirements for each of the aforementioned financial support programs, and the application process can often be complicated and overwhelming for those without experience navigating these services. It is also possible that without the provision of information about these services, stroke survivors and their carers may not be aware of the financial support available to them. Provision of this information from the stroke care team and/or inclusion of a social worker or case manager within the team is likely to improve access to financial support. In turn, access to appropriate vision care and assistive technology is also likely to improve.

1.9 CONCLUSION

In Australia, stroke continues to have a profound personal and broader community impact. Vision impairment is common after stroke and is a significant barrier to the acute and long-term recovery of stroke survivors. Pre-existing and age-related vision conditions, among other stroke-related deficits, compound the impact of stroke-related vision loss. Often stroke-related vision problems require specialist care throughout stroke recovery and there is evidence to support early assessment and intervention to reduce the burden of vision impairment during rehabilitation. Inequality in access to stroke facilities and specialist vision care services between rural and metropolitan regions within Australia presents a potential barrier to meeting this need. Currently, there is very little evidence regarding the provision of post-stroke vision care in Australia and no evidence-based guidelines specific to management of stroke related vision disorders. The Australian Clinical Guidelines for Stroke Management currently only contain limited information regarding vision, including recommendation for visual acuity and visual field testing and treatment options for visual inattention only. A systematic review of the literature pertaining to current post-stroke vision care practices in Australia and internationally is provided in Chapter 3.

2 STROKE RELATED VISUAL CONDITIONS: A NARRATIVE REVIEW

2.1 INTRODUCTION

Stroke can cause a vast array of physical, cognitive, and sensory deficits, which are relative to the area of the central nervous system that has been impacted. The purpose of this chapter is to provide an overview of the many vision and eye disorders that can arise as a consequence of stroke. In doing so, we will demonstrate the breadth and complexity of stroke-related visual conditions that need to be considered in post-stroke vision care provision. Such an overview is necessary to understand the various areas within the brain and brainstem that play a role in vision and/or eye function, how these conditions may impact a person during their stroke recovery and provide context for discussion of appropriate assessment and management strategies for these conditions. A brief overview of the general functionality of each area of the brain is provided to indicate the potential for comorbidities caused by stroke. Stroke-related vision and eye disorders are discussed according to the overarching category of visual function they relate to (e.g. eye movement, visual processing) and in relation to the anatomical structures involved (Figure 2.1). As this chapter contains a number of terms specific to vision and eye function, the glossary of terms provided at the beginning of this thesis is of particular relevance to aid understanding.

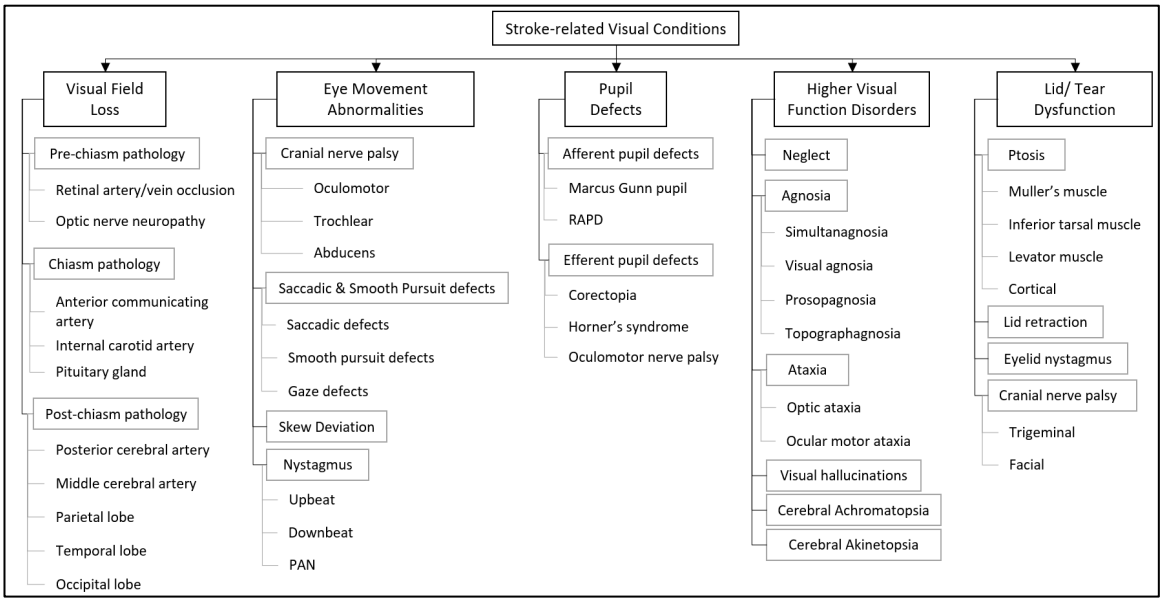


Figure 2.1 Overview of stroke-related visual conditions by category of visual function as discussed in this review.

2.2 Neuroanatomy and Localisation of Stroke Deficits

The death of CNS tissue through deprivation of oxygen and nutrients as a consequence of stroke, can result in a number of impairments. These deficits in motor, sensory, cognitive and emotional function will vary in nature depending on the location of the stroke and the extent of damage caused. The CNS is composed of the cerebrum, cerebellum, brain stem and spinal cord and also encompassed the visual pathway. The brain is divided into two hemispheres, each usually receiving input from and controlling function on the opposite, or contralateral, side of the body. The brain anatomy and function is further separated into four main areas or 'lobes': frontal, parietal, temporal and occipital (Figure 2.2) that are present in both hemispheres.[189] The frontal lobe contains several areas responsible for motor function including: the primary motor cortex, premotor cortex, frontal eye fields and supplementary motor area. Collectively these areas are responsible for the planning and initiation of voluntary movements performed by groups of muscles on the contralateral side of the body. The area of the brain responsible for expressive speech and initiation of complex motor patterns required for phonetic capability, known as Broca's area, is also located within the frontal lobe. Also within the frontal lobe is the prefrontal association cortex that contains extensive reciprocal connections with thalamic nuclei, the limbic system and other association areas within the brain. This area is responsible for complex functions such as working memory, problem solving, attention, appropriate behavioural responses, emotional regulation and intelligence.[190]

Lesions caused by stroke within the frontal lobe can result in extensive deficits, such as paralysis and/or spasticity of distal limbs on one side of the body and reduced muscle coordination.[191] If the frontal eye fields are affected, this may result in both eyes being deviated toward the side of the lesion (ipsilateral) and an inability to move both eyes toward the contralateral side.[107] Depending on the area of the prefrontal association cortex affected by a lesion, the resulting symptoms may include changes in personality traits and higher order functioning, such as judgement, creativity, analytic thinking, and responsibility. An individual with a lesion affecting this area may behave in a socially inappropriate manner, demonstrate a lack of self-respect or concern for others, have a loss of social skills, be easily distracted and emotionally unstable.[192]

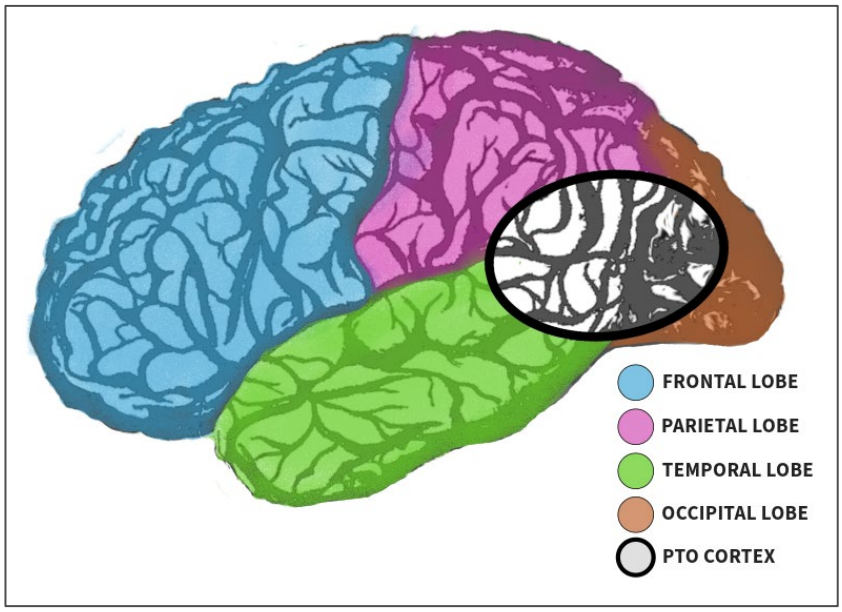


Figure 2.2 Lobes of the cortex as viewed on the lateral surface of the brain including the area where the parietal, temporal and occipital lobes converge, referred to as the 'PTO' cortex. Adapted from ten Donkelaar [189]

The parietal lobes contain the primary somatosensory cortex that receives sensory information such as touch, temperature and pain as well as taste and smell. The parietal lobes also contain the somesthetic association area that primarily functions to integrate information from different sensory systems.[191] This information is at times used to influence motor activity, and in conjunction with the posterior parietal motor area, plays a role in the programming of complex motor activity performed by groups of muscles.[190] The inferior parietal lobes contain the parietal eye fields (PEF), that are involved in steering of conjugate eye movements involved in visual tracking, such as saccades and smooth pursuits.[189,191] The parietal lobe also contains parts of the vestibular cortex, which receives input from the vestibular system in relation to the movement and orientation of the head.[190]

Lesions in the primary somesthetic area can result in loss of two-point discrimination; inability to use touch to identify items (stereognosis) or even recognise shapes traced on the skin (graphagnosis) and inability to localise touch, pain, or temperature stimulus. Lesions in the secondary somesthetic area can result in various types of agnosia characterised by an inability to interpret and recognise sensory input, astereognosis and some manifestations of neglect syndrome.[189] Unilateral lesion of the dominant hemisphere (usually left) parietal lobe can cause different types of apraxia, characterised by an inability to conduct purposeful actions. Possible conditions include Ideomotor Apraxia, where an individual is unable to perform a task

on command or by imitation, or Ideational Apraxia, in which an individual is unable to perform tasks in a sequence.[192]

The temporal lobe contains the primary auditory cortex and several auditory association areas. The primary auditory cortex receives sound input and detects auditory patterns, enables frequency discrimination and sound localisation. The auditory association areas function primarily for the interpretation of sounds, words and music. Also within the dominant temporal lobe is Wernicke's area, which is the receptive language area enabling language comprehension. This area in the non-dominant temporal lobe is an auditory association area that determines the emotional undertones of spoken language.[190] Unilateral lesions in the primary auditory cortex can cause bilateral deafness that is typically worse in the contralateral ear, and bilateral lesions may cause complete deafness. Lesions within the dominant side auditory association areas can cause receptive aphasia where an individual has difficulty or inability to understand language.[192] In the non-dominant side, a lesion in this area can cause difficulties in recognising familiar sounds and voices. Similarly, Wernicke's aphasia may result in inability to comprehend spoken language, written words (alexia), or write understandable language (agraphia). Individual's may also demonstrate fluent paraphasic speech with use of unintended sounds or words, or may mix up words in milder forms.[189] A lesion affecting both Wernicke's area in the temporal lobe and Broca's area in the frontal lobe will result in global aphasia.[190]

The occipital lobe contains the primary visual cortex (V1) and several visual association areas (V2-V5). Here visual input is received and interpreted in order to perceive colour, motion, depth, and identify objects. Various association areas make it possible to relate visual stimuli to past visual experiences and hence infer meaning or significance.[193] Visual input from the primary visual cortex is carried to the visual association areas via two main pathways. The ventral stream passes through these association areas in the occipital lobe and into the inferior temporal gyrus.[190] The processing that occurs in this pathway allows object and face recognition, based on size, shape, and colour.[191] Similarly, the dorsal stream travels through the visual association areas of the occipital lobe and continues to the posterior parietal lobe.[190] This pathway enables processing and understanding about the motion direction of viewed objects.[191]

Unilateral lesions to the occipital lobe typically result in loss of the contralateral half of the visual field in both eyes, called homonymous hemianopia.[194] However, preservation of the central visual field (corresponding to the macula area of the retina) is common in vascular

occipital lobe lesions as a result of dual blood supply from the middle and posterior cerebral arteries.[107] A bilateral lesion of the primary visual cortex will result in complete cortical blindness.[194] Lesions within the visual association areas may cause visual agnosia, where the person has unimpaired vision however they are unable to identify familiar objects.[190] Dyslexia is considered a form of visual agnosia where the individual can see and identify individual letters but have difficulty reading and writing words.[190]

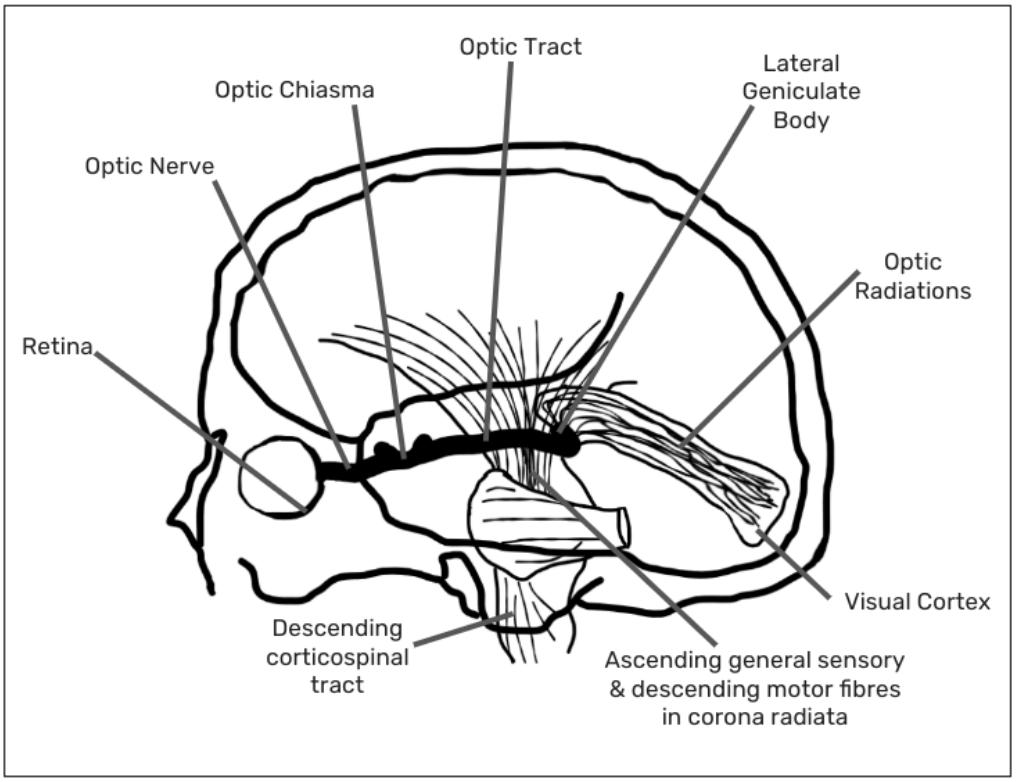


Figure 2.3 Diagram presenting a lateral view of the visual pathway travelling from the retina to the primary visual area. Adapted from *Clinical Anatomy of the Eye* by Snell and Lemp [193]

While the occipital lobe is considered the primary cortical area responsible for visual processing, the visual pathway carrying sensory visual information, passes back from the retina to various parts of the CNS, and travels through the temporal and parietal lobes before reaching the primary visual area (Figure 2.3).[189] There are also many connections made to and from other cortical areas, parts of the limbic system and brain stem that facilitate perception and functional use of visual stimuli.[163] For example, the act of reading a sentence out loud involves input from the visual cortex to Wernicke's area (responsible for comprehension of language) from which signals are sent to motor areas in the frontal lobe in order to initiate innervation of speech producing muscles (Figure 2.4a).[189] In addition to this, the control of movement and orientation of the eyes is largely facilitated through subcortical structures of the limbic system and brainstem.

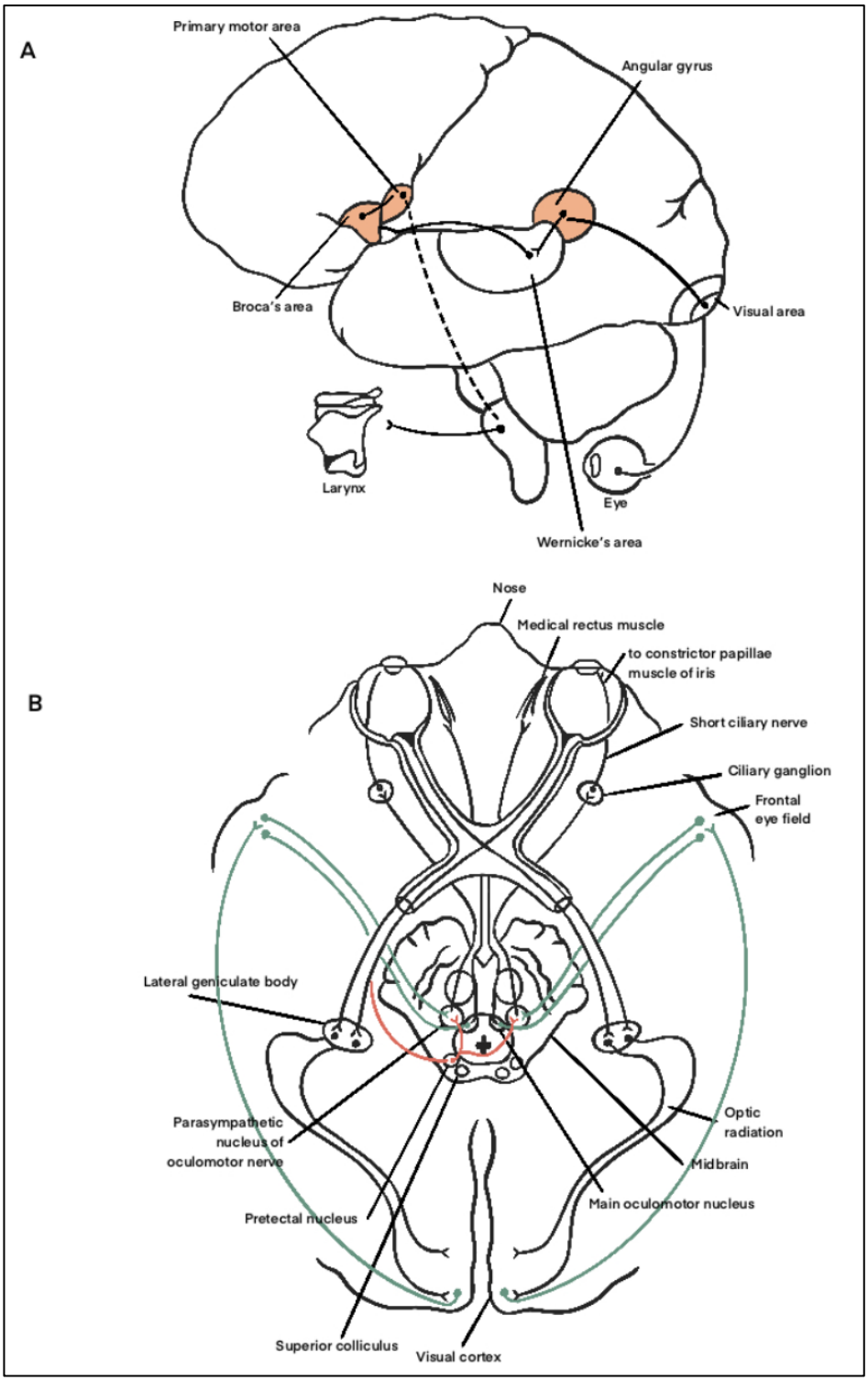


Figure 2.4 Diagrammatic representation of: **a)** the nervous pathways involved in reading a sentence and repeating it out loud; **b)** the pupil pathway (orange) and near fixation triad reflex pathway (green). Adapted from *Clinical Anatomy of the Eye* by Snell and Lemp[193]

There are also pathways involved in the involuntary constriction of pupils in response to bright light, and the physiological synkinesis of accommodation, pupil constriction and convergence

of the eyes when viewing an object in close proximity (Figure 2.4b).[193] Due to the extensive range of sites and structures within the CNS associated with visual function, visual impairment(s) can be caused by stroke induced lesions at many different locations. The specifics of these conditions are discussed in Section 2.3.1.

2.3 STROKE RELATED VISUAL CONDITIONS

2.3.1 Visual field loss

Visual field loss is the absence of any part of the normal extent of the field of vision as a result of damage to an area of the visual pathway. Locations within the external visual fields are represented on the retina in a direct point-to-point relationship. Due to the retention of the retinotopic organisation of retinal nerve fibres along the visual pathway, lesions at different points along the pathway can be located as they impact different areas of the visual field (Figure 2.5).[195]

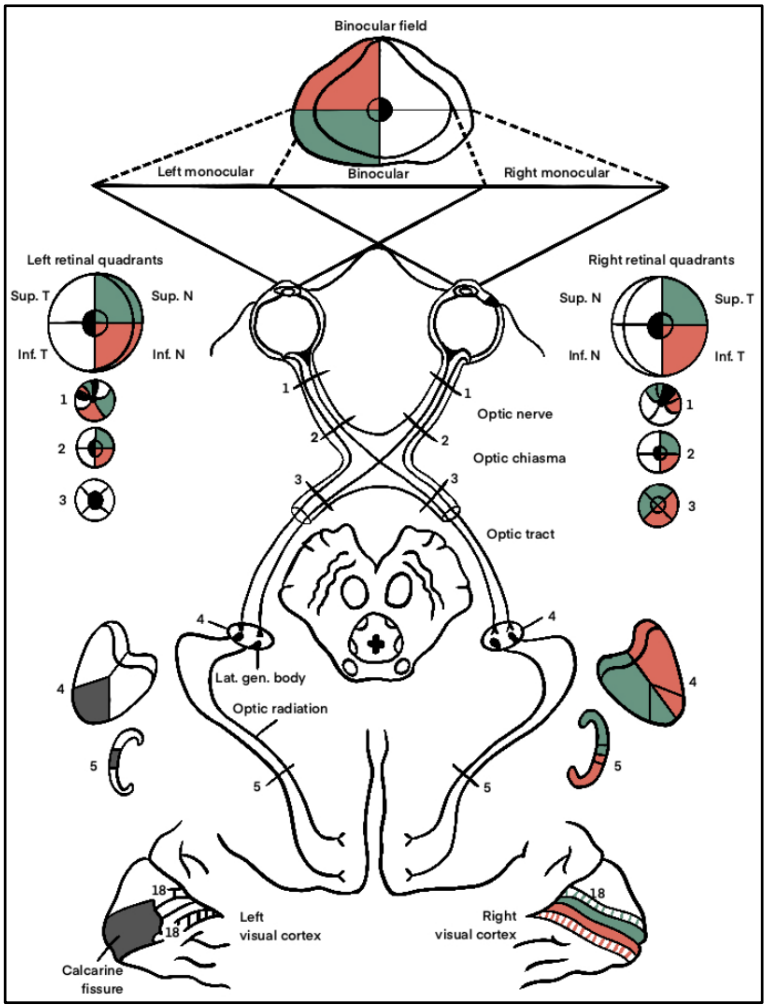


Figure 2.5 Diagrammatic representation of the retinotopic organisation of the visual pathway. Adapted from *Clinical Anatomy of the Eye* by Snell and Lemp [195]

The nerve fibres from retinal ganglion cells travel in an arcuate manner toward the optic disc and exit the eye, passing into the ON through the laminar cribrosa, then travel towards the optic chiasm. At the optic chiasm, the nasal retinal fibres from each eye (representing the temporal visual field of that eye) cross the midline (decussate) and enter the contralateral optic tract. This allows objects viewed to one side of the body's midline having their images from each eye now travelling along the same pathway to the same hemisphere of the visual cortex. In the optic tract, nerve fibres rotate their orientation so that fibres from the upper retinal quadrants travel along the medial side of the tract and those from the lower retinal quadrants travel on the lateral side to synapse in the lateral geniculate body. Similar orientation of fibres is carried through from here to the optic radiations, where the lateral radiations are the projection of the homonymous inferior retinal quadrants and loop through the temporal lobe, while the medial radiations represent the homonymous superior retinal quadrants and these pass through the parietal lobe. These fibres then terminate in the primary visual area of the occipital lobe.[195]

Pre-chiasm pathology

The ON and retina are considered extensions of the CNS, therefore infarction of the visual pathway prior to the chiasm is included in the diagnosis of stroke.[3] Pathology such as a retinal artery or vein occlusion can cause ischemia in the area of the retina supplied by the affected vessel, leading to retinal cell death.[160] As this area is no longer able to receive and transmit visual stimulus, a defect will be present in the corresponding area of the visual field. Occlusion of the central retinal artery (CRA) is classified according to occlusion occurring in the trunk (central) or branch of the artery by embolism or thrombosis. Arterial trunk occlusion presents with sudden, painless, central vision loss, diffuse fundal ischemia and a cherry-coloured macula in the affected eye.[105] This typically presents as a scotoma within the central 30 degrees of fixation of the affected eye with some preservation of peripheral vision, or complete monocular field defect.[196] Branch retinal artery occlusions also present with sudden, painless vision loss in the area of the visual field corresponding to the affected branch. Central vision may be partially preserved and the fundus appears white in colour in the ischemic area.

Occlusion of a branch of the central retinal artery typically presents with altitudinal or sectorial visual field defects.[160] Cardiovascular disease, heart disease, coagulopathies, malformations and trauma are associated with central retinal artery occlusion (CRAO).[160] Similarly, occlusion of the central retinal vein can occur in the trunk or branches.[105] Retinal vein occlusion is relatively common and is associated with diabetes mellitus, arterial hypertension and atherosclerotic cardiovascular lesions and open-angle glaucoma.[160] Occlusion of the trunk is

traditionally classified as ischemic (less common) or non-ischemic depending on the severity and/or arterial involvement, however it has recently been suggested to occur on a spectrum of severity.[160] Both present with sudden, painless, unilateral vision loss, however, the vision loss is typically more severe in ischemic retinal vein occlusion.[105] Fundal imaging will show dilated and tortuous veins, cotton wool spots, numerous small haemorrhages (dot and flame), optic disc and macula oedema. A relative afferent pupillary defect (RAPD) is often seen in ischemic retinal vein occlusion, and less commonly present and more mild in the non-ischemic form.[160] Generally, the ischemic form presents with increased severity of all symptoms and signs, with the potential for development of neoangiogenesis in the anterior segment of the eye (iris and anterior chamber angle).[105,160]

Venous branch occlusion is far more common and often occur at arteriovenous crossings and in the superior-temporal region of the retina.[105,160] Presentation again includes sudden onset of unilateral blurred vision and loss of vision in the visual field corresponding to the affected area of the retina.[160] Flame haemorrhages can be seen along the occluded branch and collateral circulation is formed between the vessel branches in the later stages.[105] Macula oedema may resolve within 6-12 months, however photocoagulation and/or anti-VEGF treatment may be required.[105] When large haemorrhages occur and bleed into the vitreous, this can cause temporary visual field loss, as the accumulated blood prevents light from reaching the retinal photoreceptors. This usually resolves on its own as the blood dissipates but can require surgical intervention, depending on the severity.[160]

Parts of the ON where there is single origin blood supply are also susceptible to infarction. For example, the laminar and post-laminar segments of the ON are supplied by thin branches of the Circle of Zinn-Haller, which itself is a branch of the short posterior ciliary arteries.[163] Within the intra-orbital segment of the ON, pial branches of the ophthalmic artery supply mainly the periphery of the ON with small collaterals of the CRA contributing to supply of its core. As such, these areas are of particular risk of occlusion and will result in distinct visual field defects.[163] At the posterior ON, prior to the chiasm, nasal and temporal retinal fibres have already begun to segregate (Figure 2.5) and so lesions at this point can have hemianopic features.[163] Lesions within the intra-orbital segment of the ON will show a distinctive field defect, corresponding to the nerve fibre bundle affected and include the blind spot (Figure 2.6).[107] Other pathologies of the ON that can cause visual field loss include NAION, and papilloedema. In NAION, the vascular condition affects the branches of the short posterior ciliary arteries that supply the optic disc.[163] Risk factors include hypertension, diabetes, ischemic heart disease and hypercholesterolemia.[105] This condition typically causes a curved

altitudinal visual field defect that follows the trajectory of the the arcuate nerve fibre bundle.[105] In addition to visual field loss, NAION also causes sudden, painless loss of central vision, RAPD and presents with abnormal optic disc appearance.[105] This differs to the arteritic form of anterior ischemic optic neuropathy, which is associated with Giant Cell Arteritis (GCA) and is considered a type of auto-immune condition.[105]

Papilledema is the term used to describe swelling of the optic disc and can be caused by a number of conditions. Generally, papilledema is consequence of increased intracranial pressure (ICP) and compression of the ON head, so typically occurs bilaterally.[107] Haemorrhagic stroke can lead to high ICP as a result of blood accumulating in the brain, ventricular system or sub-arachnoid space. Acute papilledema will cause an enlarged blind spot on visual field testing and a hyperaemic optic disc with an absence of spontaneous venous pulsations and blurred optic disc margins are observed.[107] Prolonged papilledema can result in elevation of the disc, haemorrhaging and cotton wool spots in the peripapillary area and a reduced/ absent optic cup.[107] If left untreated, atrophy of the ON occurs and causes a severely restricted visual field that can be first noticed in the inferior nasal area.[107] This stage is associated with pupillary defects and reduced visual acuity.

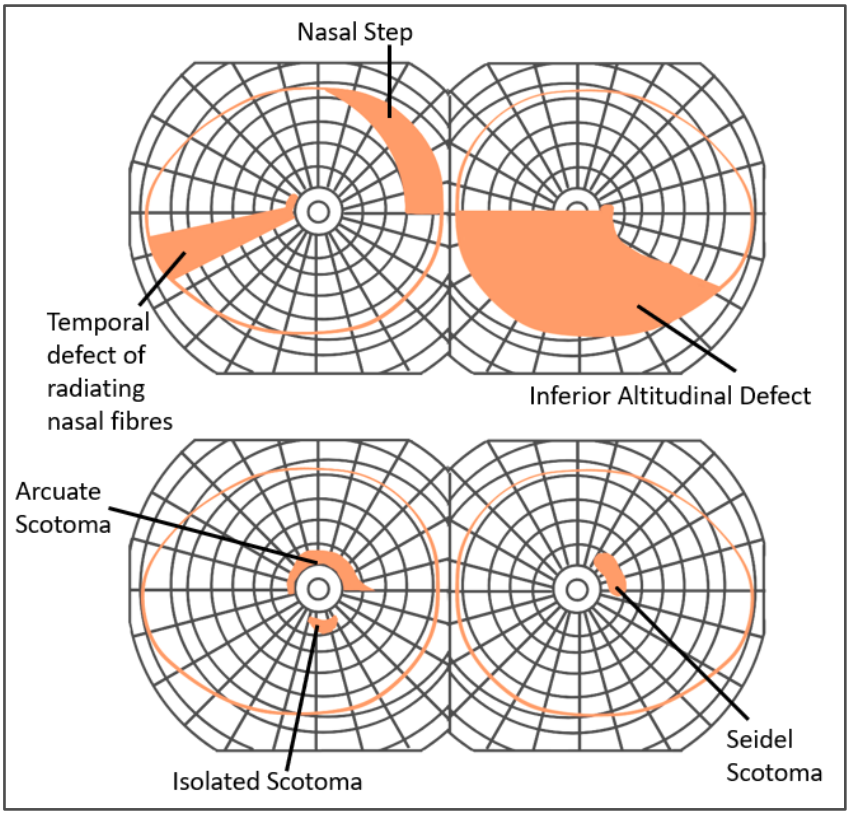


Figure 2.6 Diagrammatic representation of visual field defects according to affected retinal nerve fibres within the optic nerve. Adapted from *Neuro-Ophthalmology Review Manual* by Kline and Foroozan[107]

Chiasm pathology

The optic chiasm sits inferiorly to the anterior cerebral arteries and anterior communicating artery, and in between the internal carotid arteries. As a result, aneurysms occurring in any of these arteries may compress the optic chiasm and result in a visual field defect.[197] While aneurysms themselves are not clinically considered a stroke diagnosis, they are often a precursor to stroke. As the pituitary gland lies approximately 10mm below the optic chiasm, a pituitary apoplexy (acute haemorrhage) can also cause visual field defects that differ depending on the extent of chiasm compression.[198] Chiasmal lesions typically result in bilateral visual field defects that are non-homonymous and asymmetrical.[197] These are either bitemporal (Figure 2.7) or binasal as a result of the nasal retinal nerve fibres in each eye crossing the midline in the medial part of the chiasm.[197]

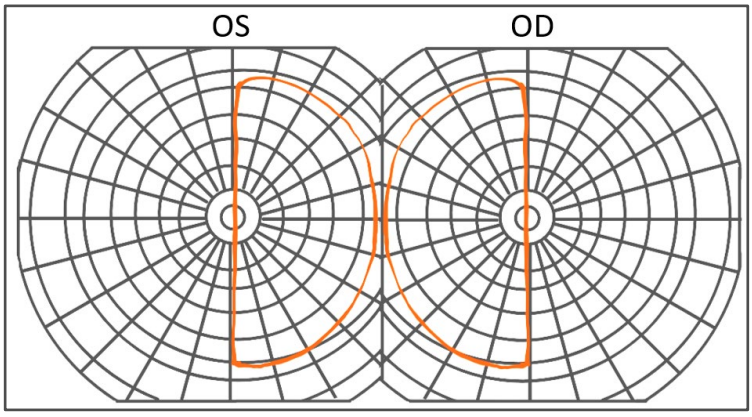


Figure 2.7 Drawing of Goldmann visual fields showing bitemporal hemianopia; OS = left eye, OD= right eye.

Due to the organisation of retinal nerve fibres within the chiasm (Figure 2.5), an aneurysm of the anterior communicating artery will compress the superior medial section of the chiasm and so the fibres of the superior nasal retina. This causes an inferior bitemporal visual field defect.[197] By the same reasoning, aneurysms of the internal carotid artery (ICA) will cause a nasal visual field defect of the ipsilateral eye if unilateral, and a binasal defect if bilateral. Some individuals have a pre-fixed chiasm (meaning that the chiasm is positioned more anteriorly than average) and others a post-fixed chiasm (where its position is more posterior).[197] This can impact whether aneurysms and pituitary conditions result in compression of the chiasm, posterior ON, or anterior optic tract. As such, pituitary apoplexy can result in bitemporal visual field loss, or may cause generalised monocular loss of vision, if the ON is also involved.

The location of chiasmal lesions can also result in the involvement of different retinal nerve fibre groups in each eye, resulting in a junctional scotoma.[197] A typical junctional scotoma will

show complete visual field loss in one eye and a portion (usually superotemporal) of field loss in the other (Figure 2.9). This occurs due to lesions at the junction of the ON and chiasm where the inferior nasal fibres cross the midline and are briefly involved with the contralateral ON before entering the chiasm. Other junctional scotomas that can occur include a 'homonymous hemianopia plus' (Figure 2.8a) and a 'bitemporal hemianopia plus' (Figure 2.8b), which correspond to the location of the lesion in the chiasm and involvement of decussating or uncrossed nerve fibres respectively.[1]

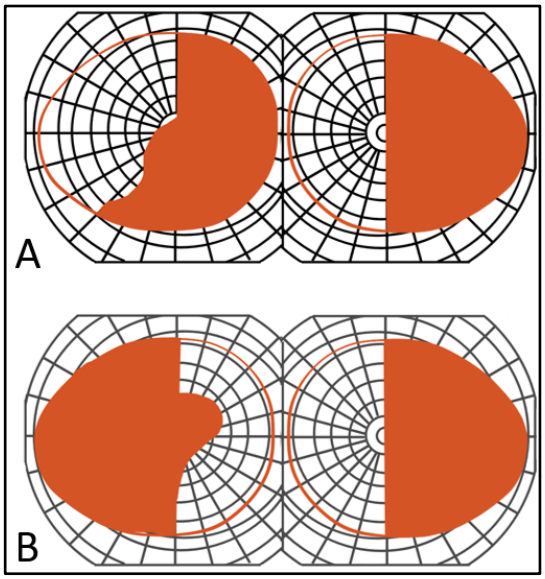


Figure 2.8 Junctional scatomas. A) homonoymous hemianopia plus B) bitemporal hemianopia plus.

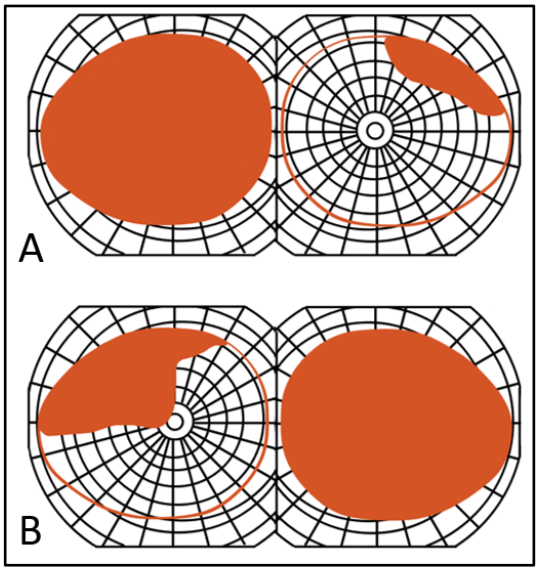


Figure 2.9 Junctional scotomas a) complete monocular loss of the left eye and incomplete superotemporal quadrantanopia of the right eye[199] b) superotemporal quadrantanopia of the left eye and complete monocular loss of the right eye[200]

Post-chiasm pathology

Optic tract

Vascular lesions of the optic tract are rare due to its blood supply coming from multiple arteries.[197] However, pathologies similar to those occurring at the chiasm may affect the optic tract depending on anatomical variations in chiasm position (i.e. those with a pre-fixed chiasm). Lesions of the optic tract result in contralateral homonymous hemianopia that is usually less congruous (Figure 2.10) than those caused by more posterior lesions and can also cause an afferent pupil defect.[1]



Figure 2.10 Diagrammatic representation of an incongruous left homonymous hemianopia.

Lateral geniculate body (LGN)

Due to the large representation of the macula within the LGN, the central visual field is often affected by lesions in this area.[190] Blood is supplied to the LGN by the posterior cerebral artery (via the lateral choroidal artery) and the middle cerebral artery (via the anterior choroidal artery).[197] The areas of the LGN supplied by these arteries. correspond to sectors of the contralateral half of the visual field and so produce highly distinctive field defects referred to as sectoranopia.[190] Where there is lesion to the lateral LGN caused by pathology of the posterior cerebral artery, upper and lower sector defects of the visual field will result (Figure 2.11a).[197] The opposite occurs in lesions of the central LGN, caused by pathology of the middle cerebral artery, with a horizontal wedge-shaped sector defect resulting that extends into the central field on one side (Figure 2.11b).[197]

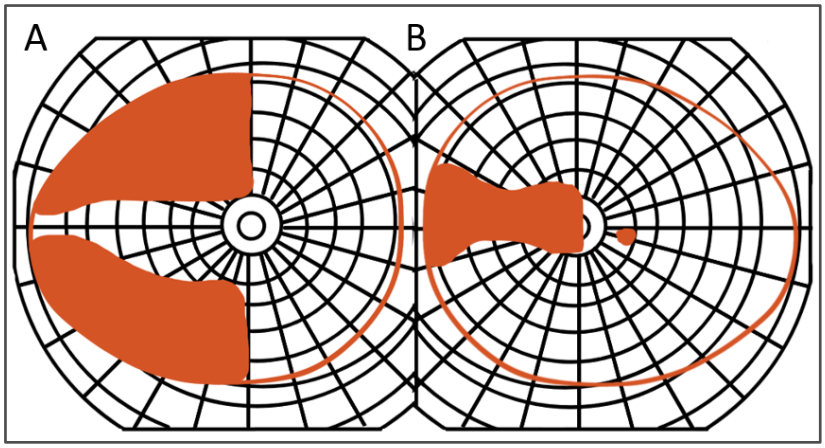


Figure 2.11 Drawing of visual field changes of the LGN caused by ischemia of different vessels a**)** lesion of the lateral areas of the LGN **b)** lesion of the central LGN.[197]

Optic radiations and visual cortex

After the LGN, the nerve fibres divide into superior and inferior optic radiations. The superior fibres travel directly through the parietal lobe and the inferior fibres travel anteriorly and downward (Meyer's loop) into the temporal lobe.[189] As such, vascular infarction of the parietal or temporal lobes will often result in visual field loss.[190] A parietal lesion will impact only the superior radiations resulting in an inferior homonymous quadrantanopia. A lesion in the temporal lobe that impacts the inferior radiations will cause a superior homonymous quadrantanopia (Figure 2.12b). However, as all fibres eventually pass through the parietal lobe more posteriorly, lesions in that region may cause homonymous hemianopia (Figure 2.12b).[190]

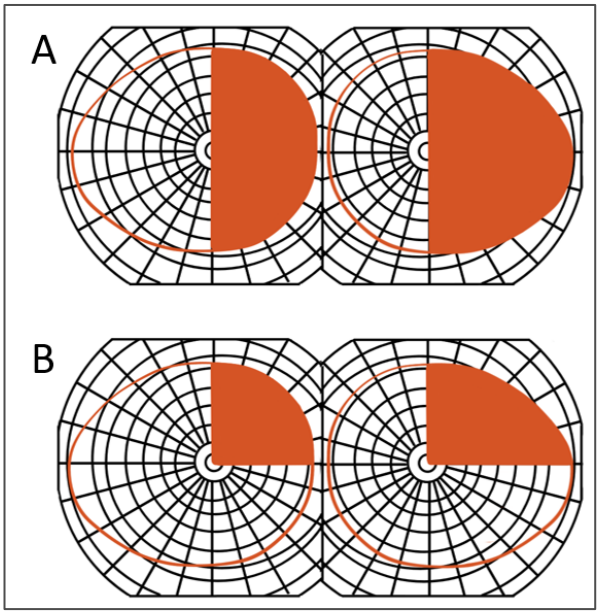


Figure 2.12 Complete and congruous retrogeniculate lesions a) right homonymous hemianopia b) right superior homonymous quadrantanopia.[1]

Lesions within the occipital lobe typically cause a complete and congruous homonymous hemianopia.[197] However, due to the dual blood supply of the area of the occipital lobe corresponding to the macula, there is in some cases 'macula sparing' (Figure 2.14b,c).[107] Quadrantanopias may also occur, particularly if it is the areas adjacent to the primary visual cortex that are affected (V2 and V3) (Figure 2.13).[197] If the posterior tip of the occipital lobe is affected in isolation, only the macula fibres will be involved and a central homonymous defect may result. Bilateral lesions of the occipital cortex will result in cortical blindness, whereby the entire field of vision is affected in both eyes. This usually occurs in cases where the two posterior cerebral arteries supplying the occipital cortex originate from a single basilar artery that then becomes occluded.[197]

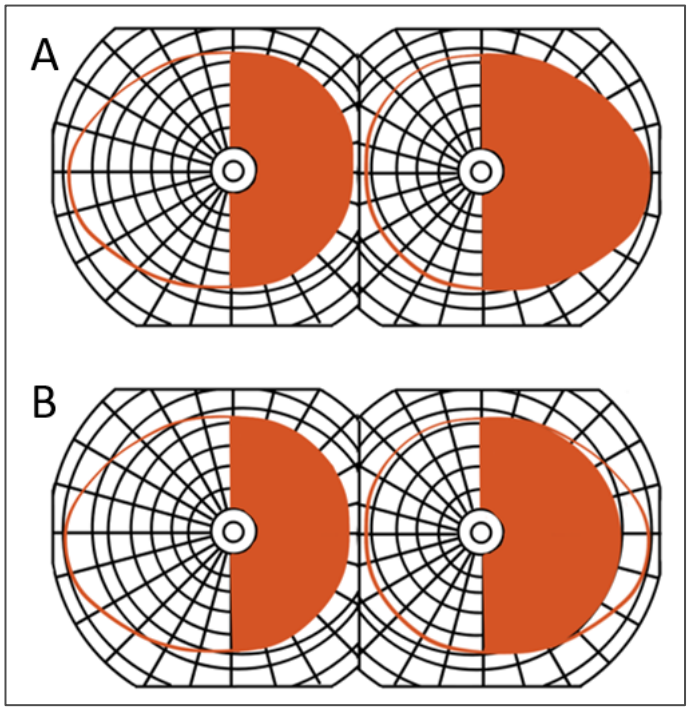


Figure 2.13 Visual field defects causes by lesions of the visual cortex **a)** right homonymous hemianopia with macula sparing, caused by extensive lesion in the left visual cortex; **b)** right homonymous hemianopia with macula sparing and temporal crescent sparing, caused by lesion in the central part of the left visual cortex.[197]

2.3.2 Eye movement abnormalities

Oculomotor nerve palsy

The Oculomotor nerve, or cranial nerve III, supplies several extraocular muscles of the eye including the superior rectus, inferior rectus, inferior oblique and medial rectus muscle as well as the Levator Palpebral Superioris (LPS) in the upper eyelid.[189] The parasympathetic fibres that travel with the oculomotor nerve innervate intraocular muscles associated with

accommodation of the crystalline lens (ciliary muscle) and pupil constriction (sphincter pupillary muscle). The Oculomotor nerve also becomes associated with the sympathetic fibres that innervate Muller's muscle within the upper eyelid.[189] The nuclear complex of the oculomotor nerve lies within the midbrain and contains paired subnuclei on either side of the midline for the inferior, medial and superior recti and the inferior oblique. It also contains single subnuclei for the LPS (central caudal subnucleus) and the sphincter pupillary muscle (Edinger-Westphal nucleus).[107]

From the nucleus, the fasciculus of the oculomotor nerve travels through the Red Nucleus and exits the midbrain between the cerebral peduncles. From here the nerve travels alongside the tentorium cerebelli and through the cavernous sinus where it divides into superior and inferior divisions.[192] Within the cavernous sinus, sympathetic fibres from the carotid plexus join the superior division of the oculomotor nerve in order to innervate Muller's muscle. Both divisions then enter the orbit through the superior orbital fissure. The superior division travels alongside the ON and divides into several branches to innervate the superior rectus, the LPS and Muller's muscle. The inferior division also branches and terminates on the inferior rectus, inferior oblique, medial rectus, ciliary and sphincter pupillary muscles.[193]

Typically a complete oculomotor nerve palsy will result in misalignment of the eyes, where the affected eye is exotropic, hypotropic and incyclotorted.[107] This will result in diplopia, may present with ptosis, and a fixed and dilated pupil in one or both eyes, depending on the location and extent of the lesion.[107] Palsies of the oculomotor nerve may also be partial, where there is limited paresis of all involved muscles, rather than total paralysis, or incomplete, where only select muscles are impacted. A nuclear Oculomotor nerve palsy may present with differing clinical signs due to the arrangement of subnuclei. A rostral lesion of the nuclear complex is more likely to involve the Edinger-Westphal nucleus (EWN) and hence affect pupil responses but spare the Central Caudal subnucleus and thus present without ptosis. The reverse is true for a more caudal nuclear lesion that will likely present with bilateral ptosis.[107] All other subnuclei supply the ipsilateral extraocular muscles, other than the superior rectus subnuclei, which supplies the contralateral superior rectus.[193] As a result, lesions of the nucleus typically impact the ipsilateral medial rectus, inferior oblique and rectus, as well as the contralateral superior rectus. Bilateral superior rectus involvement may also occur due to decussating fibres within the nucleus.[107] Although rare, a small lesion of a single subnuclei is also possible and will result in under-action of a single muscle.

A lesion of the Oculomotor fascicule causes an ipsilateral palsy and is usually associated with other neurological signs and symptoms associated with the surrounding structures within the brainstem. Nerve fibres within the fascicule are topographically arranged according to the muscle supplied and relatively spread out, hence it is possible to have a fascicule palsy that affects individual components of the oculomotor nerve in isolation. Syndromes of the oculomotor fascicule and surrounding structures are outlined in Table 2.1.[107]

Table 2.1 Syndromes of the oculomotor fascicule and surrounding structures.

Weber's Syndrome	lesion involving the cerebral peduncle resulting in contralateral hemiparesis.
Benedikt's Syndrome	lesion involving the red nucleus resulting in contralateral hemitremor.
Nothnagel's Syndrome	lesion involving the superior cerebral peduncle causing cerebellar ataxia.
Claude's syndrome	lesion involving both the superior cerebral peduncle and red nucleus with a combination of associated symptoms.

Within the subarachnoid space the oculomotor nerve is surrounded by the posterior cerebral artery, superior cerebellar artery and posterior communicating artery.[107] This makes the nerve particularly susceptible to aneurysms in this area. Again, due to the arrangement of parasympathetic fibres along the nerve's extremity, aneurysm of the posterior cerebral artery or posterior communicating artery will likely cause pupil dilation.[105] Contrary to this, aneurysm of the Basilar artery (ventral-medial to oculomotor nerve) or superior cerebellar artery (inferior to oculomotor nerve) are more likely show pupil sparing due to the dorsomedial orientation of the pupillomotor fibres within the oculomotor nerve.[105] Haemorrhagic stroke may also cause uncal herniation of the temporal lobe, resulting in compression of the oculomotor nerve against the tentorium cerebelli.[107] An ipsilateral oculomotor nerve palsy will present with all or some muscles affected, in conjunction with a fixed and dilated pupil and signs of raised ICP, such as papilledema and postural headaches.[107]

Lesions of the oculomotor nerve within the cavernous sinus are uncommon in stroke but can occur through aneurysm (and potential rupture) of the ICA due to their proximity.[107] In this case, it is common for the muscles innervated by the oculomotor nerve to be affected to differing extents. As the oculomotor nerve splits into its two divisions in the anterior cavernous sinus, lesions here may result in loss of innervation via either division. Also depending on the location of the lesion, the pupils will be affected differently. If the parasympathetic pupil fibres

along the oculomotor nerve are impacted, the pupil will be fixed and dilated. If the sympathetic pupil fibres nearby are affected, without involvement of the oculomotor nerve pupillary fibres, there will be ipsilateral Horner's syndrome, while in the case of sympathetic and parasympathetic fibre involvement, the pupil will be fixed and mid-dilated.[107] Cavernous sinus syndrome is more complex, as it typically involves a combination of nerves III, IV, V and VI as well as the sympathetic pupil pathway.[107] Presentation often includes ophthalmoplegia due to multiple ocular cranial nerve involvement, as well as loss of corneal sensation, anisocoria and localised burning sensation of the upper face corresponding to the area of nerve V innervation.[107] Occlusion of the ophthalmic artery may also result from ICA involvement and hence caused reduced visual acuity through retinal ischemia.[107]

Lesions at the superior orbital fissure or within the orbit are also uncommon in stroke but present in an almost identically form to cavernous sinus syndrome.[107] The distinction to orbital apex syndrome is typically made through the additional involvement of the ON.[107] Microvascular ischemia is a more likely cause of peripheral nerve III palsy and are typically associated with pain.[105] The peripheral oculomotor nerve has dual blood supply, with blood vessels in the pia matter supplying the surface of the nerve and the pupillary fibres, and the vaso nervorum supplying the deeper never fibres. As such, peripheral oculomotor nerve palsies have pupil sparing when caused by ischemia of the vaso nervorum.[107] Patients often have systemic risk factors include diabetes mellitus, hypertension and/or hypercholesterolemia and an absence of other neurological symptoms.[105]

Trochlear nerve palsy

The Trochlear nerve, or cranial nerve IV, supplies the superior oblique muscle, which is responsible for intorsion and depression of the eye, with a secondary action of abduction.[193] The nucleus of the trochlear nerve is located in the midbrain at the level of the inferior colliculus and sits below the oculomotor nucleus, anterior to the cerebral aqueduct and dorsal to the medial longitudinal fasciculus (MLF). From its nucleus, the trochlear fascicle travels dorsally and decussate in the anterior medullary velum before, uniquely for a cranial nerve, exiting the dorsal midbrain. The left trochlear fascicle hence becomes the right trochlear nerve that innervates the right superior oblique muscle and vice versa. Upon exiting the brainstem, the trochlear nerve then travels anteriorly around the midbrain and between the superior cerebellar and posterior cerebral arteries. It travels laterally to oculomotor nerve and enters the cavernous sinus where it lies between the oculomotor nerve and the ophthalmic division (V1) of the trigeminal nerve. Within the cavernous sinus, the trochlear nerve sends sensory fibres (believed to be proprioceptive) to the ophthalmic nerve. The trochlear nerve then enters

the orbit through the superior orbital fissure above the common tendonous ring and runs with the frontal nerve to the medial side of the orbit before terminating on the upper surface of the superior oblique muscle.[193]

When innervation to the superior oblique muscle is affected by a trochlear nerve palsy, the competing muscles in the ipsilateral eye (superior rectus, inferior oblique) act unopposed and hence cause the eye to become hypertropic and slightly esotropic. The affected person will hence have symptoms of vertical or oblique diplopia, as well as intorsion of the image in the affected eye (indicating excyclo rotated position of the eye itself). The affected person will also likely adopt an adaptive head posture, tilting toward the unaffected side with chin depressed, as a means of reducing their diplopia.[105]

Lesions of the trochlear nerve are typically caused by trauma due to its thin diameter and long intracranial course, but they can also be vascular in nature.[192] A lesion at the trochlear nucleus is near impossible to distinguish from a fascicular lesion because of the short course of the fascicles within the midbrain.[107] A haemorrhage or infarction at this site will present with palsy of the contralateral trochlear nerve as well as ipsilateral Horner's Syndrome due to involvement of the adjacent sympathetic pathway in the midbrain.[107] Subarachnoid space lesions of the trochlear nerve do not typically occur as a result of stroke but would result in an ipsilateral (or bilateral) trochlear nerve palsy. Similar to the oculomotor nerve, the trochlear nerve can be affected by aneurysm and/or rupture of the ICA or posterior cerebral artery. The resulting cavernous sinus syndrome presents as explained previously (see 2.3.2). Isolated palsies of the trochlear nerve can also occur through microvascular lesions of the small vessels supplying it's peripheral aspect and will result in an ipsilateral palsy of the superior oblique muscle.[201]

Abducens nerve palsy

The Abducens nerve, or cranial nerve VI, supplies the lateral rectus muscle of the eye that is responsible for outward horizontal movement of the eye. The pathway of the Abducens nerve begins at its nucleus in the pons, then travels ventrally through the pons and the descending corticospinal tract. It has an anchorage point at its exit from the brainstem at the pontine-medullary junction and then enters the subarachnoid space. From here the nerve travels superiorly and makes an almost 90-degree bend over the petrous temporal bone and through Dorello's canal into the cavernous sinus. The nerve then enters the orbit through the orbital fissure and terminates on the inner surface of the lateral rectus.[193] When innervation to the lateral rectus is impaired, there is an imbalance in muscle tone, with the ipsilateral medial

rectus overacting. This causes the affected eye to be pulled inwards, resulting in misalignment of the two eyes and therefore horizontal diplopia.[105]

In addition to the motoneurons that supply the lateral rectus muscle, the Abducens nucleus also contains intranuclear neurons that project via the MLF to the medial rectus subdivision of the contralateral oculomotor nucleus. This normally enables conjugate horizontal gaze movements of the eyes, and so when impacted by a lesion of the Abducens nucleus, an ipsilateral horizontal gaze palsy will occur.[107]

Lesions of the Abducens fasciculus will result in an ipsilateral VI palsy and may also be associated with other symptoms in accordance with a palsy of the facial and vestibulocochlear nerves. Lesions of the fasciculus may also be associated with contralateral hemiplegia, sensory deficits in the ipsilateral side of the face, ipsilateral Horner's Syndrome and internuclear ophthalmoplegia (INO) caused by involvement of the MLF.[107] Any combination of these deficits may be referred to as a brainstem syndrome. Commonly encountered brainstem syndrome's include Raymond's syndrome (VI nerve palsy and contralateral hemiparesis) and Millard-Gubler syndrome (VI and VII nerve palsy, contralateral hemiparesis).[201] As the Facial (VII) nerve wraps around the Abducens nucleus, an ipsilateral VII nerve palsy is commonly associated with nuclear VI palsy and is known as the eight-and-a-half syndrome.[201] Another common syndrome associated with VI nuclear palsy is Foville's syndrome, in which nerves V, VII and VIII are also affected in conjunction with the descending sympathetic tract (first neuron) of the pupil pathway. Foville's syndrome will present with an ipsilateral horizontal gaze palsy, Horner's syndrome, dry eye, impaired blink reflex, possible ectropion, paralysis of facial muscles of expression and hearing defects.[107]

Lesions of the nerve VI within the subarachnoid space are less common in stroke patients but can be caused by haemorrhagic stroke through the resultant raised ICP. When this occurs, the brainstem is displaced inferiorly and causes stretching of nerve VI and it's compression at the petrous temporal bone. This may result in unilateral or bilateral VI nerve palsy and is often associated with other symptoms of high ICP, such as postural headaches and papilledema.[107]

As discussed previously, lesions within the cavernous sinus are uncommon in stroke but can occur through aneurysm or fistula of the ICA. A palsy of nerve VI at this site will often show more widespread ophthalmoplegia due to the involvement of multiple ocular cranial nerves (oculomotor and trochlear) as well as other symptoms of cavernous sinus syndrome. Lesions of nerve VI within the superior orbital fissure are almost identical in their presentation to those within the cavernous sinus, with the exclusion of involvement of the maxillary division of the

trigeminal nerve.[107] Finally, occlusion of the vaso nervorum that supply the peripheral branch of the abducens nerve will cause an ipsilateral VI nerve palsy. Referred to as a 'microvascular palsy', there are typically no other neurological symptoms other than headache at the time of onset.

Saccade and Smooth Pursuit Defects

Saccadic Pathways

Saccades are swift movement of the eyes from one object of fixation to another which can be either voluntary or reflexive in nature. The saccadic pathway (Figure 2.15-2.16) originates in the frontal eye fields within the frontal lobe and from areas of the posterior parietal lobe, contralateral to the direction of the saccadic eye movement. Cortical saccade neurons project to the ipsilateral superior colliculus in the midbrain. From there the neurons decussate to the contralateral pontine paramedian reticular formation (PPRF) and other brainstem saccade generator areas (BSG).

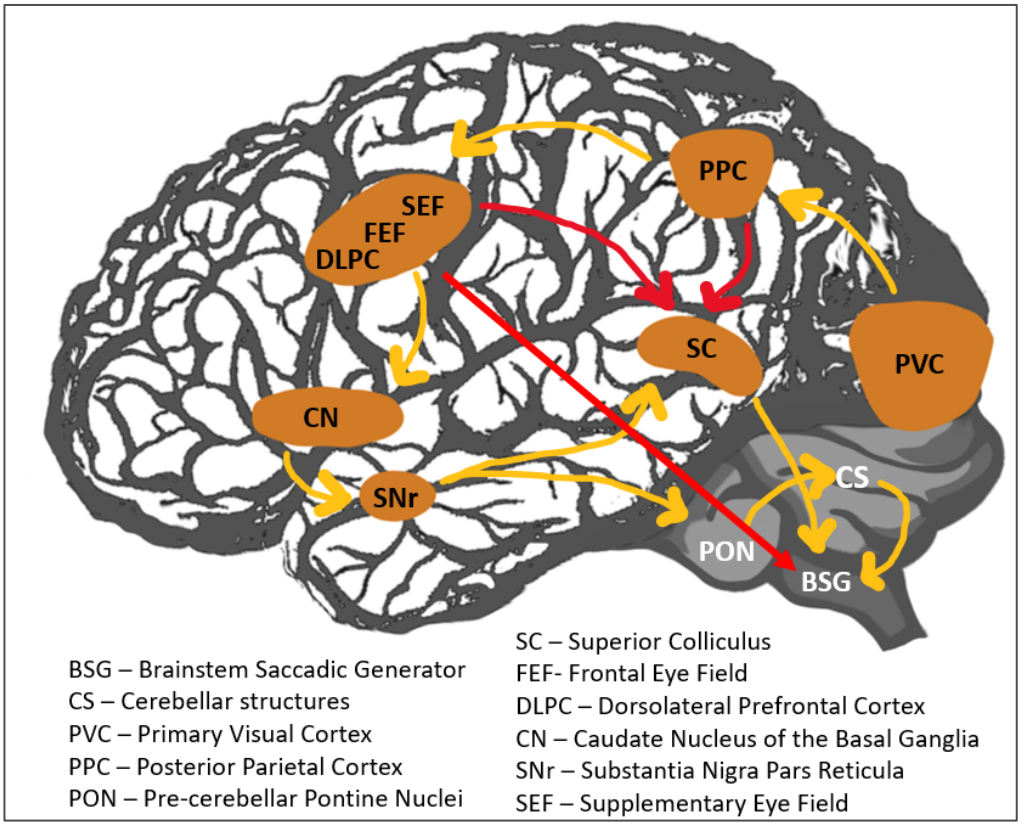


Figure 2.15 Saccadic eye movement pathways and cortical areas of importance. Adapted from *Neuro-Ophthalmology Review Manual* by Kline and Foroozan [107]

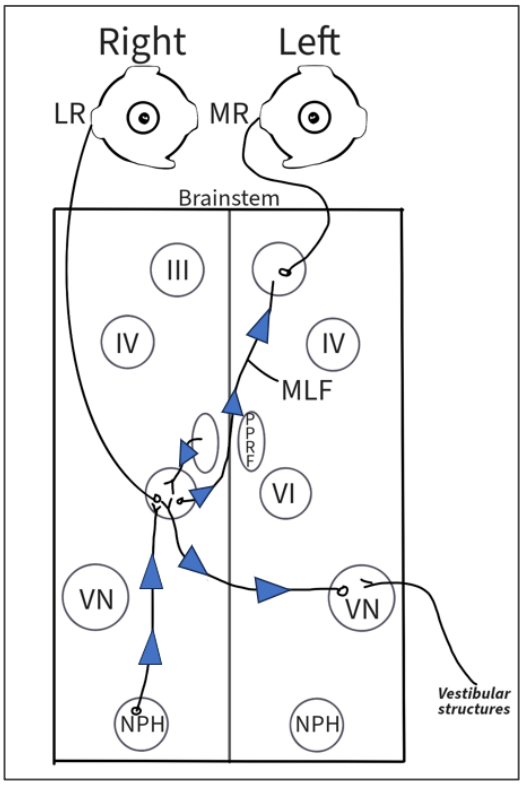


Figure 2.16 Horizontal saccadic pathway (blue arrowheads) showing the saccadic generators within the brainstem: paramedian pontine reticular formation (PPRF), nucleus prepositus hypoglossi (NPH). Adapted from *Neuro-Ophthalmology Review Manual* by Kline and Foroozan.[107]

The BSG areas convert signals from the superior colliculus into a rate code that indicates the pulse and step waveform of the saccade (see Figure 2.17).[107] The pulse provides the speed of movement into the desired position and the step allows for the eyes to be held in that position. The signal is then projected to the abducens nucleus that sits dorsally to the PPRF.

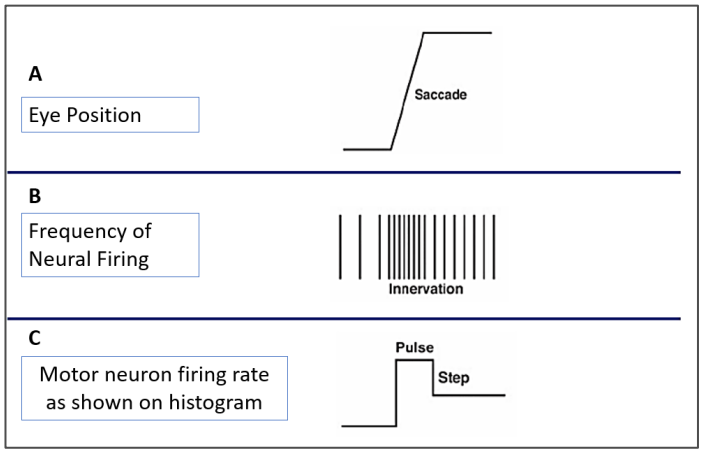


Figure 2.17 Pulse-step change of innervation that produces saccades. Adapted from the Neuro-Ophthalmology Review Manual.[107]

From the nucleus of the abducens nerve, the signal is sent to innervate the ipsilateral lateral rectus muscle, as well as to the contralateral medial rectus subnucleus of the oculomotor nerve via the MLF. The medial rectus subnucleus innervates the medial rectus muscle on the ipsilateral side, producing a conjugate movement of both eyes to either the right or left.[201]

The vertical saccade pathway begins with bilateral stimulation of the FEF and/or superior colliculus. The cortical pathway then descends to the rostral interstitial nucleus of the MLF (riMLF) in the midbrain which contains burst neurons. The riMLF also receives inhibitory input from the omnipause neurons of the nucleus raphe interpositus which enables the burst neurons to generate a burst of neural activity corresponding to the pulse component of the saccadic eye movement (Figure 2.17).[107,201] The signal is then projected to the interstitial nucleus of Cajal (INC) and bilaterally to the nucleus of the oculomotor nerve via the posterior commissure (PC) (for upward saccades) or to the ipsilateral oculomotor nucleus and trochlear nucleus (for downward saccades). The INC acts as a neural integrator and produces a 'gaze holding' signal corresponding to the step component of the saccade (Figure 2.17) as well as serving a role in the ocular counter-roll reflex.[201] The riMLF also codes for torsional saccades, with the right riMLF encoding clockwise saccades and the left riMLF encoding anticlockwise saccades as viewed by the patient.[107]

Smooth Pursuit Pathways

Smooth pursuits are a slow, tracking movement of the eye intended to allow the fovea to maintain fixation on a moving object. The smooth pursuit pathway (Figure 2.18) is more complicated and not as well understood, however are suspected to have significant overlap with the saccadic pathway.[202] As pursuits are initially triggered by visual stimuli, there are several cortical areas involved, beginning in the primary visual cortex. Areas within the parieto-temporal-occipital junction then process visual motion signals that drive pursuits.[203] It has been proposed that signals are then sent to the frontal eye fields and supplementary eye fields, then to various structures within the pontine nuclei and cerebellum.[202,203] Once reaching the vestibular nucelus within the brainstem, the Interstitial nucelus of Cajal (INC) is engaged for vertical pursuit movements and the nucelus prepositus hypoglossi for horizontal pursuit movements.[202] These structures then stimulate action of the respective vertical or horizontal ocular muscles.

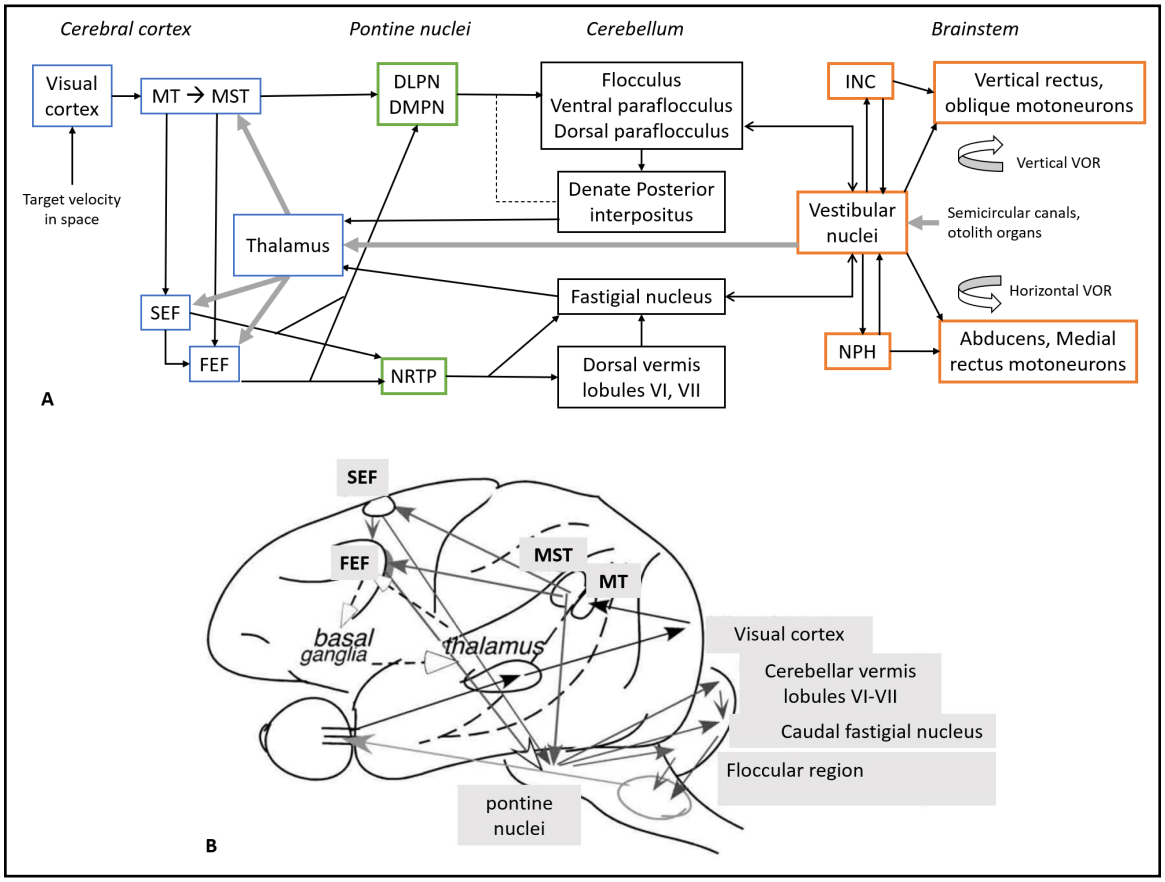


Figure 2.18 Major pathways related to smooth pursuit eye movements (A,B). "Open arrow heads with dashed lines in (B) schematically indicate a proposed smooth pursuit efference copy loop between the caudal FEF and the basal ganglia through the thalamus."[202(p9)] Abbreviations: DLPN, dorsolateral pontine nucleus; DMPN, dorsomedial pontine nucleus; INC, interstitial nucelus of Cajal; MT, middle temporal visual area; MST, medial superior temporal visual area; NRTP, nucleus reticularis tegmenti pontis; NPH, nucleus prepositus hypoglossi; VOR, vestibulo-ocular reflex. Adapted from Fukushima et al. (2013)[202]

Horizontal Gaze Defects

A horizontal gaze palsy is a complete inability to make conjugate movement of the eyes into left or right gaze that results from lesions within the horizontal saccadic pathway (Figure 2.15-1.16).[107] These palsies may occur in milder forms, where there is only gaze paresis or specific defects of saccades and/or pursuits in horizontal gaze. Lesions caused by stroke at one or more points along this pathway can cause horizontal gaze palsies of varied presentation.[204] A unilateral lesion within the frontal eye field will cause a gaze palsy to the contralateral side (e.g. left frontal eye field lesion will cause inability to generate saccades to the right) and a deviation of both eyes toward the side of the lesion in the acute stage. Lesions at this site may also present with impaired ipsilateral horizontal smooth pursuit,[203] however the vestibulo-

ocular response (VOR) will remain intact.[107,201] This condition will typically recover over time as other areas involved in saccade generation start to compensate, although more subtle saccadic defects may remain such as increased latency, inaccuracy and gaze paretic nystagmus.[204]

Lesions to the superior colliculus generally don't cause gaze palsies or saccadic defects due to additional projection from the frontal eye fields direct to the PPRF and BSG areas.[107] Lesions within the pons will cause an ipsilateral gaze palsy as the pathway has already decussated previously within the midbrain. Acute deviation of the eyes to the side contralateral to the lesion may occur and presentation will vary depending on the extent of the lesion. If the abducens nerve nucleus is affected, a non-selective gaze palsy will occur whereby saccades, pursuits and the VOR will be absent on the ipsilateral side and symptoms of facial nerve involvement may present.[201] If the PPRF is affected in isolation, ipsilateral saccades will be absent, while pursuits and the VOR are preserved. Typically the LR and MR will have normal movement on ductions, and contralateral saccades will be defective or absent with the potential for gaze evoked nystagmus.[107]

Lesions of the MLF result in the condition known as intranuclear ophthalmoplegia (INO), which is characterised by ipsilateral adduction deficit and contralateral dissociated nystagmus on contra-lesional conjugate gaze.[204] As such, the condition is named for the side with the adduction deficit. For example, a right MLF lesion will cause right INO whereby the right eye cannot adduct and the left eye will show a dissociated nystagmus when attempting conjugate left gaze. Adducting saccades, pursuits and VOR will be absent in the eye on the side of the lesion, however, the MR will typically function as normal on convergence (disjugate movement)[204] unless the lesion site is high in the midbrain.[203] Unilateral lesions typically have no deviation in primary position and hence don't complain of diplopia, however INO may at times present with a skew deviation where the ipsilateral eye is hypertropic.[107] More rarely, unilateral INO may present with an ipsilateral exotropia due to involvement of the MR subnuclei (wall-eyed monocular intranuclear ophthalmoplegia) or exotropia of the contralateral eye due to overexcitation of the contralateral PPRF when fixating with the paretic eye.[203] Bilateral MLF lesions are common due to the close anatomical proximity of the two MLF and these may present with an exotropia in primary position due to involvement of the MR subnuclei (termed wall-eyed bilateral INO or WEBINO)[205] or bilateral adduction paresis or lag.[203] If the MR subnuclei is not involved, convergence is typically spared .[204]

An infarct affecting the abducens nucleus or PPRF on one side and the contralateral MLF results in 'one and a half syndrome'.[78] This is characterised by a gaze palsy ipsilateral to the side of abducens nerve lesion and INO ipsilateral to the MLF lesion.[78,107] As a result, the VOR response will be present and able to overcome the gaze palsy but absent on the side of the MLF lesion, dissociated nystagmus will occur in the eye contralateral to the MLF lesion and there may be associated skew deviation or paralytic pontine exotropia.[78,204]

Vertical Gaze Defects

A vertical gaze palsy indicates a complete inability to make conjugate upward and/or downward eye movements, resulting from lesions within the vertical saccadic pathways (Figure 2.15).[107] As with defects of horizontal gaze, vertical gaze defects may not always present as a complete palsy, but rather as paresis or specific impairment of vertical saccades, pursuits and/or the VOR. A unilateral lesion of the riMLF will predominately affect downgaze as this pathway only projects ipsilaterally. This may result in a downgaze palsy or slowing of downward saccades, and may present with a torsional deviation on attempted vertical saccades, torsional nystagmus with contralesional beat, and/or contralesional torsional deviation.[204] Rarely bilateral infarction of the riMLF will cause an isolated downgaze palsy when a small area in the uppermost riMLF is affected.[201] This can occur in an persons with an anatomical variation whereby the paramedian thalamic arteries that indirectly supply the riMLF arise from a single artery (known as the Artery of Percheron) rather than paired branches of the posterior cerebral artery.[206] Embolism of this artery will cause ischemia of the riMLF without impacting the INC or PC and is sometimes referred to as inverse Parinaud's or inverse Dorsal Midbrain Syndrome (bilateral downgaze palsy).[207] When the INC is impacted by stroke the resultant defects will include: a skew deviation, potentially in combination with see-saw nystagmus, vertical gaze evoked nystagmus, and/or torsional nystagmus.[204] Unilateral lesions of the INC may spare the VOR, however bilateral lesions will often present with defective vertical saccades, pursuits and VOR. Specifically, bilateral lesions will show impaired gaze holding in vertical and torsional planes and may also have upbeat nystagmus.[107,201]

Bilateral lesions of the riMLF typically cause a palsy of both upward and downward gaze that may be more severe in downgaze. Such lesions are commonly caused by infarcts within the distribution of the thalamosubthalamic paramedian artery.[204] Patients with a bilateral lesion of the riMLF may present with lid retraction on attempted upgaze (Collier's sign) and complete abolition of torsional saccades, which in turn results in the absence of a torsional deviation.[107] Pursuit eye movements and VOR are often spared in this type of infarct.

The PC predominately carries output from the riMLF related to upgaze and hence causes an upgaze palsy when lesioned. The patient will show loss of upward saccades and pursuits, with or without absent VOR and Bell's phenomenon.[204]Downward saccades and pursuits may also be defective, but downward VOR is typically spared. A downward gaze deviation may be present with downbeat vertical gaze-evoked nystagmus and Collier's sign.[107] Often when infarctions occur in the area of the dorsal midbrain due to Basilar artery stroke or haemorrhage within the midbrain or thalamus, both the INC and PC are affected in conjunction with one or more surrounding structures.[204] The collection of resultant deficits is referred to as Dorsal Midbrain Syndrome, Pretectal Syndrome or Parinaud's Syndrome.[107] Again, vertical gaze is impaired with a bias for upgaze with other presenting signs such as convergence retraction nystagmus on attempted upgaze, Collier's sign and potentially convergence or divergence paralysis, convergence spasm, accommodative spasm or paresis. Pupils may also be affected due to involvement of the pretectal area, with a mid-dilated appearance and absent response to light.[107] Acutely the patient may have a downward gaze deviation but are typically orthophoric in primary position unless there is a skew deviation, ipsilateral gaze defect (such as a double elevator/depressor palsy) or involvement of the trochlear and/or oculomotor nuclei.[204]

Skew Deviation

Skew deviation is a vertical strabismus that results from lesions within the vestibulo-ocular pathways, responsible for stabilisation of fixation during head movements.[107] The vestibular system within the inner ear is comprised of three semicircular canals (anterior, lateral and posterior) and two otolithic organs (utricle and saccule). The semi-circular canals sense angular acceleration while the otoliths respond to linear acceleration.[190] The vestibular nerve projects from the vestibular ganglion to the ipsilateral vestibular complex within the pons and medulla. This complex contains the superior, inferior medial and lateral vestibular nuclei. The horizontal vestibulo-ocular response (VOR) is initiated by stimulation of the lateral semicircular canals. The lateral canal on the side of the head turn will be stimulated, and its contralateral partner canal inhibited. The excitatory signal is transmitted to the medial vestibular nucleus (MVN) via the vestibular nerve and onwards to the contralateral abducens nucleus. From here the signal is sent to the corresponding lateral rectus as well as to the medial rectus subnucleus via the MLF, producing a vergence movement of both eyes opposite to the head turn.[190] There is a simultaneous inhibitory signal sent from the inhibited lateral semicircular canal to the opposing extra-ocular muscles through the same pathway.[107] The vertical VOR is initiated within the anterior and posterior semicircular canals, where the anterior canals detect forward

movement of the head and the posterior canals detect backward movement. Direct forward or backward movement will stimulate the respective canals on both sides of the head, while such movement with associated tilt will only excite the canal on the side of the tilt.[107,190]

Forward movement of the head evokes upgaze, with the signal first being transmitted from the stimulated anterior canal to the ipsilateral superior vestibular nucleus (SVN). From here the signal is sent to the contralateral oculomotor nucleus via the brachium conjunctivum and/or MLF, which will activate the inferior oblique of the eye ipsilateral to stimulated oculomotor nucleus and the superior oblique of the other.[208] An inhibitory signal is simultaneously sent from the inhibited anterior canal to the ipsilateral trochlear and oculomotor nucleus, to relax both the contralateral superior oblique and ipsilateral inferior rectus.[190] A similar pathway is followed from the posterior canal to the medial vestibular nucleus (MVN) to evoke downgaze. The excitatory signal then continues from the MVN to the contralateral trochlear nucleus via the MLF to activate the superior oblique (ipsilateral to excited canal). Continuing through the MLF to the oculomotor nucleus, the excitatory signal also works to activate the inferior rectus on the side contralateral to the stimulated canal. An inhibitory signal is also sent to relax the opposing extraocular muscles via the SVN and MVN bilaterally.[190] Torsional VOR is facilitated by the utricles when stimulated by head tilt. The eyes will show a torsional movement away from the side of head tilt, which is known as the ocular counter-roll reflex.[107] The pathway by which this occurs is uncertain, it is thought to be either direct from the vestibular nuclei to the oculomotor nuclei, or through stimulation of the INC, as in the saccade pathway.[107]

The ocular tilt reaction (OTR) is a physiological response to head tilt, whereby the ocular motor nerves are signalled by the vestibular system to balance the vertical and torsional position of the eyes in order to maintain binocular single vision. When input from one side of the pathway is removed or impaired, there is a perceived head tilt to the contra-lesional side when the head is positioned at true vertical and hence there is a pathological ocular tilt reaction.[208] Lesions can occur at various sites within the peripheral and central otolithic pathways, with brainstem stroke being a common cause of central injury. A noteworthy diagnostic feature of skew deviation is the reduction of vertical strabismus in supine position and cyclotorsion of the hypotropic eye, which is opposite to that seen in a trochlear nerve palsy.[208]

Lesions of the vestibular nuclei within the medulla and pons cause an ipsilateral OTR, whereby the eye on the side of the lesion is hypotropic and excyclorotated and the contralateral eye is hypertropic.[208] The cyclotorsion of the contralateral eye may vary depending on the specific

site of the lesion, with lateral medullary lesions showing disproportionate or absent incyclotorsion of the contralesional eye. Torsional nystagmus with contralesional beat may also be present, or upbeat nystagmus in the case of medial medullary lesions. Lateral Medullary Syndrome or Wallenberg Syndrome, often includes skew deviation, as well as other brain stem symptoms such as impaired pain and temperature sensation over the face, ipsiversive lateropulsion, Horner's Syndrome, ataxia, dysarthria, and dysphagia.[105]

Cerebellar lesions are more rarely reported as a cause of skew deviations, particularly when the lesion is unilateral.[208] Bilateral lesions within the cerebellum have been found to cause alternating skew deviations, where the hypertropic eye changes between left and right gaze.[209] In cerebellar lesions, the abducting eye is the hypertropic eye. As the otolithic projections decussate within the upper pons, lesions of the MLF produce a contralateral OTR.[208] Lesions at this site often result in Intranuclear Ophthalmoplegia which is a horizontal gaze defect (see 2.3.2) as well as conjugate torsional nystagmus with ipsilesional beat and contralateral hypotropia.[107] Similarly with lesions of the INC, a contralateral OTR is produced, causing a contralateral hypotropia and conjugate cyclotorsion of both eyes with torsional nystagmus with ipsilesional beat.[208] Medial or bilateral midbrain lesions may cause an alternating skew deviation without bias for the abducting or adducting eye being hypertropic.[208] Lesions in this area can also result in see-saw nystagmus.[107]

Nystagmus

There is a physiological response to a 'moving visual field' that complements the VOR in stabilising the retinal image. This is known as Optokinetic Nystagmus (OKN) and consists of a slow tracking movement of the eyes (pursuit) followed by a fast re-fixation movement (saccade).[192] The pathway for this response occurs through a combination of the visual, pursuit and saccadic pathways.

Pathological nystagmus, however, is an involuntary movement of the eyes that is typically characterised by a slow drift away from fixation and a fast re-fixation movement to align the visual target with the fovea, demonstrating a jerk waveform.[192,204] This may be present persistently, including in primary position of gaze, or brought on by directional movement of gaze (gaze evoked).[204] Pathological nystagmus may be horizontal, vertical, torsional or multidirectional. Typically, both eyes are affected symmetrically but there can be variation in amplitude and velocity between the eyes, referred to as 'dissociated nystagmus'. Rarely it can be monocular.[107]

The *direction of the nystagmus* is named for the fast phase (saccadic) movement, for example, if the fast-phase is toward the right it is termed right-beat nystagmus.[107] Nystagmus with oscillations of similar velocity and amplitude (pendular nystagmus) can occur, however, this is typically caused by demyelinating conditions rather than stroke.[78] Nystagmus as a result of stroke can occur from lesions of the central vestibular system, the neural integrators, or from sensory impairment.[204]

Central vestibular impairment typically results in downbeat, upbeat or periodic-alternating nystagmus (PAN).[201] Lesions of the brainstem or cerebellar vestibular pathways will most often cause nystagmus with a vertical component but can also present as horizontal or torsional. Nystagmus from such lesions will often increase in amplitude when looking in the direction of the fast phase, and may sometimes even change direction in different gaze positions.[107,201,204,210]

Downbeat nystagmus is more commonly found in stroke patients with lesions affecting the cerebellar flocculus or ponto-medullary region.[204,211] The mechanism is unclear, however it has been proposed that when the inhibitory function of the cerebellum on the superior vestibular nucleus is impaired, the eyes will drift into upgaze.[209,212] Downbeat nystagmus will increase in intensity in lateral and downgaze and will likely be associated with postural and gait imbalance.[107,204] Patients may also perceive oscillations of their visual field if torsional nystagmus is present.

Upbeat nystagmus is far less common and results from focal lesions of the medulla, midline pons and cerebellum.[107,204] Medullary lesions causing upbeat nystagmus are thought to be caused by involvement of the vestibular nuclei, while lesions of the midbrain and pons are shown to involve the brachium conjunctivum and ventral tegmentum, respectively.[204] Impairment of these structures interrupts the signal from the anterior semicircular canals and hence cause eyes to shift downwards. Intensity of the nystagmus generally does not change on lateral gaze but may be reduced during convergence.[201]

PAN is a type of horizontal jerk nystagmus characterised by a change in direction every 3-4 minutes.[107] It is not commonly seen in stroke patients, however can occur as a result of disease of the medulla and/or cerebellum.[204]

See-saw nystagmus is another uncommon outcome of brainstem stroke. It consists of a conjugate torsional component and a disjugate vertical component.[107] The vertical component

may have a pendular or jerk waveform and the dominance of either component may vary with gaze position.[204]

Neural integrators play an important role in stabilising eccentric gaze position, that is away from the primary position.[204] Those involved in horizontal gaze are the nucleus prepositus hypoglossi (NPH) and the MVN as well as parts of the cerebellum. The most widely recognised neural integrator in vertical gaze is the INC.[107] These neural integrators stabilise gaze through generation of the 'step' signal (see Figure 2.17). Hence, if the step signal cannot be generated or rapidly decays the eyes will drift back to primary position.[107]

Gaze evoked nystagmus is only manifest on eccentric gaze (horizontal or vertical), however, rarely occurs in downgaze.[204] It is usually accompanied by defects of both the pursuit eye movement and visual fixation systems, causing saccade-like pursuit movements.[201] Gaze evoked nystagmus can also occur in conjunction with a partial gaze palsy or certain kinds of strabismus, which is termed gaze-paretic nystagmus.[107] The dissociated nystagmus that occurs in INO may be considered a type of gaze-paretic nystagmus. This is because a partial gaze palsy exists in one eye (adduction deficit of the eye ipsilateral to the lesion) in association with gaze evoked nystagmus of the other (abducting) eye when attempting gaze to the contra-lesional side.[211]

2.3.3 Disorders of higher visual function

The human visual system is complex and is extensively integrated with other neural systems relating to motor function, awareness, perception, memory, proprioception and language/ communication. As such, there are many different functions of visual processing that can be impacted through stroke beyond those already discussed. Visual processing deficits or disorders can arise from lesions within the striate cortex (V1), other areas of the visual cortex, and areas within the occipitotemporal pathway.[107,213]

Damage to V1 in the occipital cortex can cause profound vision loss known as cerebral blindness or cortical blindness. This is a loss of all conscious vision despite the retina appearing normal and the presence of normal pupil light reflexes.[190] This may also occur in conjunction with Anton's syndrome, which is the denial of blindness in the absence of dementia or delirium and occurs in approximately 10% of patients with bilateral damage to V1 or optic radiations.[107] The denial symptom is likely caused by involvement of the frontal lobe or other areas that mediate awareness. Disconnection between visual areas and areas of cerebral awareness, such as that between the parietal lobe and thalamus, may also cause this denial of vision loss.[107]

Blindsight is another unusual phenomenon that occurs in some patients with cerebral blindness or visual field loss and is the unconscious preservation of certain visual functions within the area of loss. It is mainly reported in patients with post-chiasmal vision loss.[107] Various forms exist, such as action blindsight (residual manual and saccadic localisation of visual targets), attention blindsight (residual motion perception) and affective blindsight (agnosopsia: residual form and colour perception).[107] The occurrence of blindsight in some patients with vision loss, and not others, is undetermined. However, it had been previously suspected to be dependent on the residual functioning of either the superior colliculus, the pathway from the colliculus to the extrastriate cortex via the pulvinar and/or the projections from the LGN to the extrastriate cortex.[107] More recently studies in patients with blindsight have implicated a direct anatomical connection between the LGN and the human motion area (hMT+).[214] Patients with blindsight demonstrated significant activity and sensitivity to speed in the hMT+, and showed intact functional connection with the LGN but not to other vision-related CNS structures.[214]

Lesions of the secondary visual cortex (V2 and V3) may also result in problems with figure-ground segregation (discrimination of figures from the background on which they appear) and the perception of illusory contours. However, it is difficult to characterise lesions in this area specifically, as they often also involve V1 and/or the optic radiations.[107]

Lesions within the intermediate visual cortex *(V3, V4 and V5)* are characterised by cerebral achromatopsia, and rarely, cerebral akinetopsia.[107,163] Cerebral achromatopsia is the selective loss of colour perception from damage to the posterior lingual and fusiform gyri.[191] Bilateral lesions of the intermediate visual cortex cause complete achromatopsia and unilateral lesions cause achromatopsia in the contralateral visual hemifield.[191] This is differentiated from colour vision defects associated with disorders of retinal cone cells and/or impaired ON function. Cerebral achromatopsia will often be associated with superior visual field defects and disorders of the occipitotemporal stream such as prosopagnosia (inability to recognise faces).[107] Cerebral akinetopsia refers to a loss of visual motion perception and is associated with bilateral lesions to the lateral occipital gyri.[163,191]

Dorsal occipitotemporal pathway lesions can result in a number of visual syndromes. These can occur independently or in conjunction, and can be difficult to diagnose as a collective, as it requires exclusion of extensive field defects and general cognitive impairment, both of which are common in stroke patients.[12,23] These are described as:

- *Simultanagnosia* - an attentional deficit whereby the patient is unable to interpret complex multifaceted scenes despite intact perception of individual elements.[107] Different presentations may occur where in some cases the individual may recognise only a few trees when viewing a forest (local capture) or acknowledge the forest without being aware of the trees (global capture).[107] Bilateral lesions to areas V2-V4 (Brodmann areas 18 and 19) have been implicated in this disorder.[191]
- *Optic ataxia* - refers to inaccuracy of reaching movements to objects guided by vision, despite being able to see the objects and having preserved function of the reaching limb.[163] It can result from lesions of the inferior parietal lobule, occipitofrontal white matter tracts or premotor cortex.[107] Unilateral lesions will affect the contralateral arm and may sometimes affect somatosensory targets also. The phenomenon is most pronounced when reaching for objects in the peripheral visual field.
- *Ocular motor ataxia* - can result from bilateral lesions to the parietal eye fields, frontal eye fields or both.[107] This affects voluntary saccades and may occur in conjunction with spasm of fixation where the patient is unable to make a secondary saccade if the current object of fixation is still in view. Balint's syndrome is a triad of simultanagnosia, optic ataxia and ocular motor apraxia that occurs with bilateral parietal lesions.[191]

Hemispatial Neglect is perhaps the most common visual processing disorder occurring as a consequence of stroke. It is sometimes referred to as visual neglect or visual inattention. This refers to an inability to pay attention to stimuli located in the hemifield contralateral to the lesion and is most common in right hemisphere lesions, resulting in neglect of the left hemifield.[213] The presentation is very similar to hemianopia, however, hemispatial neglect is not a defect of the visual pathway itself and so visual ability in this area is not necessarily compromised, but rather not acknowledged. Diagnosis can be difficult, as neglect can often occur in conjunction with hemianopia. However, patients with hemianopia but no neglect, show a compensatory effect whereby they show more awareness and/or make more eye movements towards the area of visual loss.[107] Lesions within the attentional network, mostly located within the right cerebral hemisphere, cause hemispatial neglect and are often localised to the posterior parietal cortex.[213] Damage to the frontal eye fields, thalamus and the white matter tracts between these areas in the right hemisphere, may also result in visual neglect.[211] Hemispatial neglect can differ in severity and is often multimodal, where somatosensory stimuli on the contralateral side of the body are not recognised or contralateral limbs are not believed to be part of their body.[107] Neglect may also be egocentric or allocentric in nature.

Agnosias are associated with lesions within the ventral occipitotemporal.[163,191] There are many forms related to visual perception:

- *Visual agnosia* - relates to an inability to recognise previously known objects by sight, but with preserved recognition of other modalities.[163] It can be selective to shape (unable to perceive properties such as curvature and volume), may be integrative (unable to piece together individual features into a perceptual whole), or associative (unable to access stored information about objects from memory).[107]
- *Prosopagnosia* - or 'face blindness' may relate to an inability to recognise familiar faces or learn new ones.[191] This can result from bilateral or right sided lesions of the fusiform gyrus and/or anterior temporal lobe. Apperceptive prosopagnosia is an inability to perceive the shape of faces with precision while associative prosopagnosia relates to a loss of facial memories.[191] The ability to recognise features such as age, gender and expression is typically preserved.
- *Topographagnosia* – is the inability to orientate and navigate in familiar surroundings and can result from lesions of the ventral occipitotemporal pathway.[107]
- *Alexia* - is the loss or reduction of reading ability in a previously literate person despite preserved writing ability (if the issue is purely visual in nature). Alexia with agraphia is a linguistic disorder and will affect both reading and writing.[191]

Visual hallucinations or illusions may also occur as a direct or indirect result of stroke. For example, Charles Bonnet Syndrome, typically associated with macular degeneration,[105] can also occur in patients with infarcts of the visual pathway where there is bilateral vision loss that overlaps in some portion of the visual field (e.g. hemianopia). Hallucinations may be simple photopsias or more complex visions of people and/or objects.[163] Evidence shows that up to 40% of hemianopia patients admit to experiencing these hallucinations when asked.[107] Visual seizures are another form of 'release hallucination' where short, often repetitive visual hallucinations occur sometimes in combination with other seizure phenomena.[107] This most often occurs in patients with occipital or temporal lobe infarcts.[191] The less understood phenomena of visual preservation refers to the continued perception of a viewed image either in time (continue to see the same image for minutes or days after viewing) or space (continue to see the same image while simultaneously viewing another).[163]

2.3.4 Pupil defects

The varying diameter of the pupil has an important role in regulating light entering the eye, with pupil dilation allowing more light to reach the retina in dim light and vice versa. This is the

light response. There is also pupil restriction in response to fixating objects in close proximity. This is the near response. Pupil constriction will also reduce the aberrations of light associated with the light hitting the spherical curve of the cornea, improving visual clarity across a wider range of distances. Pupil function is dictated by both the sympathetic nervous system (pupil dilation) and the parasympathetic nervous system (pupil constriction).

The sympathetic pupil pathway can be thought of as a three-neuron arc starting in the hypothalmus.[211] The first neuron synapses in the spinal cord from which the second neuron leaves and travels to the superior cervical ganglion on either side of the neck. The third neuron then follows a pathway alongside the ICA and into the brain via the cavernous sinus. It travels to the eye as part of the ophthalmic branch of the trigeminal nerve and then becomes long ciliary nerves that supply the pupil dilator muscle. The third neuron also sends branches to innervate the sweat glands of the face and Muller's muscle within the eyelid.[107]

The parasympathetic pupil pathway begins with the detection of light on the retina which transmits the neuronal response to the pretectal nucleus within the midbrain via the ON and tract. From here the signal is sent bilaterally to the Edinger Westphal nucleus and becomes an efferent signal sent through the oculomotor nerve. The efferent fibres travel along the inferior division of the oculomotor nerve and branch into the short ciliary nerves that supply the pupil sphincter muscle. When fixating at near, the signal for pupil constriction begins in the reticular formation of the midbrain and is relayed to the Edinger Westphal nucleus and from there it follows the same pathway to the pupil sphincter muscle.[211]

There are a number of pupillary defects that can occur as a result of stroke that vary in nature and severity according to the location of the stroke:

An afferent pupillary defect relates to damage within the afferent part of the parasympathetic pupil pathway, creating a reduced or absent direct response to light. This is typically caused by unilateral or significantly asymmetric optic neuropathy or extensive retinal damage (see Section 2.3.1).[215] Consequently, an afferent pupillary defect (or Marcus Gunn pupil) is often associated with significantly reduced visual acuity or visual field loss.[107] This is diagnosed using the swinging light test where the affected eye will show a slow, sluggish or absent response to direct light, while the unaffected eye will show normal pupil constriction to direct light.[215] In more subtle cases, a reduced direct response may only be detected by comparison to the consensual response. The affected eye will show a reduced response to direct light by a greater (normal) consensual response to light shone in the unaffected eye.[215]

A *light-near dissociation of the pupil responses* is characterised by a bilateral reduced response to light with preserved near response. This typically results from bilateral lesions of the dorsal midbrain involving the pretectal nucleus and sparing the EWN and oculomotor nucleus.[107] If there is involvement of the EWN and/or oculomotor nucleus this will result in absent direct and consensual response to light, as well as an absent near response.[192]

Corectopia, which is an eccentric or oval shaped pupil, can result from rostral midbrain disease.[105] This is thought to be due to selective inhibition of the iris sphincter muscle tone or possibly extrinsic compression from a shift in midline supratentorial structures, which can occur in haemorrhagic stroke.[107]

Horner's syndrome is characterised by a miosed pupil, ptosis and anhidrosis of the face on the affected side. It is caused by damage to the sympathetic pathway and can usually be localised to one of the three sympathetic pathway neurons.[105] Horner's syndrome occurring with stroke will typically result from a central infarction of the hypothalamus or brainstem (forms part of Wallenberg's syndrome) and will have associated symptoms respective to its location.[107,210] Anhidrosis of the affected side of the face is usually more apparent in central and preganglionic lesions, whereas postganglionic lesions are commonly associated with carotid artery dissection and will present with discomfort or pain in the ipsilateral eye and supraorbital area.[107] Postganglionic lesions may also arise from lesions within the cavernous sinus and/or superior orbital fissure. Associated signs of Horner's syndrome include anisocoria that is more apparent in dim lighting, ptosis of the upper lid and elevation of the lower lid mimicking enophthalmos, acute increased accommodation causing fluctuations in vision and sometimes dilated conjunctiva and facial vessels.[213] Diagnosis can be confirmed using 10% cocaine eye drops. A positive result will show no change in the affected pupil (remains miosed) and dilation of the unaffected pupil.[107] Further localisation of the lesion can be confirmed using Paredine eye drops: a lesion of the first or second neuron will demonstrate normal dilation of the affected eye whereas a third neuron lesion will show subnormal dilation.[107,211]

The oculomotor nerve carries parasympathetic pupillary fibres. So if the nerve is affected by stroke it will often impact the pupil, which will be fixed and dilated on the ipsi-lesional side.[216] However, pupil involvement is conditional to the location of lesion and may be total or partial depending on the severity. A rostral lesion of the oculomotor nuclear complex is more likely to involve the EWN and hence affect pupil responses, whereas a caudal lesion will likely spare the EWN and have no pupil involvement.[211] Within the fascicule, the pupillary fibres are positioned laterally,[193] and so lesions of the fascicule within the brainstem will also have pupil

involvement. Similarly, in the subarachnoid space, pupillary fibres in the oculomotor nerve are vulnerable to lesions because of their superficial superior-dorsal position and so pupil involvement is frequently seen, particularly in compressive lesions (e.g. haemorrhagic stroke).[107] The close proximity of the oculomotor nerve to various blood vessels in this location also make the pupillary fibres susceptible. Aneurysms of the posterior cerebral artery or posterior communicating artery will demonstrate a dilated pupil as one of the earliest presentations.[107] Other neighbouring blood vessels such as the basilar artery and superior cerebellar artery, are less likely to impact pupil responses due to their more lateral and inferior positions in relation to the nerve, respectively.[193]

In lesions of the cavernous sinus, a number of outcomes can occur depending on the structures affected in addition to oculomotor nerve. Pupils may be spared, or there may be pupil involvement from damaged parasympathetic pupillary fibres, or there may be concurrent damage to parasympathetic fibres within the oculomotor nerve and sympathetic fibres causing a mid-dilated pupil.[107] Once the oculomotor nerve splits into its superior and inferior divisions, pupil involvement will only result from lesions impacting the inferior division. Microvascular infarction of the vasa nervorum usually spares pupils due to the peripheral position of pupillary fibres within the oculomotor nerve.[107]

Aberrant regeneration of nerve fibres can occur after a compressive lesion and show distinctive pupil anomalies as a result.[213] Pupil-gaze dyskinesis occurs when nerve fibres originally innervating the medical rectus muscle are misdirected to then innervate the pupil sphincter muscle, causing more pupil miosis on adduction than in response to light.[211]

2.3.5 Lid/ Tear dysfunction

Several causes of lid dysfunction have already been discussed as a result of various lesions of the cranial nerves and other neural ocular pathways:

Ptosis may occur as part of Horner's syndrome, oculomotor nerve palsy and various cortical lesions.[78,213] Typically Horner's Syndrome causes mild unilateral ptosis through paralysis of the Muller's muscle in the upper lid as well a reverse ptosis of the lower lid through paresis of the inferior tarsal muscle.[107] Oculomotor nerve palsy impacts innervation to the levator muscle and may cause partial or complete ptosis.[204] Cortical ptosis may be unilateral or bilateral and can result from lesions impacting the supranuclear pathways within the temporal, occipital or frontal lobes.[107]

Lid retraction is another abnormality previously discussed that occurs as a result of dorsal midbrain lesions involving the nucleus of the PC (Collier's sign).[211] Aberrant regeneration of the

oculomotor nerve following compressive lesions can also result in lid retraction on downgaze. This occurs as a result of nerve fibres previously innervating the inferior rectus muscle being redirected to innervate the levator muscle, known as lid-gaze dyskinesis.[211] Another form of lid retraction that occurs in thalamic midbrain infarctions is bilateral eyelid lag. This refers to inhibition of the upper eyelids on downgaze and is also associated with involvement of the PC.[107] Other brainstem disorders of convergence and gaze abnormalities or vertical nystagmus can also present with eyelid nystagmus. This phenomenon involves rhythmic oscillation of the eyelids with a slow downward drift and a rapid upward phase.[107] Any disorder preventing normal eyelid closure can impact the health of the tear film and cornea through over exposure. Damage to the trigeminal and/or facial nerve can also impact the lids, tear film and/ or cornea.

Trigeminal nerve palsy

The Trigeminal nerve or CN V is a mixed sensory and motor nerve that supplies the ipsilateral side of the face.[192] The trigeminal nuclear complex within the brainstem includes sensory (within the midbrain), and motor (within the pons) nuclei. Collectively the trigeminal nerve is responsible for sensations of light touch, pain, temperature and deep sensation from muscles of mastication.[189] The peripheral trigeminal nerve is split into three divisions:

- Ophthalmic division – sensory nerve with three subdivisions: frontal, lacrimal and nasociliary
    - Supplies the forehead and scalp, cornea, upper eyelids, conjunctiva, frontal and ethmoid sinus, dorsum of the nose and lacrimal gland
    - Plays a role in the blink reflex
- Maxillary division – sensory nerve
    - Supplies the lower eyelid and tarsal conjunctiva, cheek to upper lip, maxillary sinus, nasal cavity, upper molar incisor, and superior palate
- Mandibular division – sensory and motor nerve
    - Motor nerve supplies muscles of mastication and soft palate
    - Sensory nerve supplies the base and anterior two thirds of the tongue, and large salivary glands

Stroke related lesions affecting the trigeminal nerve can result in facial numbness (oculofacial hypesthesia) or oculofacial pain on one side of the face.[189] Typically, the trigeminal nerve will be affected by central infarction at the nuclear level (within the brainstem) or within the cavernous sinus (impacting the ophthalmic division) or in carotid artery dissection.[107] Reduced

or absent corneal sensation from damage to the trigeminal nerve can cause a lack of awareness of the corneal irritation from dryness or external irritants. This will impact the regularity of instinctive or reflexive blinking and may result in corneal erosions or exposure keratopathy.[107] The blink reflex is a protective mechanism to prevent injury to the eye from external hazards and can be triggered by visual and auditory stimuli in addition to corneal sensation. Damage to the ophthalmic division can cause a defective blink reflex and hence make the eye more vulnerable to damage.[211] Similarly, the ophthalmic division supplies the lacrimal gland, which is responsible for production of the aqueous portion of the tear film. Impaired function of the lacrimal gland will result in reduced tear production and consequently dryness and subsequent damage to the cornea.[107,192]

Facial nerve palsy

The facial nerve or CN VII has motor, sensory and autonomic functions. The motor component innervates muscles of facial expression; the orbicularis oculi (used to close the eye lids) and stapedius muscle. The sensory portion provides innervation to the ear canal and the parasympathetic fibres (nervus intermedius) produce tearing, salivation and taste responses.[192] The nucleus of the facial nerve is located within the pons from which is travels through the internal auditory meatus and branches out to terminate on numerous facial structures.[192]

A supranuclear palsy of the facial nerve will cause contralateral facial weakness in the lower two thirds of the face and some weakness of the orbicularis oculi.[107] This is because the facial nerve nucleus receives contralateral input from the frontal lobe for control of the lower part of the face and bilateral input relating to control of the upper part of the face and so is not as severely impacted.[107] Supranuclear palsies can be volitional (palsy of voluntary movement that can be overcome with emotion) or emotional (palsy of emotional movement but normal voluntary movement).[189,211,213]

Conversely, a peripheral facial nerve palsy will cause ipsilateral facial weakness of the upper and lower parts.[107] There will be notable facial asymmetry, inability to frown or close eyes, depressed blink reflex and tear production on ipsilesional side, and ectropion.[189,192] Bell's phenomenon is usually preserved in a peripheral facial nerve palsy unless there is concurrent midbrain lesion.[107]

Several other ocular anomalies may also present after damage to the facial nerve. Pontine stroke may result in spastic paretic facial contracture due to involvement of the facial nerve nucleus and its supranuclear connections.[107] Similarly, blepharospasm may occur as a result of

involuntary contractions of the orbicularis oculi following supranuclear palsy or brainstem stroke.[107] The primary ocular concerns following damage to the facial nerve are the inability to close the eye and reduced tear production. The dysfunction can cause severe exposure keratopathy and eventuate to corneal scarring that significantly reduces vision.

2.4 CONCLUSION

The range and extent of visual impairment that can occur in stroke survivors is vast and often complex. As such, diagnosis and treatment of these conditions requires the expertise of specialised health professionals. Further to this, the commonality with which these conditions present,[21] as well as the significant impact they have on a patient's recovery,[36,111,217] warrants specific attention and resource allocation to this area of stroke care. Improved awareness and education on post-stroke vision impairments amongst health professionals is critical to improving how these issues are detected and addressed within the context of holistic stroke care.

With the knowledge of these stroke-related visual conditions, their impact, and the available approaches to their identification and management outlined in Chapter 1, it can be understood how the task of providing effective and timely vision care may be a challenge to health professionals working in stroke care settings without clear and targeted guidelines. This considered, together with the known factors specific to current Australian stroke care practices, guidelines and available services discussed in Chapter 1, the PRECiS Study sought to gather specific information on vision specific care provision for Australian stroke survivors. This was firstly done by undertaking a review of the literature relevant to this topic, presented in Chapter 3. This review enables a greater understanding of the information available and provides greater insight into the research context in which this study was designed and undertaken.

3 MEETING THE NEED FOR POST-STROKE VISION CARE: A SCOPING NARRATIVE REVIEW OF CURRENT PRACTICE

This chapter comprises the following paper published in *Disability and Rehabilitation* (2023).

3.1 ABSTRACT

Purpose: To determine current vision care pathways and practices for stroke survivors in Australia and internationally, with a focus on identifying reoccurring gaps in these pathways and unmet care needs.

Method: A scoping review was conducted to identify literature related to post-stroke vision care pathways, practices and perspectives of patients and health professionals. MESH terms related to stroke, stroke rehabilitation, vision and eye disorders were used.

Results: A total of 16193 articles were retrieved and 28 deemed eligible for inclusion. Of these, six were Australian, 14 from the UK, four from the USA, and one each from Finland, Denmark, Germany and Norway. Post-stroke vision care is largely unstandardized, with substantial inconsistency in the use of vision care protocols, who executes them and at what point in post-stroke care they are utilised. Both health professionals and stroke survivors expressed that unmet care needs were primarily a result of lack of education and awareness regarding post-stroke eye problems. Other reoccurring gaps in care pathways related to the timing of vision assessment, provision of management and ongoing support, and the integration of eye care specialists into the stroke team.

Conclusion: Further research is needed into current Australian post-stroke vision care to accurately assess whether the needs of stroke survivors are being met. Available evidence indicates that in Australia there is a requirement for well-defined protocols for vision screening, education, management and referral of stroke survivors.

3.2 INTRODUCTION

Stroke is the second leading cause of cardiovascular death in Australia.[218] Despite a proportional decrease in stroke events, the actual number of stroke events has increased due to an ageing population.[11] There are approximately 37,000 stroke events occurring in Australia each year.[218] Evidence indicates that 60% of these strokes will result in some form of visual impairment.[27] As stroke most commonly occurs in those aged 65 years and over,[218] there is also likely to be a high prevalence of pre-existing age-related eye conditions within this population of stroke survivors. This includes common age-related eye conditions such as

cataracts, glaucoma, macular degeneration and presbyopia. For stroke survivors, these conditions will be compounded by the presence of stroke-related visual deficits, severely impacting rehabilitation and daily life activities.[27,32] There is a strong correlation between visual impairment and increased depression,[32] falls risk[37,123,219] and overall morbidity.[34,38] Reports from stroke survivors also indicate that their visual impairment resulted in a number of barriers to reintegration into the community.[220] These included an inability to return to work, pursue hobbies such as reading, and driving. This indicates that visual impairment can be a hindrance to the successful rehabilitation of stroke survivors and resumption of independent living if not adequately addressed.

The most commonly reported post-stroke vision problems are visual field loss, eye movement abnormalities and visual processing disorders, including hemispatial neglect. There is some recovery expected post-stroke, however, the degree tends to vary depending on the type of vision problem and severity of the stroke. Only approximately 17% of visual field loss recovers completely over the first three months post stroke, while up to 34% of visual processing disorders have been found to recover in this time.[27] Eye movement abnormalities, such as most gaze defects only partially recover or do not recover at all in the six-month period after stroke.[26] For patients with ocular cranial nerve palsies, some recovery over a period of 6-12 months after onset is expected, although recovery is often partial, with only approximately 22% recovering completely.[25]

While there is no cure for some visual deficits caused by stroke, there are several management techniques and services available that have been proven to effectively reduce the burden of them. The primary complaint of eye movement abnormalities such as cranial nerve palsies, gaze palsies and vergence disorders is usually diplopia. Simple management techniques such as correctly occluding one eye, the use of prisms or the adoption of an adaptive head posture to relieve diplopia are commonly used for these conditions.[26,49] If deviations of this kind persist beyond the expected point of recovery, surgical intervention or use of Botulinum toxin to alter eye muscle actions may be appropriate. While these methods have not been systematically investigated within stroke survivors specifically, the available literature indicates their wide use and efficacy of these treatment options in adult strabismic populations.[221] Similar methods can be beneficial in some cases, to manage nystagmus, with the use of pharmacological agents such as Gabapentin and Baclofen being more common.[25,147]

For visual field loss, one of the common management techniques used is visual scanning training.[23,49] Such training is often administered through electronic programs but can also be

taught using non-computerised scanning techniques and environmental cues. It is a form of compensatory therapy that aims to improve the frequency, speed and accuracy of eye movements into the affected visual field.[126,127] Peli prisms are also used for management of visual field loss as a means of shifting images from an area of field loss into the part of the visual field that is seeing. This promotes awareness of objects in the area of vision loss and prompts/cues eye movement in that direction.[115] Another technique, visual restoration therapy (VRT) uses light stimuli at the border of the visual field defect with the aim of slowly expanding the visual field. The available evidence on VRT suggests there is little to no change in size of visual fields from this treatment and as such it is not commonly used in practice.[138,142]

Similarly, visual scanning training is often used to treat visual neglect with varying levels of success.[157] Other reported methods of treatment for this condition include perceptual retraining, typoscopes and hemifield eye patching.[49,155] However, little evidence is available regarding their success in stroke patients. Better reported is the recommendation of daily living training and the provision of aids and modifications. Services such as Guide Dogs Australia and Vision Australia can facilitate this kind of training and offer support to those with vision impairments to obtain appropriate aids and advice. Conversely other vision specific treatment such as patching, prisms, visual adaptation and orthoptic training would typically be delivered by an orthoptist, ophthalmologist or at times an occupational therapist or specialised nurse. A range of health professionals can also provide the necessary information to stroke survivors about their vision problems, what to expect and what services might be available.

Despite the range of services and treatment options available to stroke survivors with vision impairment, post-stroke vision care is scarcely addressed in Australian national stroke guidelines. The Australian Clinical Guidelines for Stroke Management currently only contain limited information regarding vision, including recommendation for visual acuity and visual field testing and treatment options for visual inattention only.[222] Not all Australian states have stroke specific guidelines, and of those that do, most do not address vision at all.[223,224] South Australia Health's Stroke Management Procedures and Protocols (2019) states that occupational therapists or physiotherapists should provide rehabilitation for functional vision loss, compensatory skills for visual field loss, visual acuity and eye movement disorders, most of which would be outside their scope of practice. The named therapies are visual training, visual scanning and use of prisms, as well as the requirement to facilitate early referral to neurological vision specialists.[225] The lack of guidance specific to post-stroke vision care makes it difficult to know if stroke survivors in Australia are getting the vision care they need to best facilitate their recovery and return to the community. As such, the aim of this review is to

determine what the current post-stroke vision care pathways and practices are in Australia and identify reoccurring gaps and unmet care needs within them.

3.3 METHODS

A review was planned to collate evidence relating to vision care pathways and practices for stroke survivors in Australia and compare these to countries with similar healthcare structures. A care pathway was defined as a process through which stroke survivors were assessed, managed and/ or referred for their vision problems. Countries of a similar healthcare structure were defined as developed countries with stroke specific services available. This review was carried out according to the PRISMA-ScR[226] guidelines.

3.3.1 Inclusion and exclusion criteria for studies

Types of studies

Studies were eligible for inclusion in the review if they provided information on post-stroke vision care practices or any stage of the post-stroke vision care pathway and were published in English. Studies included were: systematic reviews, cohort studies, observational studies, retrospective medical file reviews, randomised controlled trials and controlled trials. Case studies were not included, as they refer to isolated scenarios rather than widely utilised practices or pathways. Scoping of the literature revealed no evidence relevant to the topic published in Australia prior to 2008, hence studies conducted prior to this were excluded. For consistency, international studies published prior to 2008 were also excluded and it is noted that they may be an outdated representation of current healthcare practices. Studies were also excluded if they were conducted in developing countries under the assumption that results would vary greatly from Australian healthcare practices and hence would not be comparable.

Types of participants

We included studies of participants of all ages who were found to have visual complications following stroke. Studies relating to children (under 18 years) were analysed separately to those with adult (18 years and over) participants, as the care pathways are likely to differ based on the legal requirements for providing medical care to minors. Studies including participants of mixed health conditions were included if results for stroke survivors could be adequately differentiated. Studies with populations of health professionals who provide stroke care were also included.

3.3.2 Search methods and databases

A systematic search strategy was used to search the following key electronic databases:

- PubMed (2008- January 2022)
- Cochrane Library (2008- January 2022)
- MEDLINE (2008- January 2022)
- EMBASE (2008- January 2022)
- Australian Orthoptic Journal (2008- January 2022)

As the primary aim of this review is to identify literature relating to Australian post-stroke vision care pathways and practices, other international Orthoptic Journals were not included in the search. Search terms included a variety of MESH terms and alternatives relating to stroke, vision impairment and care provision. The complete search strategy for the PubMed database is provided as an example in Figure 3.1 manual search of reference lists from relevant Australian articles was also conducted.

Advanced search: Search #1 – (stroke[MeSH Terms]) OR (stroke rehabilitation[MeSH Terms]) Search #2 – (vision disorders[MeSH Terms]) OR (visual impairment[MeSH Terms]) OR (eye disease[MeSH Terms]) **Search #3 - #1 AND #2 Filters: from 2008 – present**

Figure 3.1 Search strategy for PubMed database

3.3.3 Study Selection

Titles and abstracts returned from the search were independently reviewed by two authors (SS, SL) using the predetermined inclusion criteria. If a study could not be properly evaluated based on title and abstract alone, the full paper was obtained. Full papers were also obtained for the studies deemed eligible for inclusion. A second review of all full paper articles was then conducted to determine those studies eligible for inclusion.

3.3.4 Data collection

Data extraction forms were designed to capture key study elements, and to inform quality assessment and categorisation. Further information collected included data pertaining to post-stroke vision care practices and pathways at each stage of care.

3.3.5 Data analysis

Data analysis was inductive and largely descriptive due to the emerging nature of the review topic and variable study types included. This resulted in a narrative review. Care pathways are likely to differ between countries, healthcare models and time, making accurate synthesis of such data difficult. The variability of study types also produces different types of data

(qualitative and quantitative) and so a thematic and descriptive approach was deemed the most appropriate. Data extracted was grouped according to the areas of post-stroke vision care. Descriptive statistics relevant to each stage of care were then collated and where possible, information on Australian post-stroke vision care was compared to that provided in other jurisdictions.

3.4 RESULTS

Figure 3.2 illustrates the results of the search. A total of 28 articles met the inclusion criteria for this review. Of the studies included, eight were cross-sectional studies, nine were cohort studies (both retrospective and prospective), five were qualitative studies, one was a mixed method study, three were multicentre prospective studies as well as one consensus study and one audit report. Studies varied in objectives, with most aiming to describe and appraise vision care provision for stroke survivors within specific regions or amongst specific professional groups. Other studies sought to explore the experience and perspectives of post-stroke vision care for stroke survivors, their carers and health professionals. The countries from which data was collected included Australia (n=6), the UK (n=12), USA (n=4), Scotland (n=2), Finland (n=1), Denmark (n=1), Germany (n=1) and Norway (n=1). Of the studies included 15 provided information on vision screening and assessment of stroke survivors, 16 included information regarding management and referral, six included information relevant to education and information dissemination and 11 discussed perceptions of care and/or barriers to care.

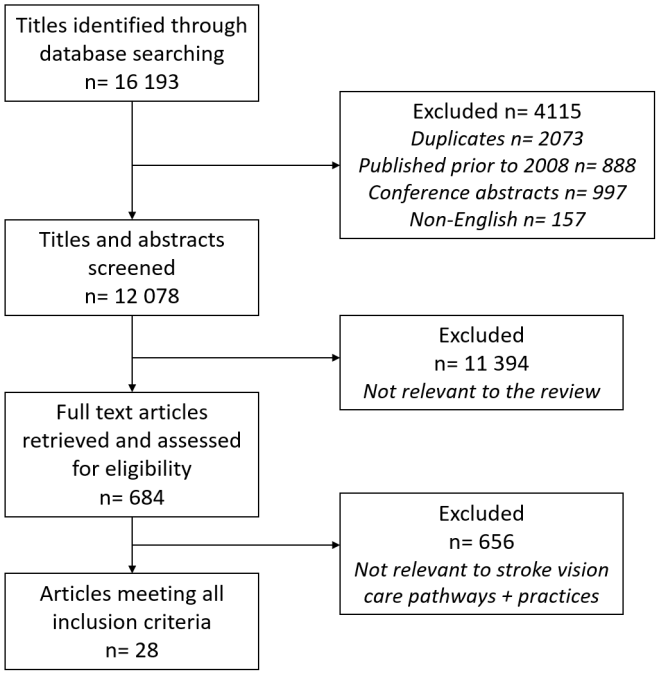


Figure 3.2 Flowchart for the pathway of included articles.

3.4.1 Care Provision

Screening & Assessment

The available evidence indicates that the timing of vision screening and assessment of stroke survivors is of key importance to the quality of overall post-stroke vision care. The Vision in Stroke (VIS) study (2006-2016) surveying outpatients with stroke found that the median duration from stroke onset to initial eye examination was 22 days among stroke patients in 20 acute Trust hospitals in the UK (primarily out-patient settings).[24] More recently (2014-2015), further UK research in the Impact of Vision Impairment after Stroke (IVIS) study, interviewed 24 stroke health professionals working in integrated stroke/vision services. These interviews revealed that there was an aim to undertake initial vision assessment within one week of stroke onset/ admission.[227] However, in a slightly earlier study by the same group, a survey of 548 stroke health professionals indicated that only 41% reported assessing vision within one week of admission to the stroke unit.[27,50] In a similar survey of orthoptists across 16 different countries, approximately half (55.6%) stated that first vision assessment was performed within four weeks of admission.[228] However, reports from stroke survivors indicated a delay in assessment, with many experiencing late or no referral to vision services.[27,36]

There is a large amount of variability in reports of how vision screening is performed. Orthoptists report most frequently testing visual acuity, using standardised letter charts, visual fields, ocular alignment and ocular movements when assessing stroke survivors.[228] From reports of stroke health professionals in the UK, 22% use a screening tool to test vision, 39.5% tested visual acuity (method unspecified), 57.7% tested visual fields, 48.5% assessed ocular movements and 58.5% tested functional vision.[27,50] When vision screening was performed by an occupational therapist, this consisted of visual attention and scanning testing, visual field assessment and visual tracking[51,124]or use of an occupational therapist vision screening tool.[183] Another group of health professionals within a Danish stroke vision team, described by Norup et al.,[51] variously assessed cranial nerve function, neuro-ophthalmic reflexes, eye movements, visual fields and inattention (neurologist); balance, gait/ posture, eye movements, hand-eye coordination, ability to measure distance, vestibular-ocular reflex, hemianopia, diplopia and neglect (physiotherapist); visuo-perceptual and visuo-spatial difficulties (neuropsychologist).[51]

When determining which health professional typically performs vision screening and assessment, each study illustrated different protocols indicative of the structure of the respective hospital departments/ units. In the UK, orthoptists reported that first vision assessment for stroke survivors was usually performed by an orthoptist (87%) in the eye clinic (78.6%).[228] In all but one National Health Service (NHS) Trust surveyed by Rowe and colleagues

(2013), stroke survivors had initial screening performed by a stroke team who had been trained by an orthoptist. Similar referral protocols were followed by other stroke services, whereby any need for secondary vision assessment was referred to an orthoptist[227] or other eye-care professional.[183]

Studies conducted in Australia found that vision assessment by non-orthoptic health professionals identified only 17% of the ocular conditions detected by an orthoptic assessment.[48,61] This improved to detection of 62% of all ocular conditions[61] and a sensitivity of 67%[229] with the use of a vision screening tool. It was also found that the availability of hospital on-site outpatient eye care did not significantly increase the number of ocular problems detected in stroke survivors, when compared to those hospitals without any ophthalmology services.[48]

Management & Referral

Reports from both orthoptists[49] and occupational therapists[124] in Scotland indicated that only 14% and 9%, respectively, had a vision protocol or management plans specific to stroke patients in their stroke unit. In the UK, 13/14 NHS Trusts indicated that they use a standardised screening and referral form for post-stroke vision care.[27] There were also notable differences in referral patterns and the health professionals involved in post-stroke vision care between countries. Stroke services within the UK often had orthoptic led post-stroke vision care services[49,227,230] or capacity to refer directly to an orthoptist when visual problems are suspected.[27,231] In the Danish service model described by Norup et al[51] stroke patients with visual deficits that affect daily living (e.g. visual field loss, loss of vision and eye movement abnormalities) were referred to an OT. Stroke patients with vision problems affecting balance and mobility were referred to a physiotherapist, and those with visuo-perceptual or visuo-spatial issues were referred to a neuropsychologist.[51]

An American study interviewed stroke survivors and their carers, who reported that they either saw an ophthalmologist, occupational therapist or 'other' unidentified care provider for their visual concerns.[217] Ophthalmologists were seen for the provision of magnifiers, glasses or patching/ occlusion. Occupational therapists addressed visual concerns with scanning, gaming and eye-hand coordination activities, while other health care professionals provided compensation techniques and therapy.[217,232] These differences may in part be explained by the availability of orthoptists and orthoptic training programs between countries. Orthoptics degrees are offered at four universities within the UK, while the USA has a limited number of post-graduate fellowship training positions available, and Denmark does not have any

orthoptic training. In Australia there are two universities offering either undergraduate or postgraduate orthoptic degrees. Australian studies were conducted across a select number of stroke facilities across Sydney,[48,61,229] and so could not provide generalisable information on referral patterns or which health professionals were typically involved in post-stroke vision care. However, when management of vision problems by orthoptists was compared to non-orthoptic inpatient staff in the participating stroke services, orthoptists more frequently provided referral and intervention to stroke patients.[48,229]

Provision of treatment was also highly variable amongst all studies. Orthoptists (65.2%)[228] and other health professionals (46.5%)[50] would only occasionally treat stroke patients who had an eye condition but without visual symptoms. However, when asked about provision of treatment for stroke survivors with vision problems, most occupational therapists (75%) report providing treatment within six weeks of stroke.[124] It should be noted that the occupational therapists participating in this survey indicated similar frequency of use of the same treatment methods across all categories of visual conditions, suggesting that treatment did not vary according to the specific vision problem.

Interviews with stroke survivors in the UK suggest that the majority did not receive any treatment or ongoing community support for their vision problems.[27,220,233] The most common types of treatment provided across studies were functional and vision advice[49,50,111,228] and scanning and or reading strategies.[13,50,51] Other treatment options provided were prisms for diplopia,[228] monocular patching,[217,228] prism adaptation,[13,51] and magnifiers/low vision aids.[217] Studies that examined the provision of post-stroke vision care by orthoptists demonstrated more frequent use of management strategies such as feedback and advice, occlusion, lid taping, driver standard management, visual scanning, convergence training and recommendation for adaptive technologies/ low vision aids.[48,112] Approximately half of the participating services in UK studies also keep a database of all referrals to ensure all patients receive appropriate assessment and follow up.[27,227]

Education & Information

Delivery of quality vision care requires appropriately trained staff as well as appropriately targeted provision of information to patients and carers. The education of healthcare professionals and the provision of vision specific information to stroke survivors is a recurrent theme in the literature. Health professionals from integrated stroke and vision services in the UK highlighted accurate and ongoing vision training for multi-disciplinary members of the stroke team as important for quality of service.[227] Of 548 stroke health professionals surveyed

in the UK, 20% rated their knowledge of visual problems as fairly poor or very poor[27] while 24% of Scottish occupational therapists report having no specific training on post-stroke vision problems.[124] This suggests that approximately one in five health professionals tasked with providing vision care to stroke survivors do not have the appropriate knowledge base and/or training to do so. This is reiterated in the experience of stroke survivors in Norway and the UK, where they reported a lack of awareness among healthcare professionals[111,220] and inappropriate solutions suggested for their vision problems.[220]

Stroke survivors in the UK also report that the provision of information about their vision problems was related the knowledge and experience of their treating health professionals. Where these were non-eye care trained staff, little to no information was provided.[111] Similarly, stroke survivors in Norway report poor information provision, particularly relating to vision rehabilitation options and support services.[220] The majority of orthoptists (85.9%) do provide patients with visual information sheets,[228] while 33.5% of UK stroke health professionals (mixed disciplines) did not provide visual information sheets.[50] In addition to providing vision information sheets, half of the participating services in the UK study by Rowe et al[227] provided lay summaries to the stroke team as well as to patients and carers. These summaries included information about the patient's vision problem, treatment needed and provided, as well as required follow up.[227]

3.4.2 Reported barriers & unmet care needs

Barriers to successful post-stroke vision care and existing unmet care needs must be identified to understand the nature of current pitfalls in post-stroke vision care services and enable improvement. Stroke survivors and health professionals alike report a number of barriers to accessing and providing appropriate post-stroke vision care. Stroke survivors in the UK and Norway identify visual impairment as a 'hidden disability', making it difficult to obtain adequate vision care in acute or rehabilitative stroke care setting.[220,233] Stroke survivors in general, reported experiencing a general lack of awareness and support amongst health care professionals relating to their post-stroke vision problems, coupled with poor provision of information about vision in general and support services.[27,111,220,231,233]

Stroke health services often do not have access to vision care specialists in the stroke unit and deemed a lack of funding as one of the primary barriers to providing this service.[27,49,227] A lack of funding was also said to impact capacity for orthoptic cover when services relied on a single orthoptist or eye care professional.[227] Where services are only able to provide one session per week, there was a perceived risk of missing patients and not being able to screen all patients in

a timely manner.[227] Other factors deemed important by health professionals to the success of stroke vision services were adequate training of multi-disciplinary team members,[27,227] use of a standardised protocols or management plans[49,50,124] and support from stroke physicians.[227]

There is also evidence of a lack of awareness about stroke related vision problems amongst the general community and health professionals when investigating pre-hospital pathways for stroke sufferers. A study by Aroor et al[234] found that amongst the stroke sufferers that did not have any symptoms relating to the F.A.S.T. mnemonic, 40% had visual presenting symptoms. Of the 14.1% of patients with missed stroke diagnosis according to F.A.S.T., 9.7% could have been identified with the inclusion of balance and vision screening.[234] Raty et al[235] found that 11.4% of occipital stroke patients with isolated visual symptoms were frequently misdiagnosed and/or frequently arrived to ED through at least 2 points of care (27.3%). As such, these patients are more likely present to emergency services outside of the 4.5 hour eligibility window for IV thrombolysis.[235] Stroke survivors themselves also report being unaware of vision symptoms as part of the stroke syndrome[220] and attributing them to other causes.[220,233,236]

Other barriers identified by focus groups of stroke survivors and health professionals in addition to those related to funding and education included poor communication and poor transfer of patient information between teams, and limited access to vision care appointments.[231] Stroke survivors reported that the impact of post-stroke visual impairment could have been improved by early formal visual assessment, provision of management and advice on adaptive strategies and rehabilitation options.[220,233]

3.5 Discussion

The main themes identified in the available literature relating to post stroke vision care pathways and practices are: screening and assessment, management and referral, education and information, barriers and unmet care needs. Within these themes, more specific questions were explored in relation to the timing of each theme, which health care professionals are and should be involved, as well as the specificity of care provision. There is very limited evidence pertaining to Australian post-stroke vision care pathways and practices, with a large portion of the existing evidence base originating in the UK. Without formal investigation, it is difficult to know whether Australian stroke survivors with vision problems are receiving adequate care, if any at all. Based on the results of one NSW health district, it would appear that inequalities in vision care for stroke survivors do exist within the healthcare system, largely dependent on access to orthoptic services.[48]

While the evidence related to the structure and protocols of each service demonstrates large amounts of variability in current practice around the world, similar trends have emerged in relation to their successes and failures. The strongest message to emerge from this evidence is the need for implementation of a vision care pathway or framework specific to Australian stroke survivors that offers clear guidance on how care should be provided, by whom, and when. In addition to this, a greater focus on stroke related vision problems is needed within stroke care teams to improve knowledge through the provision of education in this area.[50,124] Nationwide campaigns targeting awareness of stroke related vision problems among the general Australian population are also necessary moving forward, so that those suffering a stroke recognise the importance of stroke-related visual symptoms.

Studies concerning vision and ocular health assessment suggest that initial vision screening should be performed in the stroke unit on all stroke patients.[27,48,61] It is evident that this does not happen consistently across Australia and internationally, if at all. Reasons for this may relate to inadequate funding to facilitate appropriate staffing to carry out these assessments,[230] as well as a lack of expertise and/or training amongst stroke care teams.[227,235] Differences in timing of vision assessment between studies may also relate to evolution in services over time and the type of stroke service from which participants were recruited. For example, the VIS study ran from 2006-2010 with recruitment mainly from outpatient services, while the IVIS study ran from 2014-2015 and recruited participants primarily from inpatient services.

Vision screening tools specific to stroke patients appear to be a viable option to address this gap in the initial stages of stroke vision care. Several studies have found that vision screening tools improve the identification of ocular conditions in stroke survivors, even when administered by non-eye care professionals.[47,54,61,229] The efficacy of these tools is proven to be enhanced when appropriate training on use of the tool is provided.[47,54,61,229] A number of different non-eye care professionals such as occupational therapists, nurses, and physiotherapists are assigned the role of carrying out vision assessment across stroke services. While it is important to acknowledge the value of such professionals being able to identify and manage certain eye conditions, orthoptists appear to be an underutilised resource within stroke care teams. Research has shown orthoptic led assessment to be the gold-standard in stroke vision care and their inclusion in stroke teams may help address gaps in provision of information and vision rehabilitation.[27,48,61,237]

The literature reviewed suggests that limited management options for vision problems are provided to stroke patients.[24,217,233] This may be due to: the perceived potential for recovery of some stroke related vision problems within three to six months post stroke, the visual problems not being detected, or the absence of an available and appropriate care provider. However, when considering the negative impact vision problems can have on rehabilitation,[237-239] basic interventions should be provided as early as possible as a minimum. Of the services that reported providing management, the most common strategies used were advice, magnifiers, monocular patching and visual scanning training.[13,24,51] Simple interventions such as these may assist stroke survivors in participation of other rehabilitation activities and ease the burden of vision impairment in the acute stages of recovery, even though they do not cover the entirety of possible beneficial interventions.

The provision of clear and targeted information that is specific to the stroke survivor's visual impairment is also seen to be a valuable and empowering form of management.[217,220,233,240] Stroke survivors and their carers should be directed to appropriate long-term care providers and vision support services prior to discharge from hospital in order to better assist the stroke survivor's reintegration into the community. Provision of such information is reportedly done to differing levels of success across the different services described.

There is limited evidence pertaining to the provision of vision care for stroke survivors in Australia and internationally. The pooling of data from different countries and, as such, different health services also makes it difficult to draw firm conclusions about current practice. In the UK, a stroke-vision care pathway has recently been developed in attempt to address the known gaps in this area of healthcare.[231] Such a pathway enables stroke sufferers and health professionals alike to be aware of the options and appropriate actions to take in response to stroke-related vision problems. Implementation of stroke clinical pathways has also been shown to improve coordination of multidisciplinary care, reduce length of hospital stays and overall healthcare costs.[241]

The lack of evidence and specified guidelines concerning post-stroke vision care within Australia may be an indication that Australian post-stroke vision care has similar pitfalls to those found internationally. While we can look to research such as that conducted in the UK as an example, the unique demographic and geographic characteristics of Australia needs specific and targeted requirements for a healthcare framework to be successful.[242-244] The development of a stroke-vision care pathway that is appropriate for implementation in Australia would address the unmet care needs across differing services and locations of the

many Australians who suffer from stroke related vision problems. Future research should aim to describe and assess potential gaps in the current provision of stroke-vision care within Australia and work towards developing pathways that are appropriate, feasible and targeted to the needs of stroke survivors and those that care for them.

3.6 CHAPTER CONCLUSION

The manuscript presented in this chapter demonstrated the literature review undertaken in order to determine the evidence available on Australian post-stroke vision care. In doing so, it became clear that this is an emerging area of research, with limited amounts of high-quality evidence available to inform and evaluate post-stroke vision care practice in the context of Australian healthcare and in countries with a comparable healthcare system. This review illustrated a clear gap in knowledge and research in this area and hence confirmed the value of undertaking the PRECiS study, for which the approach is outlined in Chapter 4 (Section 4.2). In this outline of the study approach there is an introduction to Vanhaecht's 7-phase method for the design, implementation and evaluation of care pathways, which informed the design of the PRECiS study. The first phase of this method is the 'Screening' phase, in which care pathway developers are first encouraged to determine the need for a new approach to care and establish if a care pathway is an appropriate means of addressing this need. This phase of Vanhaecht's method was in fact performed and presented in the form of this literature review (Chapter 3) . As such, phase one of Vanhaecht's method is presented in this thesis ahead of the description of the complete study methodology and approach which align with the following phases. The order of this presentation reflects the chronology in which the PRECiS study was undertaken and also helps to establish the merit of the research to follow.

4 DETERMINING CURRENT POST-STROKE VISION CARE PATHWAYS & PRACTICES IN NSW (PRECIS: STAGE ONE): METHODOLOGY

4.1 INTRODUCTION

The ongoing strain caused by stroke on Australian communities and state-based health systems,[14] as well as the challenges faced by stroke survivors[11] has been discussed at length in Chapter 1. It is known that stroke can result in a multitude of vision impairments (Chapter 2) and occurs most frequently within the age group (60 years and older) at greatest risk of other age-related eye conditions.[24,28,29] While Australian healthcare is renowned globally for its quality and accessibility, there are reasons to suspect a large gap in care provision in relation to post-stroke vision problems. Internationally, evidence indicates that there is a consistent lack of awareness pertaining to post-stroke vision problems and appropriate vision care provision reported by health professionals[27,62,124] and the general public[111,220,245] alike. Australian national and state-based stroke guidelines scarcely mention vision problems following stroke,[52,246,247] with little information relating to their identification and management (Chapter 3). To date, there are also no protocols or guidelines that have been developed specifically in relation to post-stroke vision care within Australia. In fact, very little evidence is available regarding current care practices and pathways for stroke survivors with vision problems within the Australian healthcare context as evidence in the literature review presented in Chapter 3.

As the gap in Australian based evidence is apparent, the PRECiS study aimed to determine the gaps and unmet care needs in this area of stroke care and develop a care pathway that addresses these and is suitable for use in an Australian context. This was to be done over two stages, for which the overall approach and structure is outlined in this chapter (section 4.2). PRECiS: Stage One aimed to determine the current post-stroke vision care practices and pathways within NSW, including: the timing of screening for visual impairments in stroke survivors, any tools that are currently used, and which stroke or eye care professionals perform vision screening, while also identifying any barriers to appropriate and timely detection of visual impairments. In addition, PRECiS: Stage One aimed to identify current long term care pathways for stroke survivors with visual impairments that include referral to visual rehabilitation services, or for specialist management. In doing so, it was hoped that unmet care needs for stroke survivors with visual impairment may be identified along with contributors to unmet need such as, gaps in referral processes or access to appropriate services. Following the outline of the overall study (section 4.2), this chapter encompasses

information on the research design, development of data collection tools, sampling and recruitment methodology, and data analysis of PRECiS: Stage One.

4.2 METHODOLOGY: AN OVERVIEW

The stages of the PRECiS Study were informed by Vanhaecht's 7-phase method to design, implement, and evaluate, care pathways. The seven phases outlined by Vanhaecht are as follows:

1. Screening – determine the need for a new or revised approach to care, and if a care pathway is an appropriate means of addressing this need.
2. Project Management – planning of the project and pathway development.
3. Diagnostic and Objectification – evaluation of current care practices from the perspectives of: the 'organisation or team' providing care, the patients and families, the available evidence and/or legislation, any relevant external partners.
4. Development – the design and practical development of the pathway based on objective information and goals established in the preceding phases. This should include specification of the key interventions to be used or recommended and have a focus on communication between the team providing care and the patient(s).
5. Implementation – testing of the pathway on a small group.
6. Evaluation – evaluation of the performance of the pathway.
7. Continuous follow-up – the use and continuous re-evaluation and updating of the pathway as appropriate.

Due to the timing and resource restrictions of a doctoral research project, we aimed to undertake phases one to four of Vanhaecht's method. The first phase has been informed by the scoping review presented in Chapter 3. The information gained in Chapter 3 evolved into the planned PRECiS study (see Figure 4.1) that aligns with Vanhaecht's 'phase two'. The exploratory methods using surveys and interviews are presented in the current chapter. The data obtained from this research related to the diagnosis and evaluation of current care practices and therefore aligns with Vanhaecht's 'phase three'. These results are presented in Chapters 6 and 7 (Fig 4.1). Vanhaecht's 'phase four' of care pathway development informed the design of PRECiS: Stage Two in which the aim was to develop a post-stroke vision care pathway suitable for implementation in NSW that addresses the gaps in care provision identified in PRECiS: Stage One. The methodology and results of PRECiS: Stage Two are presented in Chapters 8 and 9, respectively (Fig 4.1). Phases five to seven of Vanhaecht's

method were not possible to carry out within the scope of this doctorate, however, are discussed further in Chapter 10.

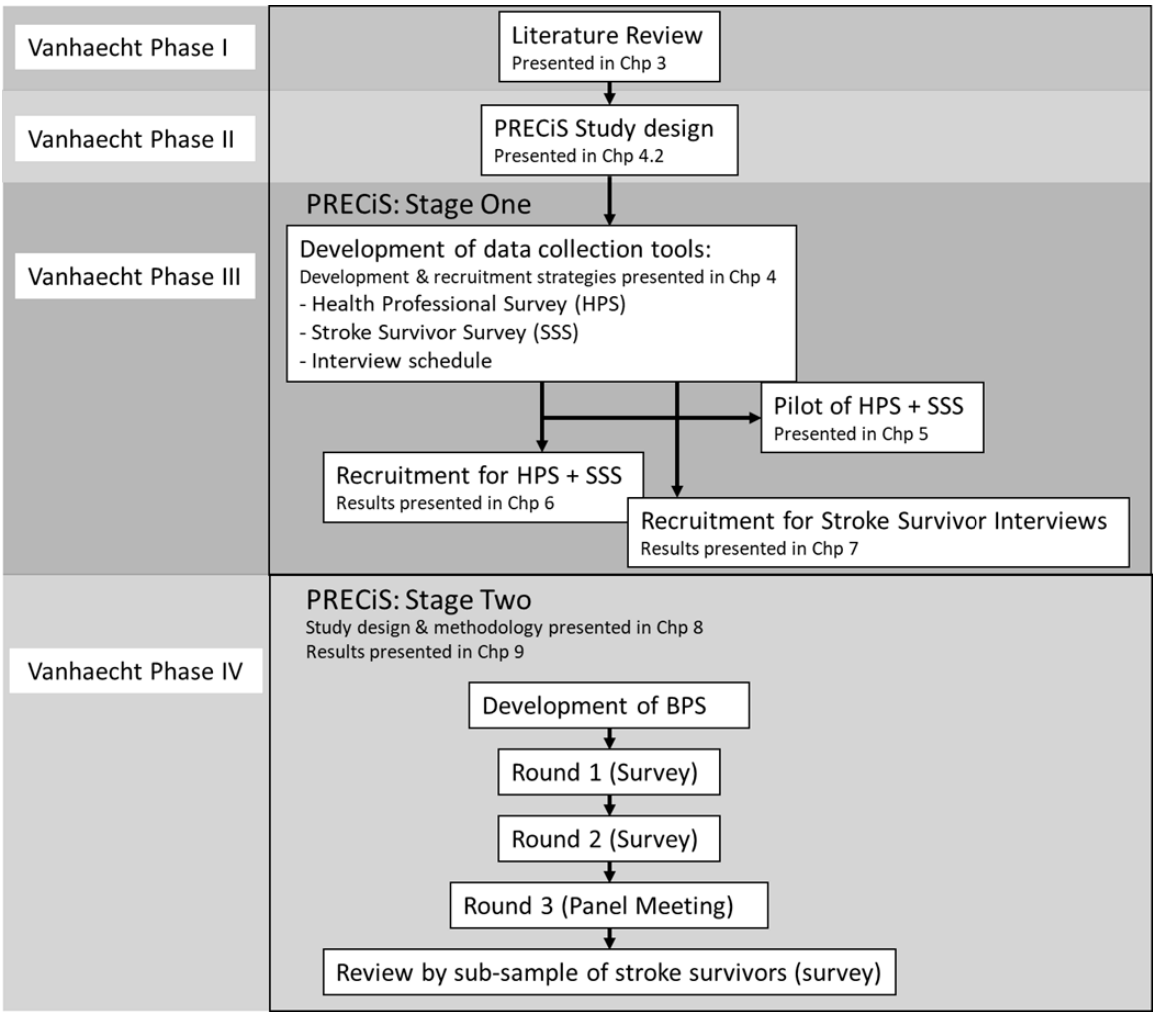


Figure 4.1 Pathway Research for Eye Care in Stroke (PRECiS) study overview demonstrating the various elements of the study in chronological order, how each aligns with the phases of Vanhaecht's method for care pathway development, and where they are presented within this thesis.

4.3 PRECiS: Stage One Methodology

4.3.1 Exploratory Research Design: Rationale

As PRECiS: Stage One is an exploratory study of existing care pathways for stroke survivors with vision impairment in NSW, a convergent, parallel, mixed methods design (Fig. 4.1) was employed using a combination of surveys and interviews as it was the most appropriate means of addressing the aims of PRECiS: Stage One as outlined previously (see 4.1). Ethical clearance for PRECiS: Stage One, inclusive of the surveys (4.2.2), interviews (4.2.3) and feasibility study

(Chapter 5), was received from the University of Technology Sydney Human Research Ethics Committee (ETH18-2675).

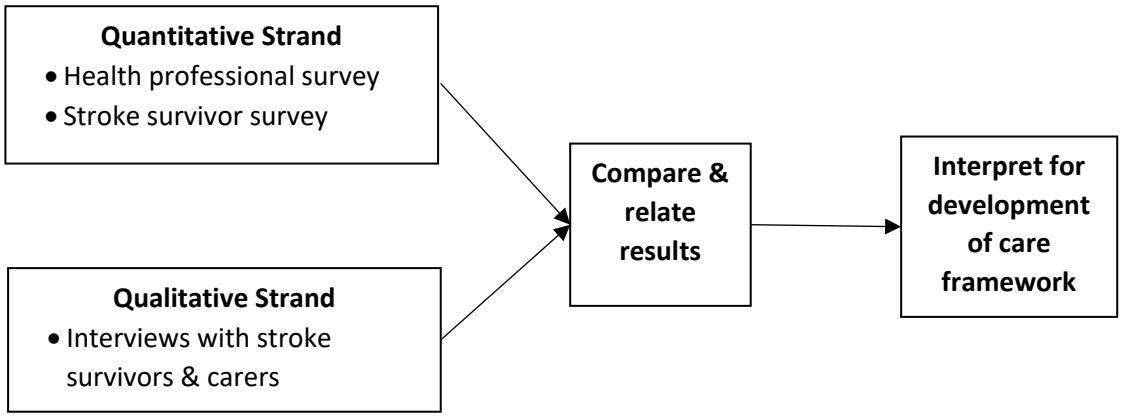


Figure 4.2 Diagrammatic representation of convergent, parallel, mixed method study design demonstrating use of qualitative and quantitative research methods to attain information on current post-stroke vision care practices and pathways used within NSW.

The purpose of the quantitative surveys was to describe the current post-stroke vision care pathways within NSW. As indicated by the literature review (Chapter 3), these pathways are likely to vary significantly depending on the type and severity of the stroke, the type and severity of the visual impairment, whether the treating hospital or facility offers a vision service, as well as location of the patient at the time of stroke. Survey methodology was deemed the most appropriate data collection tool because of the diagnostic and exploratory nature of the research. Surveys enable the collection of data from a broad range of participants. They also enable broad exploration of the likely complexity and variance of participant's experiences, and of the modes of care and pathways that are available.

The quantitative strand will consist of two surveys: one to be completed by health professionals in NSW who work with stroke patients and the other to be completed by stroke survivors residing in NSW. In keeping with the 'diagnostic and objectification' phase described by Vanhaecht, the rationale for designing two surveys was to capture the different experiences of the primary stakeholders in post-stroke vision care. Each group is likely to offer a different perspective and differing levels of detail of the various aspects of post-stroke vision care. When amalgamated, the information from both participant groups will create a more complete picture of the existing care pathways, their strengths and pitfalls.

Areas to explore in the surveys were identified in the scoping review of literature and as indicated in Chapter 3, the major components of care and their influencers were found to be:

- the screening and assessment of stroke survivors with vision problems;
    - the timing of this assessment
    - the health professional(s) who perform this assessment
    - the appropriateness and accuracy of this assessment,
- the management and referral of stroke survivors with vision problems;
    - the timing of this management and/or referral
    - the health professional who provide this management and/or referral
    - the appropriateness and success of this management and/or referral,
- the education of both stakeholder groups and the information provided to them regarding vision problems after stroke;
    - the timing in which this education/information is provided
    - the specificity of this education/ information.

Barriers to vision care and unmet vision care needs was also identified as a relevant theme in the literature review (Chapter 3) which may relate to and/or influence all of the aforementioned components of care. This theme was also explored in the surveys, although to a lesser extent, with the intent of investigating this further through the interviews.

4.3.2 Survey methodology

The data collection tools, the Stroke Survivor Survey (SSS) and the Health Professional Survey (HPS) (see Appendix 11.5), were formed with the intention of describing these components of care and assessing differences in their influencers, as well as briefly exploring the perceived barriers to care and potential unmet care needs. The SSS and HPS were designed by the candidate and refined following consultation with the supervisory team. The surveys were then piloted in a small feasibility study, which is presented in Chapter 5. Further refinement of the surveys was undertaken following feedback from stroke survivors and health professionals in the feasibility study before their use in a larger sample. The final versions of these surveys are presented in Appendices 11.1 (SSS) and 11.2 (HPS). While these surveys were designed with the intention of administering them online, hardcopy alternatives were also created in the event that participants could not complete them online. The surveys were built using Research Electronic Data Capture (REDCap) software. Time to complete survey was not to exceed 30 minutes in order to reduce participant burden and increase completion rates by increasing the likelihood of respondents completing the survey in one sitting.

Stroke Survivor Survey

Design of the SSS (Appendix 11.1) included unique considerations for the intended population. Stroke survivors with vision impairment may potentially have vastly varied types of physical and cognitive deficits of differing severities in addition to their vision impairment. To address this, and make the survey as broadly accessible as possible, the following features were included in the SSS:

- respondent controlled font size (large print for hardcopy surveys)
- simple/ clear wording, with mostly closed questions
- text-to-speech audio (online only)
- explanation of questions and instructions on how to complete the survey where appropriate

The SSS could be completed by the primary carer of the participant if appropriate consent was provided, in order to allow responses from more severely affected stroke survivors. Survey length was also an important consideration, and so questions were kept to a minimum, while still capturing all relevant components of the care experience. In comparison to other surveys and questionnaires carried out in similar populations, the SSS was of similar length,[248,249] with 47 items. Respondents were also given the option to save their responses and return at a later stage to complete the survey using a unique survey code.

Health Professional Survey

The HPS (Appendix 11.2) was intended to be completed by a wide range of health professionals who work with stroke survivors, both with and without specialised knowledge relating to vision or eye health. To enable the questioning of vision specific care within a broad range of health specialties, vision specific medical jargon was kept to a minimum and explained where necessary. Stroke care also takes place over many different care settings, in which different processes and modes of care provision take place. The survey needed to be inclusive and applicable to inpatient, outpatient, and mixed care facilities, as well as public, private and non-government organisations. The survey design also had to consider the different stages of stroke care, which are typically divided into hyper-acute, acute, sub-acute and rehabilitation. Branching logic within the question progression was used to address this. This allowed respondents at the start of the survey to first identify the type of care setting they worked in, and then they were directed to the questions applicable to that setting. Again, survey length has important implications for burden on respondents and completion rates. The

HPS was of similar length, or slightly longer (by 2-4 items) than other surveys administered to stroke health professionals,[124,228] with a total of 25 items.

Sampling & Recruitment

The sampling and recruitment methodology outlined below relates to PRECiS: Stage One participants only (results presented in Chapter 6). Separate recruitment methods for the survey feasibility study are presented in Chapter 5. Survey data from the feasibility study (Chapter 5) was not included in the final survey results (Chapter 6) due to the considerable amendments made to the surveys following the feasibility study.

Stroke Survivors

Stroke survivors were eligible to participate in the survey if their stroke had occurred at least three months prior, but no more than ten years ago. This criteria was put in place because stroke survivors may still have significant cognitive and physical deficits within three months of their stroke. These could have had the potential to limit their ability to provide informed consent, participate, and provide accurate responses. A limit of ten years since the stroke event was chosen in order to limit recall bias, as well as redundancies in terms of changes in care processes and facilities that may have occurred. Stroke survivors had to be 18 years or older at the time of participation. This was deemed appropriate as the majority of stroke occurs in people over the age of 65[250] and because it is likely that the care pathway for childhood stroke would vary significantly from adult stroke and so should be investigated as a separate population. Finally, stroke survivors had to reside in NSW, as differences in health systems between states would have potentially confounded outcomes, and also to attract sufficient participants from one health system within the period for data collection to make meaningful analysis.

Table 4.1 Eligibility criteria for stroke survivor participant group.

Inclusion Criteria	Exclusion Criteria
• Has previously had a stroke or is the carer of a consenting stroke survivor • Received treatment for stroke in NSW • Has/ had a vision or eye problem	• Participants who are unable to provide consent themselves or do not pass the cognitive assessment portion of the survey • If the stroke event was less than 3 months ago or more than 10 years ago

Stroke survivors were recruited through a number of different avenues in an attempt to make the recruitment process as inclusive as possible. This also facilitated recruitment of stroke survivors with a variety of socio-demographic and socio-economic characteristics, and from within metropolitan and regional/ remote areas of NSW. Recruitment strategies included:

- online advertisement on:
    - the Stroke Foundation website
    - Stroke Recovery NSW website
    - social media forum 'Enable Me'
    - social media outlets (Facebook/ Twitter) through Australian-based support groups/ stroke specific pages
- direct approach and advertisement through Stroke Recovery NSW support groups and conferences
- paper based advertisement within eye clinics and rehabilitation facilities throughout NSW

A sample size of 100 stroke survivors was chosen based on achievability inferred from known Australian statistics. In NSW approximately 50 stroke survivors are admitted to rehabilitation per year.[251] Based on a prevalence of 60% for visual impairments in this population,[27] there would be approximately 30 new stroke survivors eligible to participate per year. Given the eligible time period in relation to onset of the stroke, a total of 100 responses to the survey was thought to be achievable.

Due to the descriptive nature of the data generated by such surveys (with some free text responses), there was no statistical means of calculating sample size. Rather, we can only calculate an estimate of the probable sampling error. A conventional cut-off value of 5% has been chosen. Sampling error is calculated using the least sensitive measure form in a survey, which in the SSS are 'Yes/No' questions. As such, the relevant formula is to calculate sampling error is:

= SQRT [(P x Q) /n]

= SQRT [(0.5x0.5)/100]

= 0.05

where P=0.5 and Q=0.5 if half of respondents answer 'yes' and half 'no'. This is the highest possible sampling error, because as one response becomes more popular than the other, the

sampling error decreases. As such, the maximum sampling error with 100 participants satisfies the standard cut off of 5% for the SSS.

Health Professionals

Health professionals were eligible to participate in the survey if they currently or had previously worked with stroke patients in NSW within the last five years (see Table 4.2). Again, due to differences in state-based health systems and the time constraints for recruitment, the investigation has been contained to NSW. A limit of five years for previous work with stroke patients was included to limit inaccuracies with regard to changing practice. This was deemed to be appropriate, in contrast to the 10-year cut off for stroke survivors, as the HPS asked more specific and detailed questions about care provision, whereas the questions asked to stroke survivors were more generalised and targeted to their personal experience of their post-stroke vision care. As such, it seemed appropriate to place greater limitations on the HPS group to ensure greater currency of information. It was also anticipated that there would be greater numbers of eligible health care professionals likely to participate than there would be eligible stroke survivors, when considering factors such as capacity to consent, physical and cognitive burden of completing the survey within a stroke affected population.

Table 4.2 Eligibility criteria for health professional participant group

Inclusion Criteria	Exclusion Criteria
• Works with stroke patients in their current or previous workplace	• If work with stroke patients was outside of NSW • If work with stroke patients or in the area of stroke care was more than 5 years ago

Health professionals were recruited via email invitation to NSW members of a number of professional organisations, including:

- Agency for Clinical Innovation (Stroke Network)
- Orthoptics Australia
- Acute Stroke Nurses Network
- Stroke Society of Australasia
- Australian Physiotherapy Association
- Speech Pathology Australia

- Occupational Therapy Australia
- Optometry Australia
- Royal Australian and New Zealand College of Ophthalmology
- Australian and New Zealand Association of Neurologists
- NSW Nurses and Midwives Association
- Australian Association of Social Workers

Health professionals in rehabilitation and non-government organisations (e.g. Guide Dogs NSW and Vision Australia) as well as heads of stroke units within NSW were directly approached and invited to participate and disseminate information to their colleagues. Online advertisement was also made through social media outlets (Facebook and Twitter) via relevant Australian-based professional organisational pages, and stroke care pages/groups. A sample size of 200 health professionals was deemed achievable based on the wide range of professionals who work within the stroke care pathway. Using the same rationale as was used for the stroke survivor group, the sampling error was calculated for a health professional group with n=200:

= SQRT [(P x Q) /n]
= SQRT [(0.5x0.5)/200]
= 0.04

Again, using the highest possible sampling error, where P=0.5 and Q=0.5, the sample size of 200 satisfies the cut off of 5%.

Informed Consent

Participant information and consent forms were included in the pre-text to the web-based and hardcopy surveys (see Appendix 11.1.1,11.2.1). Web-based surveys clearly stated that by submitting their survey responses, participants were consenting to participation in the survey. Respondents completing the hardcopy survey were asked to sign the consent form and return it with the survey. Participants were informed of their ability to withdraw their responses at any time using their reference number and provided instructions on how to do so. Due to the potential for stroke survivors to have cognitive deficits that may cause difficulty with comprehension, a modified version of the UCSD Brief Assessment of Capacity to Consent (UBACC)[252] was incorporated into the beginning of the SSS. Participant data was excluded if they did not achieve the minimum score of 7.25/10 as determined by the UBACC scoring methods. This tool allowed the investigators to determine if the participant information was accurately understood, and participants proved the capacity to properly understand what they

were consenting to. The UBACC was deemed most appropriate because it is brief and limits the additional burden of lengthening the survey, while also proving effective and reliable in comparison to other similar tools.[253]

Data Analysis Plan

The analysis of survey data will render primarily descriptive statistics. The data from both surveys will be amalgamated and categorised according to the major components of care (outlined in Section 4.3.1). Each component of care will be described in relation to the pre-determined influencers and in turn identifying potential barriers and/or gaps in the current provision of post-stroke vision care in NSW. Free-text responses will be thematically analysed in order to further inform trends seen in the descriptive data, as well as provide more targeted direction for later interview questions with stroke survivors.

Additional quantitative analysis of survey data will be conducted using IBM SPSS 27 to compare vision care practices amongst stroke health care professionals who are eye-care specialists and those that are not, where possible. Using the same software, the Chi Square test will be used to determine if there is a statistically significant difference in vision care experienced by stroke survivors living in major cities compared to those living in regional and remote areas of NSW.

4.3.3 INTERVIEWS

Theoretical Framework & Design

Semi- structured interviews were developed in order to gather information on the perspectives and experiences of stroke survivors in relation to their post-stroke vision care. The theoretical framework used in the development of the interview schedule was determined by the systematic literature review (Figure 4.2) and allowed for consistency in investigation between quantitative surveys and these qualitative methods. The aim of the interviews was to provide further description of the care pathways from the viewpoint of the patient but also to develop an understanding of when and why the major components of care are important and how the influencers can impact on the experience of individual stroke survivors.

The interviews were developed within the paradigm of social constructivism.[254,255] That is, that care provision is a social phenomenon that is shaped by interactions between individuals. The interpretation of stroke survivor's experience of post-stroke vision care would be influenced by their individual experiences and viewpoints. Hence, interview responses would vary and so, flexibility in the interview schedule was necessary to allow for and capture these variances

between individuals, and also between the interviewer and interviewee. However, major questions within the interview schedule were based around the theoretical framework and kept consistent between interviews in order to ensure responses were centred around post-stroke vision care and covered these topic areas as a minimum (see Appendix 11.3). Participants were encouraged to speak more broadly about their experience of post-stroke vision care and expand on answers provided where deemed appropriate by the interviewer. This was done by asking follow-up questions outside of the interview schedule and/or asking participants to provide examples. Interviews were not strictly conducted in the order stipulated within the interview schedule, but rather in a manner that allowed for organic flow of conversation and as such, allowing for discussion of more topic areas than stipulated in the schedule.

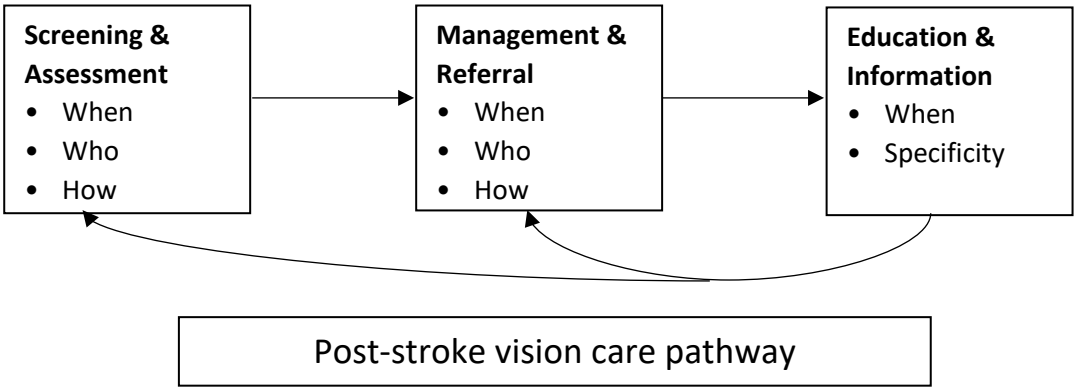


Figure 4.3 Theoretical framework. The post-stroke vision care pathway is comprised of three major components of care: screening and assessment, management and referral, education and information. The relationship between screening and assessment, and management and referral is linear, however education and information can and should occur throughout multiple stages of the pathway. The success of screening and assessment, and management and referral are influenced by when they occur, which health professionals execute this component of care and how. The outcome of education and information is influenced by when this is provided and its specificity.

Sampling & Recruitment

Stroke survivors were given the option to nominate themselves to participate in an interview upon completion of the SSS. Purposive sampling was used to ensure responses from a range of stroke survivors taking account of varying experiences due to differing severities of stroke and visual impairment, and differing levels of care satisfaction. Recruitment was also conducted through directly approaching stroke survivors through community stroke support groups, and at Stroke Recovery NSW conferences, in order to encourage involvement from those who

don't actively seek out research involvement. As such, not all interview participants were stroke survivors who had completed the SSS. It was intended for the interviews to increase the overall inclusivity of PRECiS: Stage One by enabling participation from stroke survivors who could not participate via survey due to physical, circumstantial or other limitations. Interviews were conducted in participant homes, via telephone, or video conference according to the preference of the participant and subject to COVID-19 related public health orders in place at the time. Interviews continued until saturation of data was reached.

Data Analysis

Interviews were audio recorded and transcribed by a member of the research team (SS). Transcripts were checked for accuracy against the audio recording prior to importation into the data analysis programme. Thematic analysis of interview data was undertaken using NVivo 12.1. The coding of data was both concept (based on the theoretical framework employed) and data driven.[256] The unit of coding for first cycle coding was by sentence. First cycle coding was performed by one investigator (SS) who also developed the first draft code book. Inter-coder agreement was then checked after the first five interviews with another investigator (AF), and the code book revised accordingly. This process was repeated for every fifth interview thereafter, to ensure ongoing inter-coder reliability and face validity.[257,258] Coding continued until saturation of codes was reached.[256] Second cycle coding was elaborative in nature, as a means of confirming/ disproving or extending the existing framework of post-stroke vision care (Figure 4.2) as indicated by existing literature presented in Chapter 3. From this framework, key themes were identified and related to the experience of post-stroke vision care (as derived from first cycle coding of interviews) and further categorised according to the nature of the experience as positive/successful or negative/failure in relation to each of the major components of care.

Ethical Considerations and addressing interviewer bias

People who have suffered a stroke and have resultant cognitive deficits are considered a vulnerable population. It is important that the research methods and practices used in PRECiS: Stage One consider the potential vulnerability of the participants involved and does not unethically coerce stroke survivors into participation or manipulate data collection methods to obtain biased responses from participants. There are also potential issues around informed consent when researching stroke populations as not all stroke survivors will be able to provide informed consent due to limitations in cognition, memory and or understanding of the information provided. In order to mitigate this, both the surveys and interviews will start with

a screening process using a modified UBACC. This will help to ensure that those who are providing consent for their participation understand the information provided to them in the participant information sheet, and are doing so with an ethically acceptable level of cognition. Interview schedules have also been designed in a semi-structured fashion to ensure that questioning of participants follows the same topic areas around post-stoke vision care and are delivered in a way that is not leading to help reduce bias. The semi-structured style of interview however still allows enough flexibility for natural flow of conversation and expression of diversity in experience between participants.

Problems and Limitations

Problems that may arise from the proposed methodology include issues with meeting recruitment targets. For stroke survivors, the majority of eligible participants will be those aged 60 years and over, and so have a lower presence online. This may make recruitment through social media platforms and online mailing lists more difficult. The aim is to ensure that advertising also occurs in places frequently visited by the target population such as vision and rehabilitation health services (ophthalmology clinics, rehabilitation centres, physiotherapy clinics, etc) as well as in-person recruitment through stroke support groups and Stroke NSW conferences.

Problems may also arise within the stroke survivor group due to the length of the survey and/or interview due to cognitive fatigue experienced by many stroke survivors. For this reason, the SSS was designed to allow participants to save their responses and return to complete their online survey at another time. Stroke survivors participating in interviews are also provided the option of completing the interview over two stages at separate times to reduce the impact of fatigue where appropriate. Recruitment of health professionals may also be problematic due to the time taken to complete the survey. As health professionals working within NSW typically see patients most of their day, there is likely little time during their workday in which they will be able to complete the survey. Health professionals may be less likely to participate in research that requires them to take time out of their personal lives. The survey was designed to be as brief and easy to complete as possible, while still obtaining the information required. It was also designed to allow participants to save their responses and return to complete the survey at another time to increase convenience.

With the proposed data collection tools (survey, interview) there is also potential for recall bias. In order to reduce this in the health professional group the eligibility criteria stipulated that participants should be currently working with stroke patients or have done so within the

last five years. Similar restrictions in eligibility were placed on the stroke survivor group whereby stroke survivors were not eligible to participate if they had a stroke within the last three months, as this would be considered too soon after the stroke event to allow for appropriate cognitive recovery. Eligible stroke survivors also had their last stroke within the last 10 years to ensure their experience correlated with current stroke care practices and to reduce recall bias of the events. Stroke survivors were also encouraged to seek support from carers or family to assist with answering questions where needed to reduce the impact of memory deficits.

4.4 CONCLUSION

The overall design and approach of the PRECiS study has been informed by Vanhaecht's method for care pathway development as outlined in this chapter. The resultant study design consists of two stages which employ different methodologies in order to appropriately address the respective aims of each. PRECiS: Stage One aligns with phase three of the Vanhaecht method and aimed to determine current post-stroke vision care practices and pathways in NSW, Australia while also identifying gaps in care provision and unmet care needs. PRECiS: Stage Two aimed to utilise the information gained in PRECiS: Stage One to develop a care framework that aids health professionals to meets the needs of Australian stroke survivors with vision impairment, thus forming phase four of Vanhaecht's method.

A mixed methods approach was chosen to facilitate the exploratory study of PRECiS: Stage One in order to collect a vast amount of rich information on a relatively unexplored area of stroke care. These methods included a stroke health professional survey, a stroke survivor survey and a series of interviews with stroke survivors and their carers. The study design hence enables inclusion of a variety of key stakeholders within the research as is necessary when considered in the broader context of the PRECiS study and care pathway development. Due to breadth and complexity of data intended to be collected from the surveys, and the unique accessibility considerations of the populations to be recruited, the surveys were first piloted in a small feasibility study. The methods and results of this feasibility study are presented in Chapter 5, while the results of PRECiS: Stage One are presented in the chapters 6 (surveys) and 7 (interviews).

5 DETERMINING POST-STROKE VISION CARE PATHWAYS & PRACTICES IN NSW: A FEASIBILITY STUDY OF TWO SURVEYS

5.1 INTRODUCTION

The quantitative arm of PRECiS: Stage One consists of two surveys, one for stroke survivors with vision problems, and the other for health professionals who work with stroke survivors. The surveys were developed to gather information on current post-stroke vision care practices and pathways used in NSW across all stages of care, in order to gain an overall understanding of the effectiveness of these practices/pathways (see 4.3). As demonstrated in Chapters 1-3, the provision of vision care to Australian stroke survivors encompasses many different and complex aspects of care across a range of stroke care settings and involving a variety of health disciplines. As such, the aims of PRECiS: Stage One (outlined in Chapter 4) describe a large undertaking in attempt to fill a significant gap in information pertaining to this area of stroke care in NSW. To ensure that the data collection tools designed were capable of facilitating these aims and collecting all relevant data, a small feasibility study was conducted.

Further to the challenge of such broad data collection, stroke survivors are considered a vulnerable population who are likely to have varying cognitive,[39,40,45] physical[41,259] and/or sensory[21,158] impairments. Data collection tools for use in this population need to be carefully developed, in order to ensure that they are accessible and appropriate, while still able to obtain useful, high-quality data. Stroke health professionals as a population present a different set of challenges. They are often time-poor and comprise a mix of disciplines with varying levels of eye care knowledge. As such, surveys targeting this population will need to be comprehensive but brief, in order to facilitate a reasonable response rate. They will also need to be accessible to health professionals with a limited understanding of eye conditions and related terminology.

As the surveys were developed to be completed by the respondent without a member of the research member present, the comprehension of survey questions, ease of completion and overall inclusiveness of questions, were important considerations prior to use in the study. The semi-structured interviews with stroke survivors and their carers, forming the qualitative arm of PRECiS: Stage One, were to be conducted by a member of the research team with the interview schedule designed as a modifiable guide for the interviewer. The interviews were also intended to have a greater focus on the personal experience of the stroke survivors rather than collecting information specific to clinical practices. As a result of these considerations,

coupled with the timing and resource restraints of a doctoral project, it was decided to pilot only the surveys in this feasibility study. In doing so, we aimed to examine the appropriateness, accessibility, comprehensiveness and reliability of these surveys within an Australian context, prior to their use in a larger sample. The methods and results of the feasibility study are presented in this current chapter.

5.2 METHODS

5.2.1 Study Design

A mixed-method study design was used to determine the feasibility and functionality of the two web-based surveys. The survey questions piloted in this study are presented in Appendix 11.5. The surveys were piloted with a small group of stroke survivors and health professionals, who met the intended inclusion criteria. Upon completion of the respective surveys, participants provided feedback via a telephone interview on the time to complete, content, clarity and applicability (see Appendix 11.4). Participants were then asked to repeat the survey within 2-4 weeks of first completion to determine survey reliability.

5.2.2 Participants

Health professionals working with stroke patients and stroke survivors were identified as the key stakeholders in post-stroke vision care. Participants from either participant group were eligible to participant if they met the criteria outlined in Table 5.1.

Table 5.1 Inclusion and exclusion criteria for the Stroke Survivor and Health Professional groups.

	Inclusion Criteria	Exclusion Criteria
Stroke Survivors	• Has previously had a stroke or is the carer of a consenting stroke survivor • Received treatment for stroke in NSW • Has/ had a vision or eye problem	• Participants who are unable to provide consent themselves or do not pass the cognitive assessment portion of the survey • If the stroke event was less than 3 months ago or more than 10 years ago

Health Professionals	• Works with stroke patients in their current or previous workplace	• If work with stroke patients was outside of NSW • If work with stroke patients was more than 5 years ago

5.2.3 Survey Design

A Stroke Survivor Survey (SSS) and a Health Professional Survey (HPS) were constructed with the purpose of capturing all aspects of post-stroke vision care across a broad range of Australian stroke survivors and health professionals respectively (Appendix 11.5). As explained in Chapter 4 (4.3.2) the major components of post-stroke vision care and their influencers were identified through a literature review presented in Chapter 3:

a) the screening and assessment of stroke survivors with vision problems;
    i. the timing of this assessment
    ii. the health professional(s) who perform this assessment
    iii. the appropriateness and accuracy of this assessment,

b) the management and referral of stroke survivors with vision problems;
    i. the timing of this management and/or referral
    ii. the health professional who provide this management and/or referral
    iii. the appropriateness and success of this management and/or referral,

c) the education of both stakeholder groups and the information provided to them regarding vision problems after stroke;
    i. the timing in which this education/information is provided
    ii. the specificity of this education/ information.

The questions in both the SSS and the HPS were based around investigation of these care components. Detailed description of the design of the surveys is presented in Chapter 4 (4.3.2). A modified version of the UCSD Brief Assessment of Capacity to Consent (UBACC)[252] was incorporated into the SSS, as a means of ensuring valid consent within this vulnerable population. Participant data was excluded if they did not achieve the minimum score of

7.25/10 as indicated by the UBACC scoring methods. Survey design was informed by guidelines[260] to ensure best practice in web-based survey construction for both the SSS and HPS (see Appendix 11.5).

5.2.4 Recruitment

Ethical clearance was received from the University of Technology Sydney Human Research Ethics Committee (ETH18-2675). A convenience sample of stroke survivors who expressed interest in participating through the Stroke Foundation 'Enable Me' forum and who met the inclusion criteria, were invited to participate. Purposive sampling was used for the HPS to ensure a mix of eye health and non-eye health professionals involved in stroke care were included in the feasibility study. The intention was to recruit health professionals from a range of disciplines and as such, with varied levels of experience and exposure to eye care. This was achieved through advertisement on relevant social media outlets (Facebook and Twitter) via relevant Australian-based professional organisational pages, and stroke care pages/groups. Recruitment continued until a minimum of five participants from each group was achieved.

5.3 RESULTS

A total of five participants from both the stroke survivor and health professional groups completed the survey and the feedback telephone interview. Of the five stroke survivor participants, one elected their primary carer to complete the survey and interview on their behalf. The health professional group consisted of an orthoptist, an occupational therapist, a speech pathologist and two medical practitioners. The revised versions of both the SSS and HPS, following the results of this feasibility study, are presented in appendices 11.1 and 11.2 respectively.

Time

The researchers had estimated that the SSS and HPS would take a maximum of 30 minutes to complete and instructed accordingly on the patient information sheet. The average time taken to complete the survey was 18.75±8.5 min and 14±6.5 min for the SSS and HPS respectively. All participants responded 'yes' when asked if they felt this was a reasonable amount of time.

Comprehension (clarity of questions)

All stroke survivors reported that they felt the survey questions were clear and easy to understand. One health professional felt that the HPS questions relating specifically to vision screening methods and management options were not easily understood due to the inclusion of eye-related jargon.

"On some occasions the jargon made it difficult for me to be sure about some of my responses, in the eye conditions. I know heaps, but not everything of my interdisciplinary colleagues." – Stroke health professional

This was addressed in the revised survey through further explanation of these terms in questions that specifically named vision assessment methods and visual conditions (Question 11,14,18 in Appendix 11.5.2). All other health professionals felt that the HPS questions were clear and easily understood.

Appropriateness (relevance of questions)

Two of the five stroke survivors felt that the SSS questions were not relevant to their experience of post-stroke vision care. Elaboration on these responses indicated that these participants felt this way because the questions related mainly to the care they did or did not receive, rather than their experience of the vision loss and stroke.

"It was more to do with the fact that the questions seemed to be questioning how the care of the hospital and carers was, rather than my experience. If that was the intention of the survey, was the survey meant to check on the carers or the caree I suppose. That's why, I felt it was more focused on what the hospital had done rather than what my experience was, that's all." – Stroke survivor

This was addressed through revision of the survey pre-text describing the aims of PRECiS: Stage One to explain the purpose of the survey more clearly (see revised pre-text in Appendix 11.1.1). All health professionals felt that the HPS was relevant to their experience of the provision of post-stroke vision care.

Inclusivity/ Completeness

One stroke survivor felt that there were aspects of their experience that were not questioned in the SSS. This related mainly to the long term impact of post-stroke vision impairment and the implications of this for people living in rural areas of NSW.

"That is somewhat irrelevant to me because it is what happens after I get out that is more relevant to me… because vision can change within 3 months of having a stroke, quite frankly the help you get in hospital is fine, but once you get out of that network, it becomes more difficult. Also, dealing with consequences of that in terms of vision and mobility and that's where it becomes more difficult. Particularly when you live in the country." – Stroke survivor

This was in part addressed through the inclusion of an additional free-text response question about the stroke survivor's unmet care needs following the care plan and/or referrals provided. The question regarding remoteness of residency at time of stroke (Question 4, Appendix 11.5.1) was also revised to reflect the categories used by the Australian Bureau of Statistics (ABS), with an accompanying image of the ABS remoteness area map included to help participants to respond more accurately. This revision was made to better enable researchers to investigate the impact of remoteness on participant responses and perspectives by categorising and comparing data according to remoteness level. All other stroke survivors felt that the SSS was inclusive of all aspects of their post-stroke vision care. Four out of the five health professionals felt that the HPS was missing aspects relevant to their experience of the provision of post-stroke vision care. Elaboration on this indicated that revision of answer options was needed to create more flexibility, for example, the use of scales instead of yes/no answers in some questions, and the inclusion of an 'I don't know' option in others to allow respondents to answer with more accuracy (see Appendix 11.2.2).

"The thing I found most difficult was that it relied on there being an actual presence of vision screening being in place. So, I think the answers that I could give were really pertinent if there was a protocol in place but if there is not then it was really hard to put in the answers. Maybe having a 'not applicable' answer option or something would have made it easier to respond in these circumstances." – Stroke health professional

The other aspect of care that health professionals felt should be questioned more explicitly was the composition of the multi-disciplinary team within their workplace and their role in post-stroke vision care. This feedback was addressed through the modification of responses throughout the survey where the inclusion of multi-disciplinary team care provision was appropriate e.g. questions regarding the likely management outcomes for different visual conditions (see Appendix 11.2.2). Two additional questions were also included regarding the composition of the multi-disciplinary team in the respondent's workplace and their involvement in post-stroke vision care (Appendix 11.2.2).

"The only thing I didn't feel that we could put into the surveys was what the multidisciplinary team contribute to the treatment, but you might not want to drill down that far. I know you had a box for MDT treatment but the setting I was in, rehab or palliative care, it's not really the right setting to be referring to an ophthalmologist. So it just depends on what information that you want." – Stroke health professional

Reliability (test-retest)

Out of the five stroke survivors, three repeated the survey within 2-4 weeks after first completion. The responses showed 91% repeatability between individual survey responses, with an average of 11 ± 2.6 response difference out of 119 potential responses. Of the five health professionals, two repeated the survey within the given period. These responses showed 84% repeatability with an average of 49 ±1.4 response difference out of 307 potential responses.

5.4 DISCUSSION

To our knowledge, currently, there is no evidence that provides a complete picture of post-stroke vision care pathways in Australia. There is also no information available on the success of these pathways and the quality of care received by stroke survivors with vision impairment. The SSS and HPS described and evaluated in this feasibility study will be the first step in acquiring this evidence in an Australian context. Our study found that with minor refinements, both the SSS and the HPS are appropriate and feasible tools for the investigation of post-stroke vision care in Australia. The further development of these surveys will include review of the changes based on the results presented in this chapter by an expert advisory panel consisting of health professionals, stroke survivors and expert academics in the field of stroke rehabilitation.

The SSS and HPS were designed to collect information on the broad, complex and variable pathways of post-stroke vision care that exist, from two different population groups, while still attaining enough detail to accurately describe the major components of care and their influencers. The consideration of survey length and time was of utmost importance for both participant groups. Time-poor health professionals may be more greatly burdened by a lengthy survey and hence less likely to participate, while stroke survivors may find a long survey onerous and difficult to complete with accuracy due to poor general health and associated fatigue. In comparison to other surveys that have been administered to stroke health care professionals, the HPS is only slightly longer (additional 2-4 questions).[124,228] The SSS is of similar length[249] or shorter[248] than other surveys/ questionnaires administered to similar populations of stroke survivors.

Within any survey or questionnaire it is important that the questions are worded in such a way that they are clear and without room for misinterpretation. This was facilitated in both surveys by making the majority of questions closed, short, and with full explanations where appropriate. Consideration was given to avoid medical jargon within the SSS, and maintain a reasonable level of simplicity in each question. However, this has implications in terms of the

specificity of the data collected. For example, questions relating to whether respondents had a 'vision test or eye check' could relate to any form of visual assessment, grouping very brief, gross examinations with those more accurate and extensive. This is aided to an extent by further questioning of where, and by whom, the assessment was performed. Further information can then be provided from the HPS with regard to what an initial vision assessment usually consists of respective to different health professionals and care settings.

The scoping literature review conducted in advance of the development of the surveys, was essential in determining what the relevant aspects of post-stroke vision care are, and how they should be questioned. However, with such a limited evidence base, it was important to cross reference the relevance and completeness of survey questions with the intended populations. Inevitably, this feasibility study brought to light a few questions that required modification and the need for additional questions in order to improve appropriateness and completeness. While it may not be possible to capture each individual experience with complete accuracy through survey, the intentions of the surveys are to describe the major components of care and their influencers, showing the variations in these specific aspects. The minimal changes required based on the feedback received, indicates that this model of questioning covers the majority of relevant post-stroke vision care components as agreed upon by stroke survivors and health professionals.

5.5 CONCLUSIONS

Both the SSS and HPS demonstrated good test-retest reliability, however the HPS was less reliable than the SSS. Analysis of response differences between initial HPS completion and the repeat indicated that this may be due to less questions being answered in the repeat survey. Also, as only two respondents repeated the HPS this may have implications for the accuracy of the test-retest reliability. While the small sample size in this feasibility study may be a limitation, the purposive sampling utilised ensured that a range of perspectives and experiences have been included. The stroke survivor group included those from both regional and metropolitan NSW, as well as patients admitted to hospitals with and without eye care services. The health professional group included those from different medical and allied health professions both with and without specialities in eye care.

The SSS and the HPS are of a length that is unlikely to pose a significant burden, easily comprehended, have good levels of appropriateness, completeness and indications of reasonable test-retest reliability. These elements make them feasible tools for the investigation of post-stroke vision care pathways in NSW as intended in PRECiS: Stage One. The

primary outcome of the survey data will be to describe these pathways in entirety and hence determine if and where there are gaps in the pathways. While they also include some investigation of perceptions and barriers around these pathways, this is supplemented with interview data in the qualitative arm of PRECiS: Stage One, while PRECiS: Stage Two encompasses focus groups with stroke health professionals. These elements collectively are utilised to acquire more rich evidence about the personal experience of the key stakeholders in this area of stroke rehabilitation. In doing so, we can better understand potential barriers in achieving a more appropriate and standardised care model for post-stroke vision care.

6 DESCRIBING EXISTING POST-STROKE VISION CARE IN NSW: SURVEY RESULTS

6.1 INTRODUCTION

This chapter outlines the results of both the stroke survivor survey (SSS) and health professional survey (HPS) conducted as part of Stage One of the PRECiS study. Evidence presented in Chapters 1 and 3 demonstrated a current lack of evidence and guidelines relating to the provision of post-stroke vision care within Australia. In order to determine if current practices and pathways are working to effectively meet the vision care needs of stroke survivors, we must first determine what is in place within Australian stroke and vision care services. The primary aim of the surveys was to identify and describe current post-stroke vision care practices and pathways within NSW, Australia. The surveys were designed to collect the perspective of both stroke survivors and stroke health professionals at all stages of post-stroke vision care provision, including initial presentation to health services, referral pathways, identification and diagnosis of visual conditions, short- and long-term management, provision of information and support services. Both surveys also included questions around the perception and/or experience of whether post-stroke vision care needs were met through the existing practices and pathways, as well as perceived or experienced barriers to vision care provision.

6.2 STROKE SURVIVOR SURVEY

6.2.1 Demographics and ocular history

A total of 45 stroke survivors agreed to undertake the survey, however two of these respondents did not meet the required minimum score on the modified UBACC (7.25/10) and were therefore excluded. Of the remaining 43 stroke survivors who met the required minimum UBACC score (Table 6.1), the mean age was 60 years, 46.5% identified as male, 51.2% as female, and one respondent nominated an alternate sexual identification. The survey was completed by the stroke survivor themselves in most cases (83.3%) or with the assistance of their primary carer (16.7%). Just over half of stroke survivors lived in major cities (55.5%) with the remainder living in inner regional (18.6%), outer regional (25.6%) or remote (2.3%) NSW. The majority of respondents suffered from ischemic stroke (66.7%). As the survey was made openly available to any stroke survivor over the age of 18 years within NSW and circulated through a number of NSW based networks, it is not possible to calculate the percentage return of surveys.

Table 6.1 Stroke survivor demographics.

	Stroke survivors (n=43)
Mean Age in Years (range)	60 (23-88)
Sex n (%)	
Male	20 (46.5)
Female	22 (51.2)
Other	1 (2.3)
Remoteness index classification n (%)	
Major city	24 (55.8)
Inner regional	8 (18.6)
Outer regional	10 (23.3)
Remote to Very Remote	1 (2.3)
Type of stroke n (%)	
Haemorrhagic	12 (28.6)
Ischemic	28 (66.7)
Don't know	2 (4.8)

The majority of respondents felt that their vision had been affected by their stroke (87.8%) and had new visual symptoms as a consequence (76.2%) (Table 6.2). Just over 60% received a formal diagnosis for their stroke-related vision problem(s) and approximately 40% had pre-existing eye conditions prior to stroke (Table 6.2). Less than half of stroke survivors reported that they are currently under the care of an eye health professional (41.5%). Table 6.2 shows the breakdown of self-reported pre-existing visual conditions, the most frequently reported being refractive error (29%) and cataract (21%). The most commonly reported stroke related vision problems were visual neglect (15%) and blurred vision (15%), loss of vision in one (8%) or both eyes (10%), and loss of one side of vision (16%). Most stroke-related visual symptoms reportedly lasted for more than two years, with the exception of double vision (Figure 6.1). Of the 43 respondents, eight reported that they have had one or more new visual diagnoses since their last stroke that was unrelated to the stroke itself. These conditions included refractive error (n=3), glaucoma (n=2), cataract (n=6), retinal tear or detachment (n=1), dry eye (n=2), lid defects (n=1), diabetic retinopathy (n=1), pinguecula (n=1) and loss of peripheral vision (n=1).

Table 6.2 Stroke survivor survey responses regarding stroke-related and pre-existing visual conditions.

	Yes	No
Felt vision/ eyes were affected by stroke (%)	87.8	12.2
New visual symptoms relating to stroke (%)	76.2	23.8
Loss of vision in one eye	*8*	
Loss of vision in both eyes	*10*	
Loss of vision left side	*10*	
Loss of vision right side	*6*	
Loss of part of vision (scotoma)	*5*	
Double vision	*9*	
Nystagmus	*5*	
Blurred vision	*15*	
Gaze defect	*8*	
Visual neglect	*15*	
Other	*9*	
Formal diagnosis of stroke-related visual condition (%)	64.3	35.7
Pre-existing eye conditions (%)	38.1	61.9
Spherical refractive error	*29*	
Astigmatism	*9*	
Glaucoma	*8*	
Cataract	*21*	
Dry Eye	*4*	
Macular Degeneration	*4*	
Eyelid droop (ptosis)	*4*	
Double vision	*4*	
Flashes/Floaters	*4*	
Other	*13*	

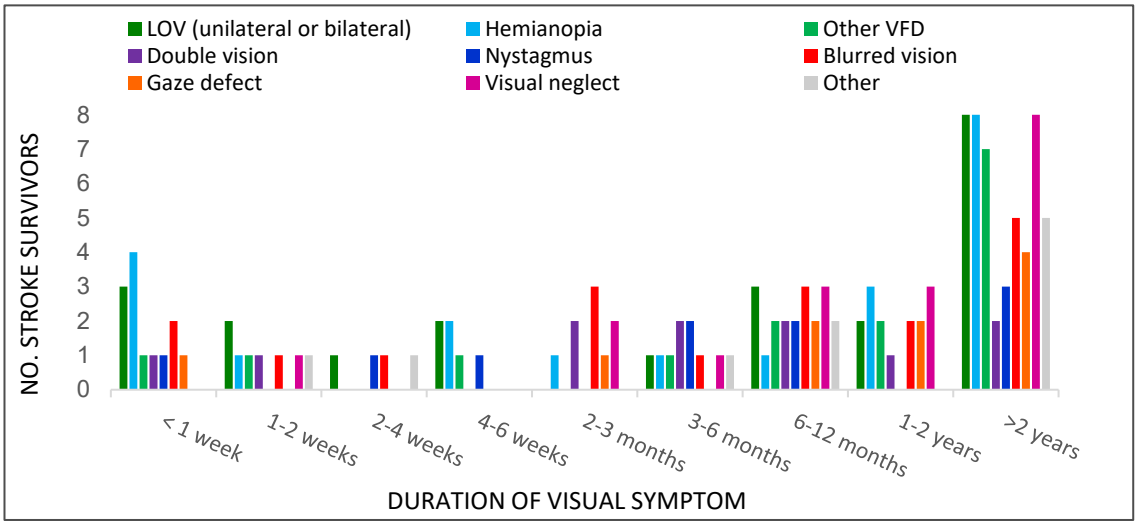


Figure 6.1 Duration of stroke-related vision problems as reported by stroke survivors.

6.2.2 Vision Assessment

Survey responses relating to initial vision assessment after stroke revealed that over a quarter (27.9%) of stroke survivors did not have any vision assessment within six months of their stroke. Of those that did have a vision assessment, approximately half (51.6%) had the assessment within six weeks of their stroke, and 22.6% within 3-6 months of stroke onset (Figure 6.2). Figure 6.3 demonstrates that approximately half of these vision assessments took place in an external eye clinic (48.4%), that is, not within the treating hospital and only 16% occurred on the stroke ward. Orthoptists were most often reported as the health professional who performed vision assessment (55%), followed by the treating doctor (19%) and nurse (10%) (Figure 6.4).

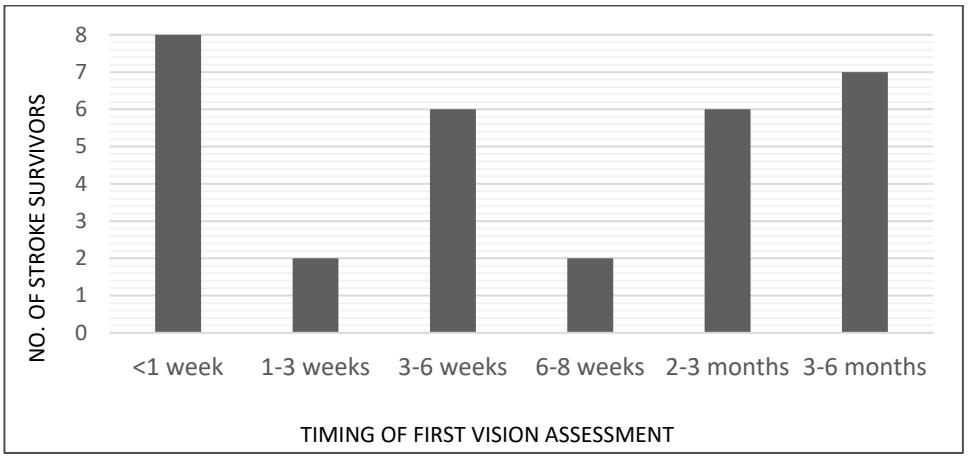


Figure 6.2 Timing of initial vision assessment as reported by stroke survivors who had vision assessment within six months of their stroke (n=31).

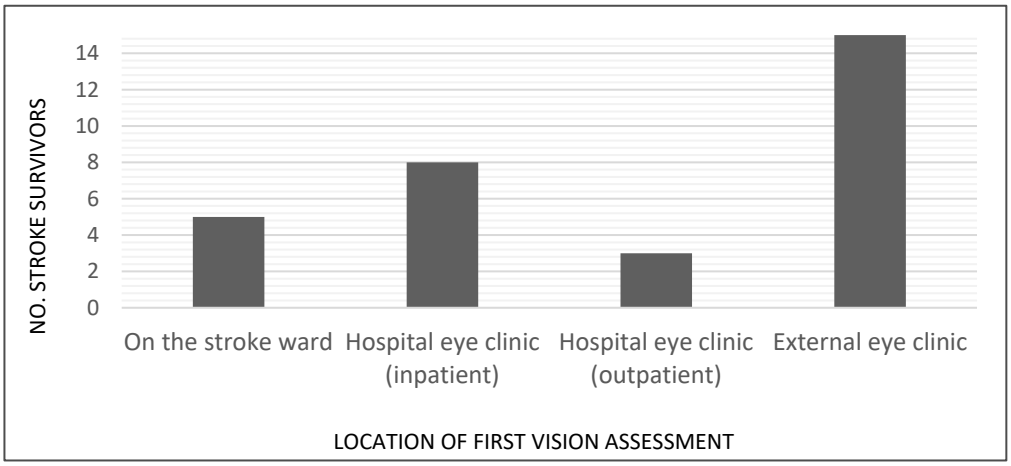


Figure 6.3 Location of initial vision assessment as reported by stroke survivors (n=31).

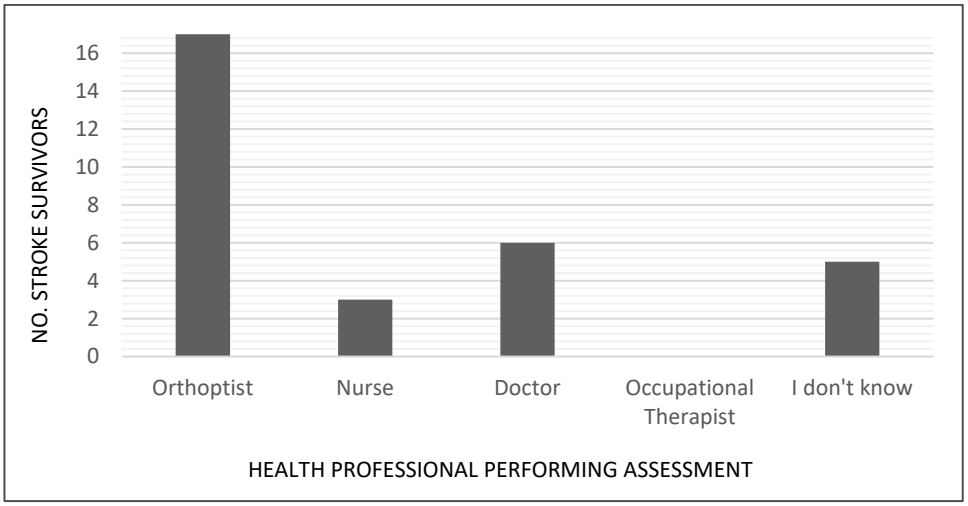


Figure 6.4 Health professionals performing initial vision assessment as reported by stroke survivors (n=31).

6.2.3 Management

When asked about the management provided by their treating hospital, less than half of stroke survivors reported receiving a care plan upon discharge (46.3%), and of those that were provided a care plan, less than a third (31.6%) included management options for their visual condition(s) (Table 6.3). The vast majority of stroke survivors received no treatment or assistance for their vision problems as an inpatient (88.1%). Further to this, more than half of stroke survivors (61.0%) did not receive a referral to an eye care professional by the treating hospital prior to discharge (Figure 6.5). Those who did receive a referral for their vision problems were referred to an ophthalmologist (26.8%), optometrist (9.8%) or low vision service (2.4%). Similar trends occurred in rehabilitation hospitals or facilities where most stroke survivors received no treatment for their vision problems (78.3%) and no referral to an eye care professional (77.5%) during their stay or on discharge (Figure 6.6). Stroke survivors who received referral from their rehabilitation facility for their vision problems were again most frequently referred to an ophthalmologist (15%), optometrist (5%) or low vision service (2.5%).

Five stroke survivors (11.6%) received some form of management for their vision problems as an inpatient at their treating hospital: one received eye exercises, one received a vision aid or magnifier, two had visual scanning training, and one had eye surgery. All treatments other than eye surgery were performed by a nurse, occupational therapist or stroke physician as a single treatment.

Table 6.3 Stroke survivor responses regarding the provision of management of post-stroke vision problems.

	Yes (%)	No (%)
Were you provided a care plan upon discharge?	46.3	53.7
Did the care plan include management options for visual symptoms?	31.6	68.4
Treatment or assistance provided for vision problems as an inpatient?	11.9	88.1
Did you attend a rehabilitation hospital/ facility?	59.0	41.0
Treatment for vision problems provided by rehabilitation hospital/ facility?	21.7	78.3
Are you under the care of an eye care professional at present?	42.5	57.5
Have you since had diagnosis of a new visual condition unrelated to stroke?	20.5	79.5

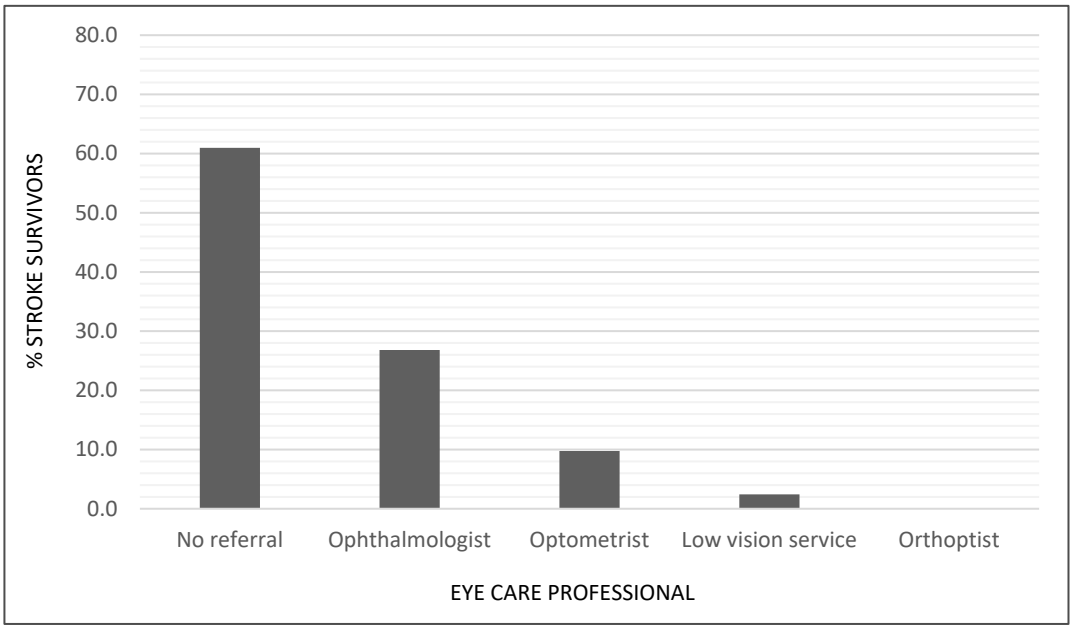


Figure 6.5 The proportion of referral options for ocular conditions made by the treating hospital as reported by stroke survivors (n=17).

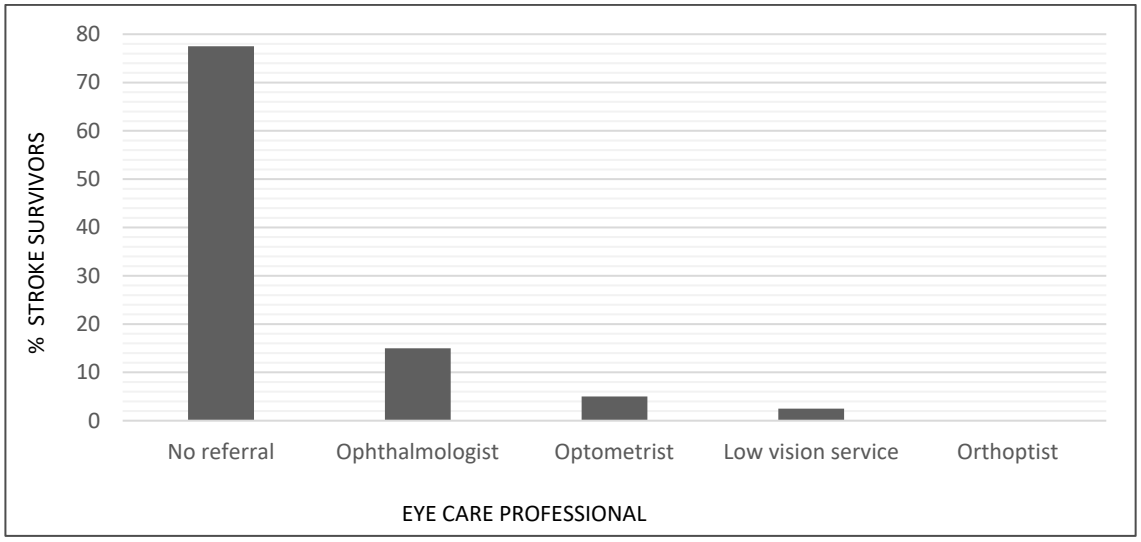


Figure 6.6 Proportion of referral options for ocular conditions made by the rehabilitation facility as reported by stroke survivors (n=25).

Of those who attended a rehabilitation facility and received some form of management for their vision problems (11.6%), one received glasses, one a magnifier, one had eye exercises on a daily basis, one received weekly visual scanning training and one had this training as a one-off treatment episode. Glasses were provided by an optometrist and other treatments were primarily provided by an occupational therapist.

6.2.4 Provision of information

The majority of stroke survivors were not provided information about their post-stroke vision problems (65.9%) nor provided with information about their specific vision problem (67.5%). Of those who were provided general information about post-stroke vision loss (Table 6.4), this was most often verbal (42.9%) and provided by the treating stroke physician (50%), nurse (21.4%) or orthoptist (14.3%). For those who were provided information specific to their vision problems (Table 6.4), this was most often verbal (53.8%) and provided by an orthoptist (38.5%), nurse (23.1%) or doctor (23.1%).

Table 6.4 Format of information provided to stroke survivors regarding general post-stroke vision problems and/or their specific vision problem(s).

	General (%)	**Condition specific (%)**
Verbal	42.9	53.8
Written	14.3	15.4
Both	42.8	30.8

6.2.5 Barriers and unmet care needs

Most stroke survivors felt as though their vision care needs were not successfully met prior to discharge from the treating hospital (60%) or by the care plan and/or referrals they received (61%). Free text responses allowed respondents to elaborate on why they felt this way. Stroke survivors stated that they felt their vision care needs were not met prior to discharge because nothing was done in relation to their vision problems. They did not receive adequate information, or did not receive any options for vision rehabilitation. Comments from stroke survivors included:

- *"I was not provided any eye care"*
- *"no vision testing was done"*
- *"I got written exercises that I couldn't read."*
- *"Nothing was said about my eyes. I didn't realise my eyes were bad until after I had left the hospital"*

Stroke survivors felt that their vision care needs were not met by the care plan and/or referrals received because they were not specific to vision. They stated that they were told to address follow up vision care with their general practitioner and, as a consequence, experienced long delays in receiving eye care, or had no information on what financial assistance was available to them to aid their care. Comments from stroke survivors explaining their answer included:

- *"Nothing was ever referred for my eyes at all"*
- *"I had to see my own GP upon returning home. It was 12 months before I seen an optometrist and is nearly 2 years on now. Still on waiting list to see an ophthalmologist."*
- *"I was not referred to an ophthalmologist a neuro ophthalmologist or an OT because my disability was invisible and physically, I have no other seen impairments. There were no referrals made. I found this really hard."*
- *"Only tested for driving requirements and failed. No help after this"*

Most stroke survivors (76.7%) also reported that they felt their vision problems negatively impacted their overall stroke rehabilitation. Despite this, the majority of stroke survivors did not feel that there were barriers to them receiving appropriate vision care during their recovery (70%). Of those that did feel that they had experienced barriers to receiving appropriate post-stroke vision care, these included: a lack of information, a lack of attention paid to vision problems by treating health professionals, misdiagnosis, limited access to vision rehabilitation in NSW, moving to a different city or town after stroke, and dealing with the

multiplicity of health problems following stroke. Comments made by stroke survivors relating to these barriers included:

- *"My stroke was misdiagnosed"*
- *"I was dealing with other more serious medical issues as result of the stroke"*
- *"I was told there was nothing that could be done"*
- *"Vision loss was never discussed or mentioned."*
- *"NSW not set up to help with Vision rehab"*

Most felt that their vision problems have had a moderate to severe impact on their daily life (78.4%), and on their overall success in rehabilitation (62.8%). The activities of daily living most frequently reported as impacted by post-stroke vision problems were reading and driving (Figure 6.7).

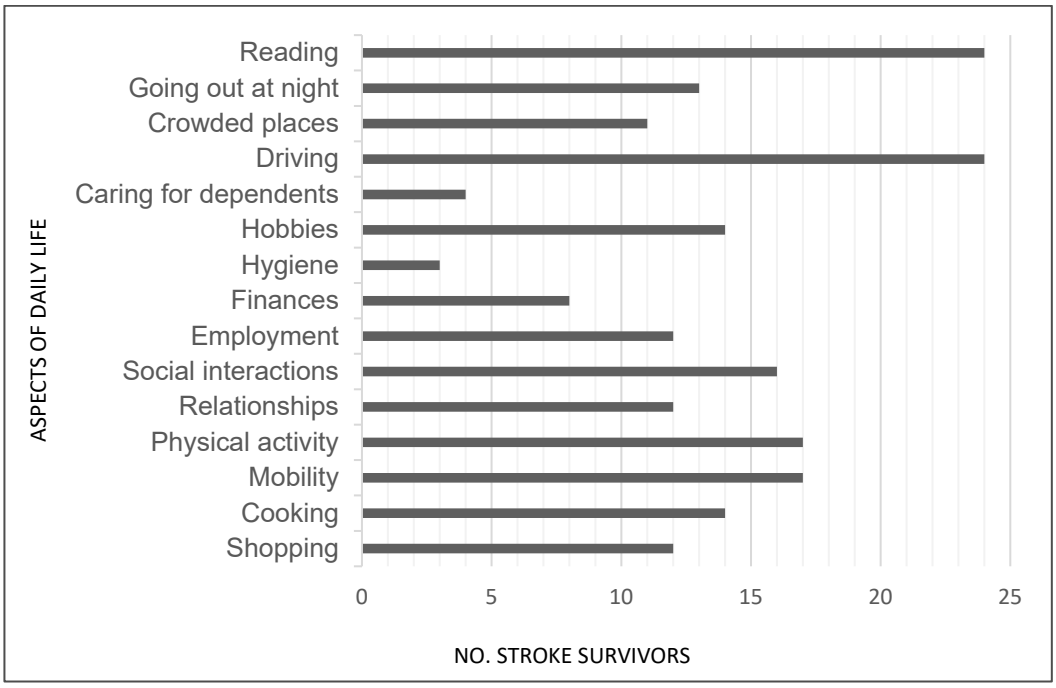


Figure 6.7 Activities of daily living impacted by post-stroke vision problems as reported by stroke survivors (n=43).

6.2.6 Provision of care in major cities vs. regional and remote areas

Responses were compared for stroke survivors living in major cities (n=24) to those living in either inner regional, outer regional or remote areas (n=19). With regard to vision assessment, a similar number of stroke survivors living in major cities (67%) reported having a vision assessment within six months of their stroke to those living in regional and remote areas (79%). In both groups, approximately half (major cities= 44%, regional/remote=53%) of these

assessments occurred in external eye clinics, not within the treating hospital. A larger discrepancy was present with regard to management, with only 37% of stroke survivors living in regional or remote NSW receiving a care plan upon discharge from their treating hospital compared to 58% of those living in major cities, however this difference was not found to be statistically significant (p=0.296). Over half of stroke survivors in both groups did not receive referral to an eye care professional upon discharge (major cities=67%, regional/remote= 53%) and the vast majority received no treatment for their vision problems as inpatients (major cities= 96%, regional/remote= 79%).

The proportion of stroke survivors who felt that there were barriers to receiving appropriate vision care was slightly higher in the regional/remote group (37%) compared to those living in major cities (25%). However, when asked if their vision problems have impacted their daily living, the proportion of stroke survivors indicating a moderate to severe impact was significantly higher in the regional/remote group (68%) compared to those living in major cities (29%). Similarly, a smaller proportion of stroke survivors living in major cities (21%) felt their vision problems impacted their overall stroke rehabilitation when compared to those living in regional or remote NSW (42%).

6.2.7 Discussion

We received 43 eligible responses to our stroke survivor survey, with roughly equal numbers of respondents living within major cities and regional or remote areas of NSW, at the time of their stroke. The majority of stroke survivors with vision impairment receiving care in NSW (60%) reported that the post-stroke vision care they were provided did not adequately meet their needs. This alone is a strong indication of a need for change in post-stroke vision care provision within NSW. A significant proportion of respondents (28%) also indicated that their first vision assessment was more than six months after stroke onset. This would suggest that vision assessment is not routinely performed on stroke survivors within NSW primary care facilities, and this has implications for the early diagnosis and management of stroke-related vision problems. Early intervention for vision problems can alleviate problematic visual symptoms and provide strategies to optimise the utilisation of residual visual function. The importance of early diagnosis and management of vision problems within a stroke population is reinforced by the large number of stroke survivors within PRECiS: Stage One (63%) who reported that their vision problems had an impact on their overall stroke recovery. A delay in diagnosis can also lead to a failure to provide timely and accurate information about their eye condition to the patient and their carers/ family. This can result in prolonged emotional

distress and confusion relating to their visual symptoms, following an already traumatic stroke event.

Information regarding post-stroke vision problems was also not routinely provided, with over 60% of respondents indicating they did not receive any information on this aspect of their stroke or on any visual condition specifically. When information was provided, in most cases it was delivered verbally. This raises concerns about the appropriateness of the content and format of the information provided to stroke survivors, as verbal information may not be consistent or well retained following stroke. Provision of information in an appropriate format is important in a stroke population, as each patient is likely to have different requirements in terms of how they best receive and retain information. For example, those with communication difficulties may require information delivery guided by a Speech Pathologist, while those with memory deficits may require written information that they can refer to repeatedly. Management in relation to vision problems was not provided for over 80% of stroke survivors during their acute care, and over 60% did not receive any vision specific referrals from their treating hospital or rehabilitation facility. These results suggest that in both the acute and long-term stages of stroke recovery, the majority of stroke survivors with vision impairment are not provided any treatment or clear guidance as to where to seek treatment for their visual conditions. The lack of management and referral provided is a plausible explanation for the significant impact felt by stroke survivors (78%) on their daily life.

When comparing responses from stroke survivors living in major cities with those living in regional or remote areas, little difference was found between groups with regard to the timing and location of vision assessment. A more notable difference between groups can be seen in the provision of care plans, however, this difference was not found to be statistically significant. Provision of vision related management and referral was poor amongst both groups. However, stroke survivors living in regional or remote areas of NSW more often reported that they felt there were barriers to them receiving appropriate vision care when compared to stroke survivors living in major cities. There was also a significantly higher proportion of stroke survivors in the regional and remote group who felt that their vision problem had a moderate to severe impact on their daily life in comparison to those living in major cities. These differences between urban and regional/rural areas may be amplified in a large sample of stroke survivors.

While an inequity in healthcare between metropolitan and rural areas of Australia is a well-established and documented problem,[261,262] efforts by state and federal governments have

aimed to close this gap. In NSW, evidence suggests that the redistribution of resources can improve access to primary care in regional and remote areas for children,[263] however, a significant inequity remains in secondary and tertiary care. Better primary care services than secondary/tertiary care in rural areas may partially explain the results of this study, whereby initial assessment and short-term management, while inadequate, are similar between the two geographical locations. A more clear division is evident with regard to the long-term impact of vision problems on daily life, and is likely a result of the inequity in accessing tertiary care, specifically, a lack of access to specialist eye care services in regional and remote NSW.

The results of PRECiS: Stage One are limited by a lower than expected response rate among stroke survivors that may be a combined result of the time taken to complete the survey, survey complexity and particularly the onset of the COVID-19 pandemic and lockdowns during the time of recruitment. It had been previously estimated that 100 responses to the survey would be achievable based on the number of strokes that occur within NSW each year and the prevalence of vision problems amongst them. Despite extensive dissemination of the survey link and recruitment materials, we were only able to obtain eligible, complete responses from 43 stroke survivors (less than half of the target sample size). It is probable that the original target did not account for the proportion of stroke survivors who were physically and cognitively capable to complete the survey. The UBACC[252] with a cut-off score of 75% was also implemented as part of the inclusion criteria. While the number of stroke survivors excluded based on their UBACC score was small (n=2), this additional criterion also contributed to reducing the number of eligible responses in PRECiS: Stage One.

Consideration was given to those elements of the survey design that may have limited full participation by stroke survivors. Elements of design to improve accessibility included: respondent controlled font size (and large print hardcopy surveys); simple, clear wording, with minimal use of medical jargon; text-to-speech audio functionality (online survey only), explanation of questions and terminology where appropriate; and instructions on how to respond to questions. Care was also taken to ensure that the survey was as brief as possible, with the option of respondents being able to save their responses and return to complete the survey at another time. When compared to other surveys and questionnaires carried out in stroke populations,[248,249] the SSS in PRECiS: Stage One was similar in length, with 47 items. A small feasibility study of the surveys was conducted prior to recruitment and showed that the SSS took an average of less than 20 minutes to complete (Chapter 5), with all participants reporting that they felt the questions were clear and easy to understand. Questionnaires however, have the potential for recall bias. The inclusion and exclusion criteria for the sample

population of this survey aimed to reduce recall bias by ensuring that stroke survivors were at least 3 months post-stroke, and were not included if their stroke occurred more than 10 years ago.

While the survey was open to both stroke survivors and their carers, it is possible that the carers of more severely disabled stroke survivors were not able to answer all questions accurately due to potential limited communication by the stroke survivor. This feasibility study excluded those who were not deemed cognitively capable of providing consent based on results of a modified UBACC[252] tool. In consideration of these aspects of recruitment and those with communication difficulties potentially less likely to participate, it is possible that the results of PRECiS: Stage One are biased towards a stroke population with less severe long-term impairments. If this bias is present, it is likely that the results underestimate the compounded impact on recovery and daily life of vision impairment when coupled with other stroke related deficits. It is also unlikely that stroke survivors with more severe deficits receive better or more timely vision care, as there is evidence within this study and previously published literature, to suggest that vision care is given lower priority by stroke health professionals when occurring in conjunction with more urgent or seemingly more detrimental stroke deficits.[111,220] The impact of the COVID-19 pandemic also had a significant impact on recruitment, as it limited face to face opportunities for recruitment, such as stroke support meetings and conferences, which are often more effective means of recruiting in older populations. The onset of the pandemic may also have affected stroke survivors willingness and/or capacity to participate, as the target population of PRECiS: Stage One were also amongst the most vulnerable to the COVID-19 virus.[264] It is possible that people within this population were under more psychological stress during this time[265] and hence less inclined to participate in voluntary research.

The majority of stroke survivors with vision impairment in NSW feel that their vision care needs are not adequately met by the current care practices. This population indicate that a lack of information, management options and appropriate referral are the primary barriers they experience preventing successful provision of vision care, while there is limited evidence of any consistent pathway. While vision assessment seems to be a more widely provided service than provision of relevant information, management, and referral, such assessment is often not provided in a timely manner. Vision management strategies are seldom provided to stroke survivors and most do not receive vision specific referrals upon discharge. Inequities in post-stroke vision care provision between major cities and regional or remote areas of NSW are indicated by these results, particularly when trying to access community-based eye care specialist services within regional and remote NSW.

6.3 HEALTH PROFESSIONAL SURVEY

6.3.1 Participant demographics

Surveys completed by health professionals were obtained from 27 respondents from different stroke care facilities around NSW. The numbers of different health professionals working in stroke care in NSW is not known, so it is not possible to calculate the overall proportion of return surveys from the workforce. Most of the respondents stated that they worked in primary care (71.4%), providing both acute and rehabilitative stroke care (mixed stroke care setting, 52.4%) to inpatients and outpatients (47.6%) within the public sector (57.1%) (Table 6.5). Figure 6.8 shows the geographical distribution of respondents. Most were based across Sydney and inner regional areas of NSW, with some working in outer regional and remote care facilities. Approximately one third of respondents were orthoptists (n=9), and four were Ophthalmologists (15%). Other respondents included nurses (n=4,15%), speech pathologists (n=3, 11%), occupational therapists (n=2, 7%), physiotherapists (n=2, 7%), medical practitioners (n=2, 7%) and neurologists (n=1, 4%).

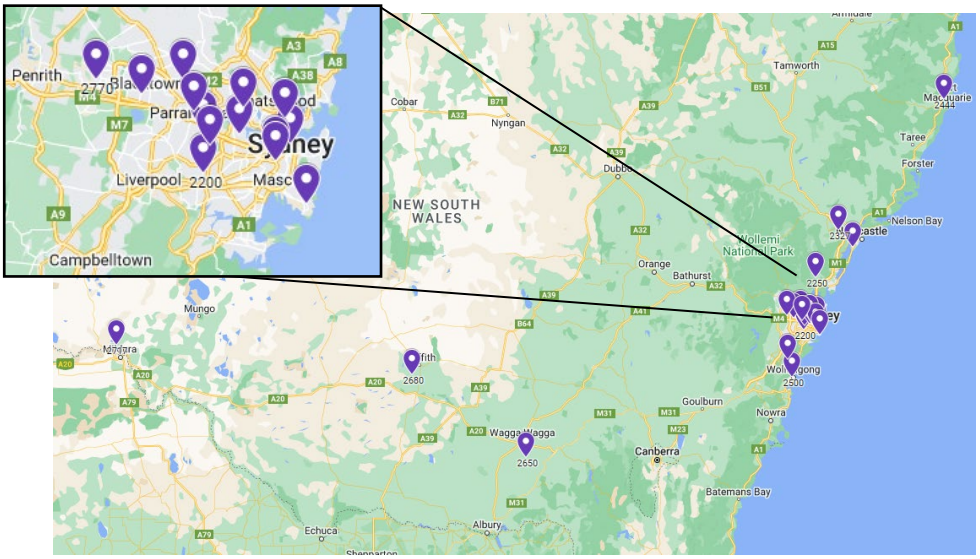


Figure 6.8 Geographical distribution of respondent workplace(s) across NSW by post-code.

Table 6.5 Proportion of health professional respondents (%) working within varied stroke care settings in NSW (n=27).

Primary care	71.4	Acute	9.5	Outpatient	33.3	Public	57.1
Community care	28.6	Rehabilitation	38.1	Inpatient	19.0	Private	38.1
-	-	Mixed	52.4	Mixed	47.6	NGO	4.8

Approximately half of respondents reported that they carried out assessment or management of eye conditions in their workplace (48%) and of these, the majority had stroke patients referred to their service directly (74%) (Table 6.6). Only 8% state that they ordinarily receive information pertaining to previous vision assessment as part of this referral. Referral of stroke survivors with vision problems to the respondent's workplace were typically made from acute stroke units or hospitals (Figure 6.9), with neurologists, optometrists and rehabilitation hospitals also reported as common sources.

Table 6.6 Stroke health professional responses (n=27) regarding referral and management of stroke-related vision problems within their workplace.

	Yes n(%)	**No n(%)**	**Sometimes n(%)**
Do you specifically assess and/or manage eye conditions?	13 (48)	14 (52)	-
Are stroke patients referred to your service directly?	20 (74)	2 (7)	5 (19)
Do you ordinarily receive information pertaining to previous vision assessments as part of this referral?	2 (8)	7 (28)	16 (64)

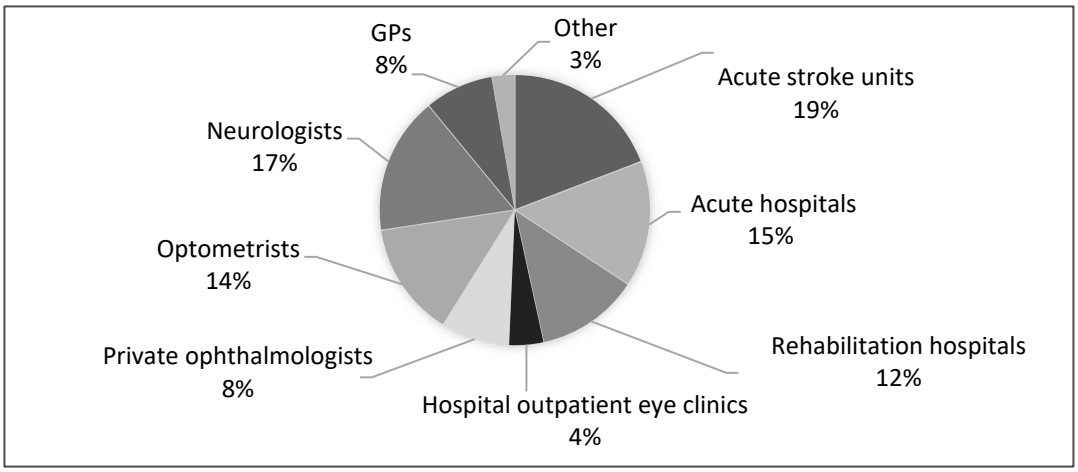


Figure 6.9 Reported origin of stroke referrals to respondents (n=27) workplace.

6.3.2 Vision assessment

The vast majority of health professionals report that their workplace does not have a protocol or care plan that includes, or is specific to, vision problems after stroke (88.9%). Most health professionals (56%) reported that vision problems are often mentioned by stroke patients and that the most commonly reported are visual field loss, visual neglect and double vision (Figure 6.10). Figure 6.11 shows that the health professional who typically carries out initial visual

assessment, as reported by stroke health professionals, is an orthoptist (44%) followed by occupational therapist (19%) and neurologist (15%).

The standard for when an initial vision assessment occurred within inpatient services varied significantly. Some stating such assessment occurred on admission or at first visit, while others stated that it occurred only if vision problems were reported or noticed by a health professional, and this would typically take place within two weeks of the stroke event. In outpatient and mixed stroke care services, initial vision assessment for stroke survivors typically occurred within two to six weeks (25%), six to 12 weeks (25%), three to six months (33.3%) or more than six months (16.7%) post stroke onset.

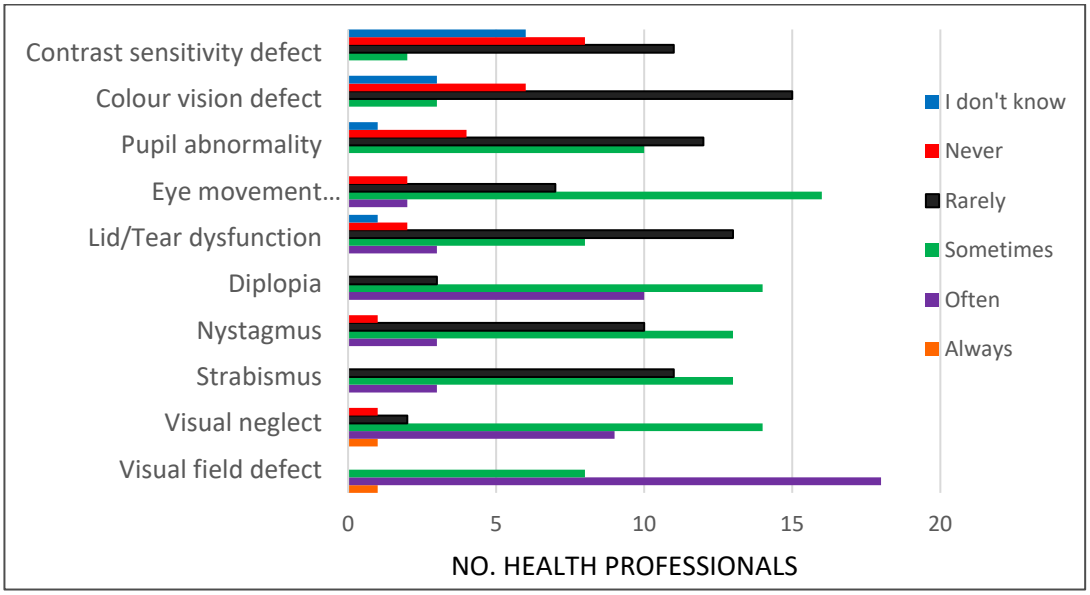


Figure 6.10 Number of health professionals reporting observed frequency of post-stroke visual conditions within their workplace.

There is large variability in the vision tests and screening tools that were used for the vision assessment of stroke patients. When asked what tests are typically undertaken in the initial visual assessment of a stroke survivor, just over half of respondents reported testing visual acuity, visual fields, ocular movements and pupil function with every patient (Figure 6.12).

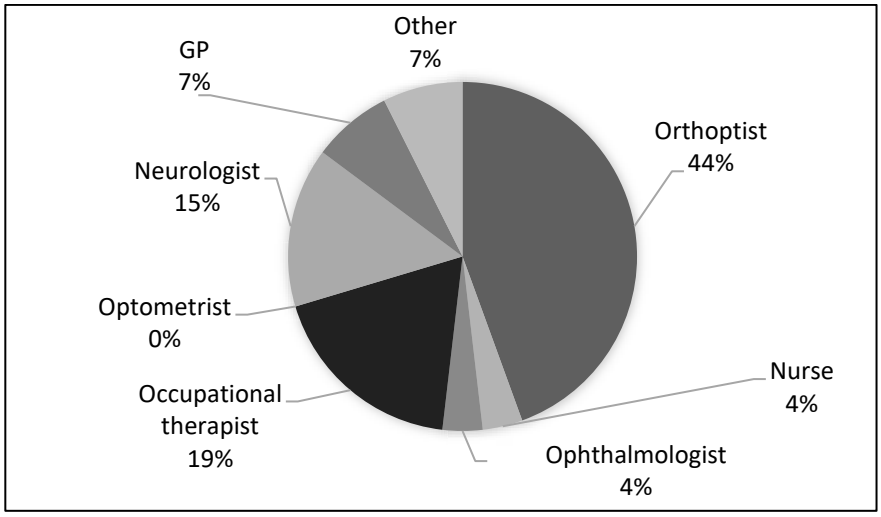


Figure 6.11 Health professional who carries out initial vision assessment in the workplace as reported by stroke health professionals (n=27)

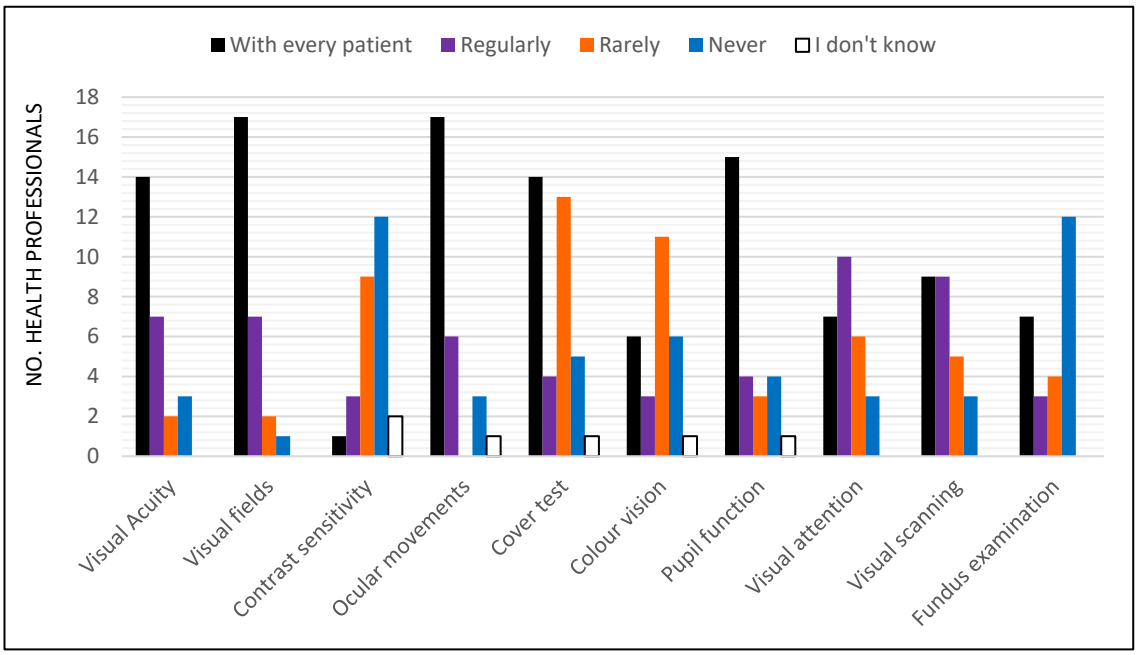


Figure 6.12 Use of vision tests during initial vision assessment of stroke patients as reported by stroke health professionals (n=27)

There was little consistency reported in terms of screening tools used, with the behavioural inattention test battery used regularly by 10 respondents (Figure 6.13). The SVDST[63] was used with every patient or regularly by only 7% of respondents, was rarely used by 22%, and never used by 67%. Other screening tests reportedly used include: Queens square test for visual processing difficulties, NIHSS, and 'Reading Fluency'. Those working within inpatient or mixed stroke care settings reported that initial vision assessment of stroke survivors is ordinarily

carried out either at bedside (53.3%), in a dedicated vision testing room (26.7%), in the on-site eye clinic (13.3%) or in a multipurpose room (6.7%).

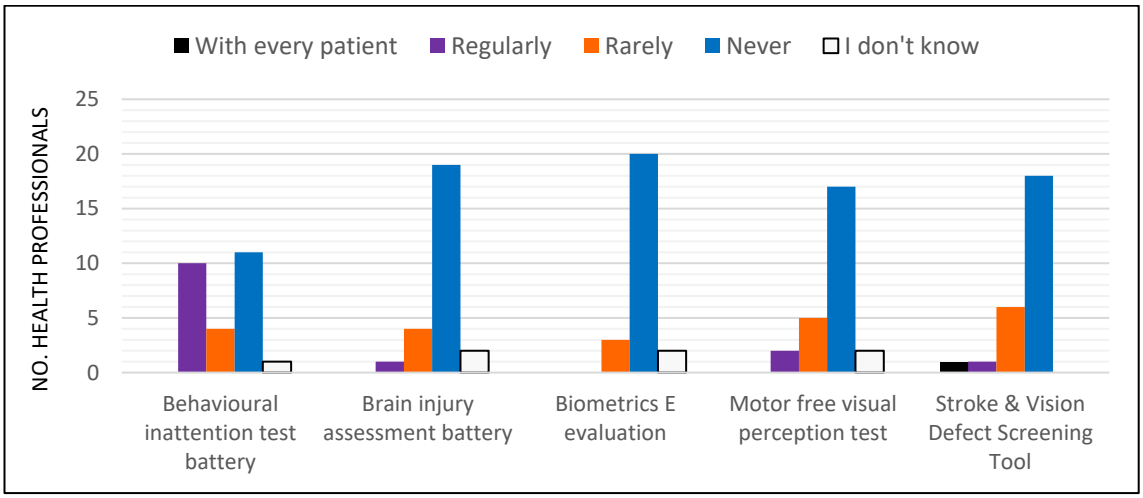


Figure 6.13 Use of vision screening tools during initial vision assessment of stroke patients as reported by stroke health professionals (n=27).

6.3.3 Information

Approximately half of health professionals report that information about post stroke vision problems was provided to patients routinely (52.4%), with the remainder reporting that it was not routinely provided (23.8%) or were not sure (23.8%). Similar responses were given in regard to provision of the Stroke Foundation 'My Stroke Journey' pack, which contains a section on vision (Table 6.7). The most commonly provided information on post-stroke vision problems related to driving regulations and specific information about the patient's individual vision problem (Figure 6.14).

Table 6.7 Responses from stroke health professionals working in a hospital or rehabilitation setting (n=21) regarding the provision of information about post-stroke vision problems.

	Yes n(%)	**No n(%)**	**I don't know n(%)**
Are patients routinely provided with information about post-stroke vision problems?	11 (52.4)	5 (23.8)	5 (23.8)
Are patients routinely provided with the Stroke Foundation 'My Stroke Journey' pack?	10 (47.6)	7 (33.3)	4 (19.0)

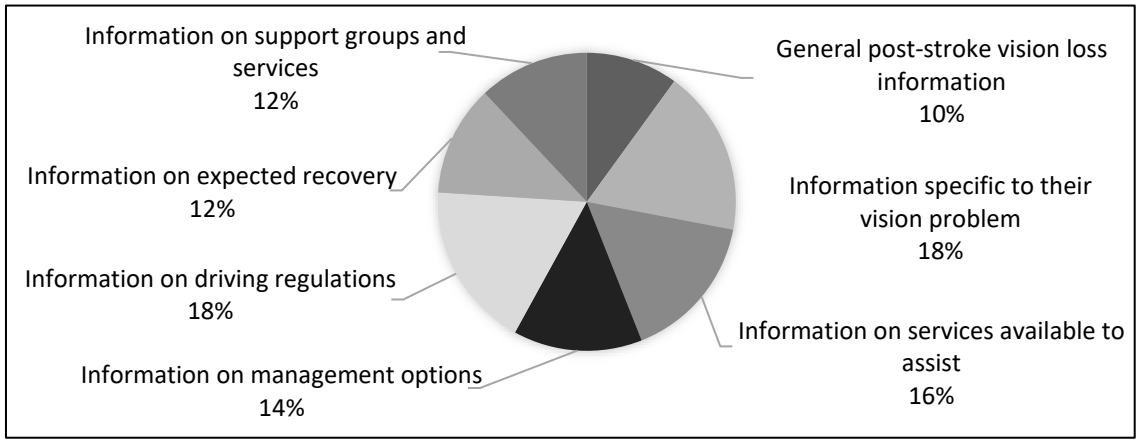


Figure 6.14 Type of information provided to stroke patients about post-stroke vision problems as reported by stroke health professionals (n=27)

6.3.4 Management

Members of the stroke multidisciplinary team as reported by respondents are shown in Figure 6.15. A significant number of health professionals report having an orthoptist as part of their multidisciplinary stroke team (41%), however, many report having no eye-care professional as part of their team or weren't sure (30%). Others report that their multidisciplinary team included an ophthalmologist (26%) or optometrist (4%). Respondents indicated that within this team, the health professional responsible for providing vision care to stroke survivors was the orthoptist (38.1%), ophthalmologist (33.3%), occupational therapist (33.3%), stroke physician (19%), nurse (9.5%), or physiotherapist (4.8%). The majority of health professionals (81%) report that within their workplace stroke survivors are routinely provided treatment if a vision problem is present.

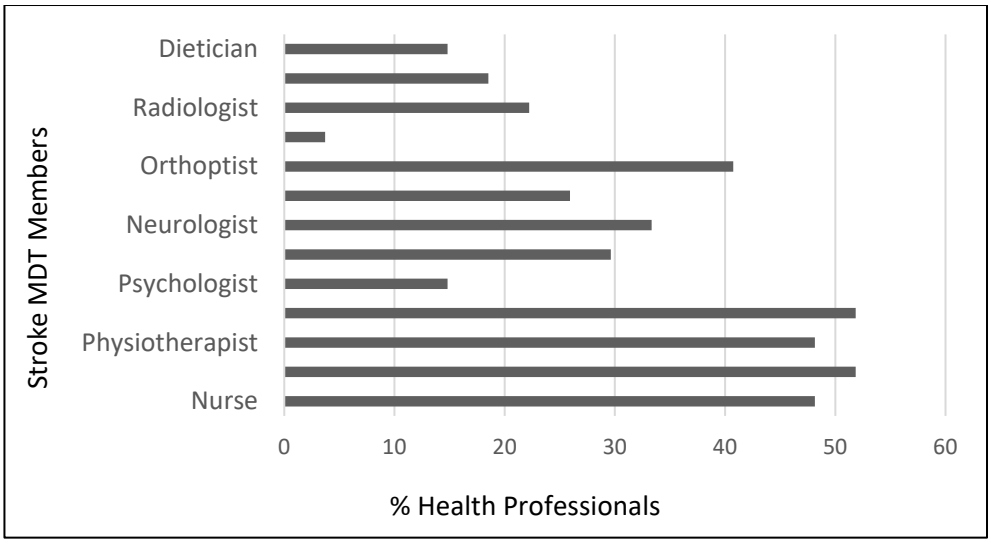


Figure 6.15 Members of the stroke multidisciplinary team (MDT) as reported by stroke health professionals in NSW.

Most health professionals reported providing treatment or management of vision problems within two weeks of stroke (67%), with the majority of these treatments being continued for as long as needed (80%) (Table 6.8). Conditions such as visual field loss and visual neglect were more often reported as receiving management in-house, or from the multidisciplinary stroke team, compared to other conditions (Figure 6.16).

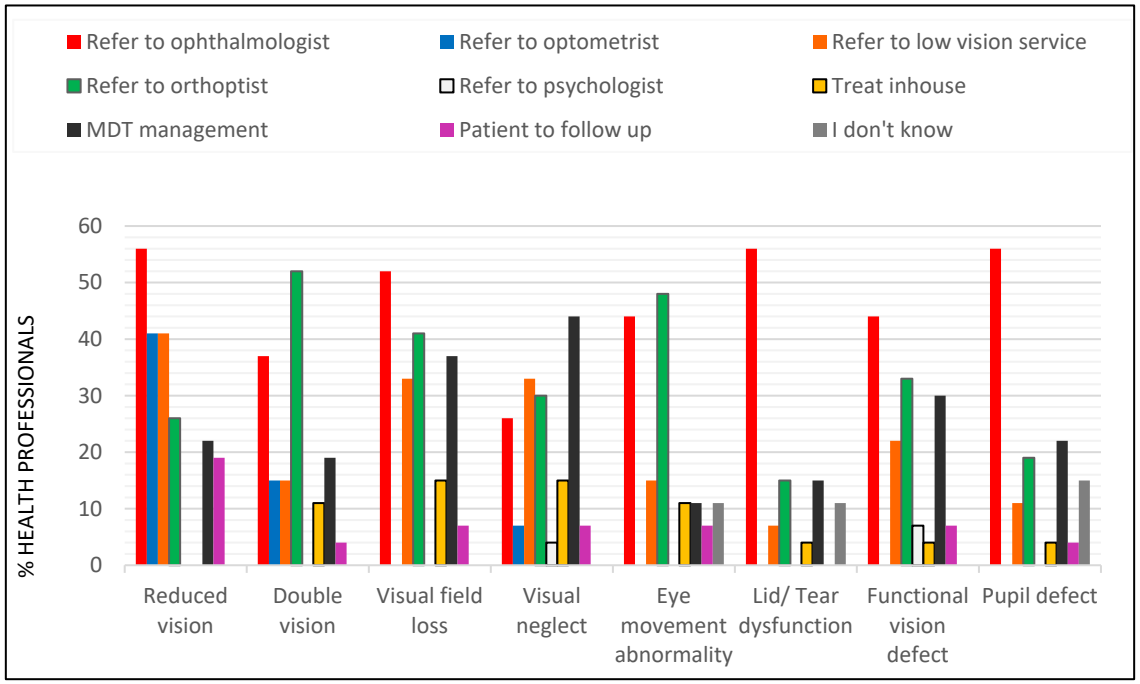


Figure 6.16 Likely outcomes for stroke patients with visual conditions as reported by stroke health professionals (n=27).

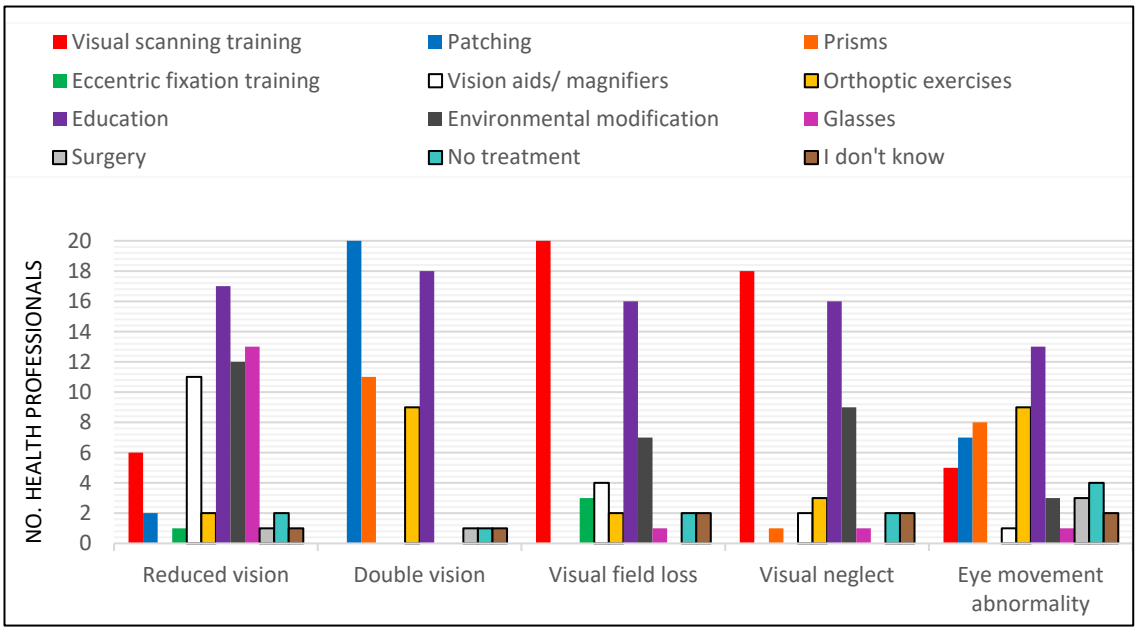


Figure 6.17 Treatment(s) provided within the workplace of health professionals (n=27) for visual conditions found in stroke patients

Eye movement abnormalities and double vision were most likely to be referred to an orthoptist, while conditions such as reduced central vision, pupil defects, lid/ tear dysfunction or functional vision defects were most likely to be referred to an ophthalmologist (Figure 6.16). Visual neglect was the only eye condition where management by the multidisciplinary team was the highest reported outcome. This management option was also reported in comparatively high numbers for visual field loss and functional vision loss. When in-house treatment was provided, most professionals stated that education was provided for all visual conditions and education was the most commonly reported treatment option for reduced vision and eye movement abnormalities (Figure 6.17). Visual neglect and visual field loss was mostly treated with visual scanning training and double vision treated most frequently treated with patching of one eye (Figure 6.17). Health professionals indicated varied follow up periods for all post-stroke vision problems (Table 6.9), with treatment continuing for anywhere between two weeks to 12 months.

Table 6.8 Stroke health professional responses (n=27) regarding initiation and continuation of treatment for post-stroke vision problems.

How long after stroke do you usually begin treatment for visual problems?*		How long do you generally continue to treat patients for visual problems?*	
<2 weeks	67%	Once	27%
2-6 weeks	13%	Up to 1 month	27%
6 weeks	7%	Up to 3 months	20%
3-6 months	13%	Up to 6 months	7%
-		Up to 1 year	20%
		As long as needed	80%

*Respondents were allowed to choose more than one option

Table 6.9 Proportion of health professionals (%) reporting typical follow-up time for stroke-related visual conditions in their workplace.

	Reduced vision	Double vision	Visual field loss	Visual neglect	Eye movement problem	Lid/tear dysfunction	Functional vision defect	Pupil defect
2 weeks	22.2	18.5	18.5	18.5	18.5	29.6	22.2	25.9
4 weeks	14.8	14.8	11.1	14.8	14.8	11.1	14.8	11.1
6 weeks	14.8	7.4	7.4	7.4	7.4	7.4	11.1	7.4

8 weeks	7.4	7.4	7.4	7.4	3.7	7.4	7.4	3.7
3 months	7.4	11.1	11.1	7.4	11.1	11.1	3.7	11.1
6 months	7.4	11.1	7.4	11.1	14.8	7.4	11.1	18.5
12 months	25.9	29.6	37.0	33.3	29.6	25.9	29.6	22.2

6.3.4.1 Barriers

Health professionals most frequently reported a lack of care protocol or management plan as the primary barrier they experience in the identification and/or management of post-stroke vision problems (Figure 6.18). Health professionals believe that the primary barrier for stroke survivors receiving appropriate vision care is their vision problems not being identified (Figure 6.19). They also indicate inaccessibility of appropriate specialist care/ rehabilitation, absent or late referral, financial burden and inappropriate referral as perceived barriers for these patients.

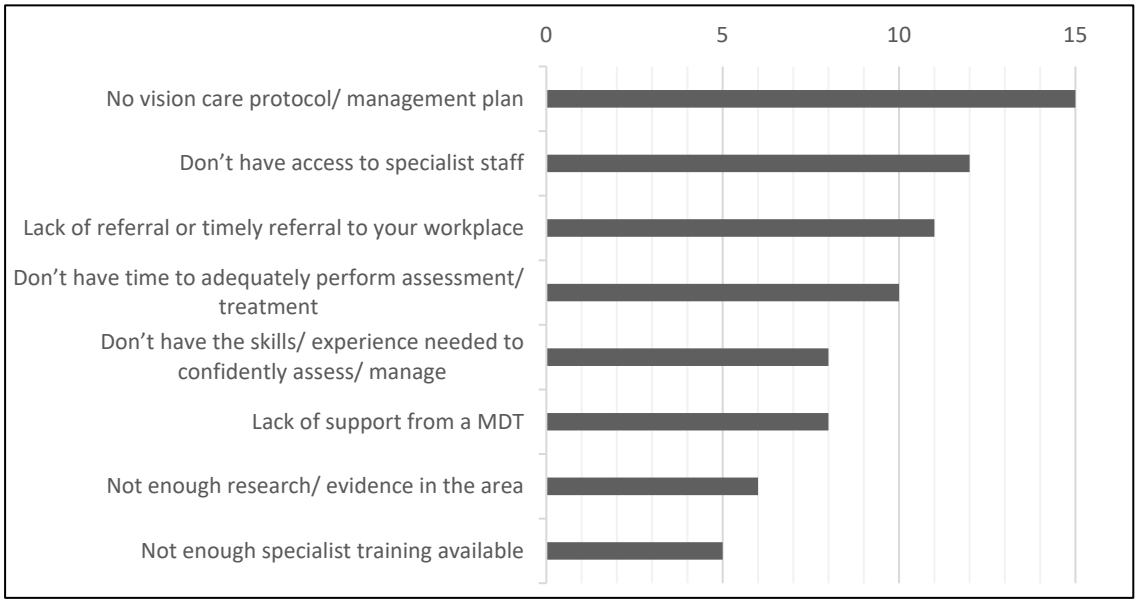


Figure 6.18 Reported barriers experienced by healthcare professionals (n=27) in the identification and/or management of post-stroke vision problems.

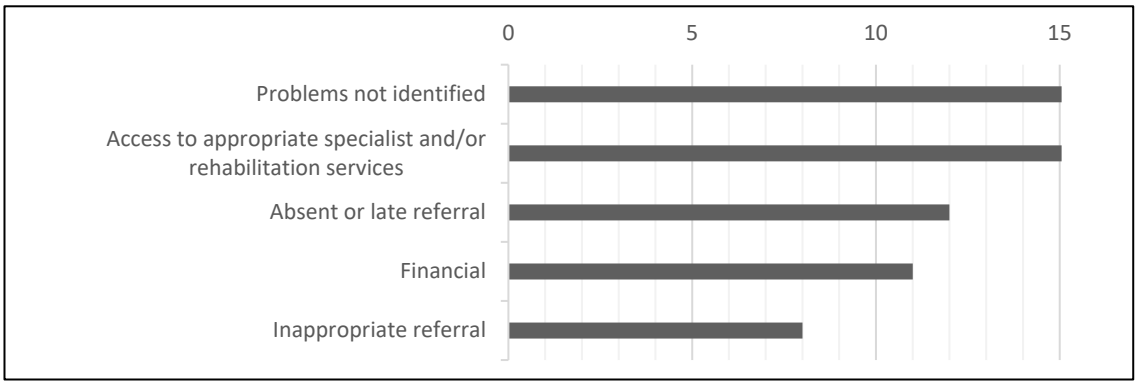


Figure 6.19 Health professionals' (n=27) perceived barriers for stroke patients receiving successful vision care.

When asked how the management of post-stroke vision problems could be improved, most felt that a standardised referral or management protocol that the multidisciplinary team were trained for, would help. Equally reported was the need for established links or direct access to specialist eye services prior to discharge from acute care. Other suggestions were the inclusion of orthoptists/ ophthalmology service onsite, increased vision training for the multidisciplinary team, improved education and awareness of post-stroke vision problems amongst patients and staff, more research in the area, closer relationship between inpatient and community care to ensure follow up of visual problems, and clearer indications of what funding is available for different age groups. Health professional comments regarding how to improve the identification and management of post-stroke vision problems included:

- *"Through patient discussion and liaison with the appropriate health professionals the visual problems after stroke will be better identified."*
- *"Inpatient referral is often more timely to facilitate rehab and alleviate impact on visual function, but unfortunately this is happening less frequently as intake and funding of services is prolonged process."*
- *"Staff use the stroke vision screening tool; more Orthoptic positions in stroke units; improved reporting / observations at bedside early on in the stroke pathway"*
- *"More education to clinicians and stroke survivors"*
- *"Ensuring that there are mandatory guidelines on what is to happen, by whom, and when for acute and rehab services, and ensure this is included in audit data so they are made more accountable. Also increasing hours for therapists to meet the guidelines for staff to patient ratios to enable staff to do their jobs."*

6.3.5 Provision of care from eye-care professionals vs. other health professionals

Of the 27 health professional respondents, 13 identified as belonging to an eye-care specific discipline (orthoptists or ophthalmologists) and 14 as belonging to non-eye care specific disciplines. There were insufficient numbers of health professionals with and without an eye care background to perform meaningful statistical analysis. Consequently, the planned analysis regarding difference in practice between these groups could not be performed. The results have instead been presented as a descriptive comparison of vision assessment practices between eye-care health professionals (ECHP) and non-eye care health professionals (NECHP) in Table 6.10. Higher proportions of ECHP assessed visual acuity, visual fields, contrast sensitivity, ocular movements, eye alignment, colour vision, pupil function and fundus health with every patient or regularly when compared to NECHP. More NECHP assess visual attention and visual scanning with every patient (43% and 43% respectively) when compared to ECHP.

However, most ECHP utilise these tests regularly (visual attention 54%, visual scanning 46%). Use of vision screening tools or test batteries was reported as infrequent by the majority in both professional groups.

Typical management strategies or interventions used for different visual conditions were also compared between ECHP and NECHP (Table 6.11) Inconsistencies in the typical management strategies used are evident between ECHP and NECHP for reduced vision, diplopia, visual field defects, visual neglect and ocular motility defects. Greater alignment between the groups is seen when managing eye conditions such as lid or tear defects, functional vision defects and pupil defects. Across all visual conditions, education on the condition and its impacts is a widely used management strategy by both groups.

Table 6.10 Frequency of use of visual assessments by eye-care health professionals (ECHP) and non-eye-care health professionals (NECHP) when assessing stroke patients.

	ECHP % (n=13)				**NECHP %** (n=14)			
	Always	Regularly	Rarely	Never	Always	Regularly	Rarely	Never
Visual acuity	100	0	0	0	7	57	14	21
Visual fields	92	8	0	0	36	36	14	7
Contrast sensitivity	8	23	31	38	0	0	36	50
Ocular movements	92	8	0	0	36	36	0	21
Cover test	92	0	0	8	14	29	21	29
Colour vision	46	23	23	8	0	0	57	36
Pupils	69	8	15	8	43	21	7	21
Visual attention	8	54	31	8	43	21	14	14
Visual scanning	23	46	31	0	43	21	7	21
Fundus exam	54	0	15	31	0	21	14	57
BIT[a]	0	54	8	38	0	21	21	43
BIVAB[b]	0	0	23	77	0	7	7	64
Biometrics E	0	0	15	85	0	0	7	64
MFVP[c]	0	8	23	69	0	7	14	57
SVDST[d]	0	0	15	85	7	7	29	50

[a] BIT = Behavioural inattention test
[b] BIVAB = Brain injury visual assessment battery for adults
[c] MFVP = Motor free visual perception test
[d] SVDST = Stroke and vision defect screening tool

Table 6.11 Comparison of management strategies used by eye-care health professionals (ECHP) and non-eye-care health professionals (NECHP) for stroke-related visual conditions.

ECHP % (n=13)

	Visual scanning training	Patching	Prisms	Eccentric fixation training	Vision aids/Magnifiers	Orthoptic Exercises	Education	Environmental modification	Glasses	Surgery	No Rx[c]	I don't know
Reduced Vision	8	8	0	8	46	15	69	38	69	0	0	0
Diplopia	8	92	77	0	8	46	85	31	31	15	0	0
VFD[a]	85	0	0	23	23	15	69	38	8	0	0	8
Neglect	69	0	8	0	8	15	69	31	8	0	0	8
OM defect[b]	31	38	54	0	8	69	69	15	8	23	0	0
Lid/Tear	0	0	0	0	0	0	54	23	0	0	15	15
Functional vision defect	0	0	0	0	0	0	46	15	0	0	46	0
Pupil Defect	0	0	0	0	0	0	54	8	8	8	23	15

NECHP % (n=14)

Reduced Vision	36	7	0	0	36	0	57	50	29	7	14	7
Diplopia	14	57	7	0	0	21	50	21	0	0	14	0
VFD[a]	64	0	0	0	7	0	50	29	0	0	14	7
Neglect	64	0	0	0	7	7	50	36	0	0	14	7
OM defect[b]	7	14	7	0	0	0	29	7	0	0	29	14
Lid/Tear	0	0	0	0	0	0	29	7	0	0	29	36
Functional vision defect	0	0	0	0	0	0	21	0	0	0	36	43
Pupil Defect	0	0	0	0	0	0	21	0	0	0	36	29

[a] VFD = visual field defect

[b] OM defect = ocular motility defect

[c] No Rx = no treatment

6.3.6 Discussion

We received 27 complete responses to our survey from a circulation of the online survey through 12 professional organisations and additional recruitment strategies utilising social media and direct approach of stroke/vision care facilities within NSW. Almost equal numbers of respondents were from an eye-care specific discipline (48%) and a non-eye-care specific discipline (52%). The highest numbers of responses were received from orthoptists and nurses, which may indicate more frequent involvement of these professions in post-stroke vision care within NSW. Similar trends have been found in other studies assessing post-stroke vision care practices within the UK.[27,62,184,227,228,230] Responses from stroke health professionals within NSW indicated a large amount of variance in post-stroke vision care practices across all stages of care. This is unsurprising as there is currently no established guidelines or protocols for the provision of post-stroke vision care within Australia.[52,246,247] The results of this survey also indicate that most stroke care facilities do not have a developed post-stroke vision care protocol or pathway, with almost 90% of respondents indicating that their workplace does not have or use any specific guidelines for this area of stroke care. This figure is similar to those in surveys of orthoptists[49] and occupational therapists[124] in Scotland performed in 2011, where access to protocols for post-stroke vision impairment was reported by only 9% and 12% respectively. Since then, a UK wide survey indicated improvement, with 44% of stroke professionals utilising post-stroke vision care protocols or pathways in 2015,[50] and 85% in 2019.[230]

Over half of health professional respondents (56%) indicated that vision problems are often reported by stroke survivors. However, only 25% of professionals working in outpatient and mixed (inpatient and outpatient) stroke services reported assessing vision within six weeks of a stroke occurring. Those working in inpatient stroke services mostly report that visual acuity is typically assessed within two weeks of a stroke event, but this was often only done if vision problems were reported by the patient or suspected by a member of the stroke team. The lack of uniformity in vision assessment protocols within inpatient stroke services suggests a high probability of stroke survivors with vision problems missing out on vision assessment if they are unable to self-report, as many post-stroke visual conditions are not evident through observation alone. In outpatient and mixed stroke services, 75% of respondents indicated there was a significant delay in vision assessment for stroke survivors. These reports are problematic as a delay in vision assessment will result in a delay in treatment for vision problems, and hence increase the impact of the condition on the individual's rehabilitation.

Vision screening tools are seldom used by stroke health professionals in NSW, with only two respondents indicating that they use the SVDST,[28] which was developed specifically for use by non-eye care health professionals for stroke survivors and is freely available on the Agency for Clinical Innovation website.[266] It is possible that a lack of protocol and/or guidelines specific to post-stroke vision care has also contributed to a lack of awareness of the tools available for use in this population. Just over one third (37%) of respondents reported using the Behavioural Inattention Test Battery[101] regularly. However, this screening tool only assesses one aspect of visual function and requires other formal vision testing to be performed in order to rule out differential diagnoses. Where formal vision assessment was performed, approximately half of respondents (52%) reported testing visual acuity with every patient. Similar numbers report testing visual fields (63%), ocular movements (63%) and pupil function (56%) with every patient. The aforementioned tests are crucial to diagnosis of vision problems in stroke survivors and should form the basis of assessment in this population. Unfortunately, these results indicate that these are, again, not performed uniformly for all stroke survivors receiving care in NSW. The method of testing for these visual functions was also not specified in these responses, and so it cannot be determined if the most accurate and appropriate test methods were being utilised when assessing visual function in a stroke population.

Information provision on post-stroke vision problems was routinely provided to patients by approximately half (52%) of respondents. This highlights yet another shortcoming of current post-stroke vision care provision in NSW, with almost half of stroke health professionals not providing basic information on this area of stroke care. This demonstrates a potential lack of awareness regarding post-stroke vision problems among health professionals but will also contribute to a lack of awareness among stroke survivors and their carers. When information is provided, this is most often relating to the patient's vision condition specifically and driving regulations (18%). A small number of respondents also report providing information on management options (14%), services available to assist with vision problems (16%) and support groups available (12%). Without appropriate provision of information, stroke survivors and their families are likely to experience heightened levels of anxiety and confusion around the vision problems experienced[220] while causing a delay in accessing appropriate care.[27,50]

In contrast, most health professionals report providing treatment if a vision problem is found (81%). In-house management was the most frequently reported outcome for visual field loss and visual neglect, with the most common management option provided being visual scanning training. For eye movement abnormalities and double vision, the most likely outcome reported by health professionals (48%, 52% respectively) was referral to an orthoptist. Referral to an

ophthalmologist was the most likely outcome reported for reduced visual acuity, pupil defects, lid/ tear dysfunction and functional vision defects. These results indicate that if assessed and diagnosed, vision problems in stroke survivors receive appropriate management and/or referral in around half of cases. This is not confirmed by reports from the SSS, whereby the majority of stroke survivors indicated that they were not provided any management options or referral(s) for their vision problems. This discrepancy may be explained by the low rates of vision assessment reported and a lack of standardisation in vision assessment among NSW stroke care facilities.

If vision problems in stroke survivors are often missed due to a lack of vision screening or formal assessment, there are likely a large proportion of stroke survivors with vision problems who are not detected and therefore not receiving appropriate management or referral, unbeknown to the health professionals providing stroke care. This issue may be exacerbated by an absence of eye-care professionals within stroke teams, with only 40% of respondents indicating that their workplace had an orthoptist as part of the stroke multidisciplinary team. Even lower rates are reported for ophthalmologists (26%) and optometrists (4%). Evidence indicates that stroke health professionals without an eye care background are not as accurate or effective in detecting visual conditions in stroke survivors when compared to eye-care professionals.[54,61] It stands to reason that eye care professionals should be present in both acute and rehabilitative stroke care teams to minimise undiagnosed or misdiagnosed visual problems and ensure appropriate information, management and/or referral is provided. This notion is supported by stroke health professionals, who indicated a lack of protocol specific to post-stroke vision care and limited access to specialist staff as the most widely acknowledged barriers to the provision of appropriate vision care.

The primary limitation of this survey is the low response rate (n=27). We identified professions involved in eye and stroke care and circulated the online survey as a web-link via targeted social media pages relevant to allied health and stroke care within NSW. NSW members of relevant health professional organisations were also emailed. Heads of stroke units within NSW were also identified and sent recruitment materials, including the survey web-link, and asked to disseminate to their colleagues. Despite this, it was not possible to determine if the survey was sufficiently disseminated to stroke health professionals. However, we received responses from a range of health professionals within key disciplines of stroke and vision care, with new and useful information provided. The responses were also almost equal in number from eye care and non-eye care professionals working with stroke patients, and inclusive of professionals working within metropolitan and rural areas of NSW.

The length of the survey may have been a possible deterrent for time-poor health professionals, however, a previously conducted feasibility study found that the survey was completed on average within 15 minutes. This is of similar length to other surveys conducted with stroke health professionals that received significantly higher numbers of respondents. The feasibility study conducted also highlighted that many non-eye care health professionals felt they did not possess the knowledge required to accurately answer some of the specific questions around vision assessment and/ or management. In response to this, an 'I don't know' option was added to most questions. It is possible that those with limited knowledge and or experience of vision care did not feel they would be able to provide an adequate response to the survey and so did not participate. This would have created a bias within our sample towards those with a greater understanding of visual problems. If biased in this way, it likely that there is in fact greater variation in care practices and a poorer knowledge base than indicated by these results, hence underestimating the current limitations in care provision.

6.3.7 Conclusions from the Stroke Survivor & Health Professional Surveys

The data obtained from both the SSS and HPS provides novel insight into the current post-stroke vision care practices in NSW. There is significant variation in the provision of vision care to stroke patients across the state as indicated by stroke survivors and stroke health professionals. Reports from both groups of respondents indicate that initial post-stroke vision assessment does not occur in a timely manner, with health professionals indicating that this might occur anywhere between two weeks and six months post-stroke. Almost one third of stroke survivors reported not having any vision assessment within the first six months following their stroke, and of those that did, only half occurred within the first six weeks. Greater discrepancy is noted between the groups when reporting on management of post-stroke problems. The data from the HPS indicates that management (unspecified) is typically provided to stroke patients if an eye condition is identified, however, it may only be provided as a one-off service and it is not possible to ascertain if it is the most appropriate form of management for the stroke survivor's condition. In contrast, the vast majority of stroke survivors report not receiving any form of eye care management as inpatients and most did not receive a referral to an eye care professional.

Similarity between the groups is again evident when reporting on the lack of provision of information pertaining to stroke-related eye conditions. Both indicate that this is not uniformly provided to stroke survivors in NSW, and often does not include crucial information on management and support services. With regard to perceived barriers to appropriate vision

care for stroke survivors, both groups identify similar issues in current practice. A lack of clear, evidence-based guidelines in conjunction with limited access to specialist staff, have been identified as primary barriers to the provision of appropriate post-stroke vision care by stroke health professionals in NSW. For stroke survivors, a lack of information, management options and appropriate referral were the primary barriers they experienced, preventing successful provision of vision care. In this comparison, it becomes clear that the barriers identified by the health professional group could lead to those identified and experienced by stroke survivors.

Vision problems following stroke have a significant impact on the individual with regard to their rehabilitation and even more so on their daily life, once they return to the community. Appropriate vision care for stroke survivors may help to mediate this impact, however, the results of these surveys indicate that post-stroke vision care within NSW is highly variable. The majority of stroke survivors with vision impairment in NSW feel that their vision care needs are not adequately met by the current care practices. In order to ensure equitable, high-quality care to stroke survivors with vision impairment, improvements to care practices and pathways must be made. Central to this is the need for a standardised, evidence-based approach to the provision of vision care for Australian stroke survivors that is feasible to implement and covers all stages of stroke recovery. The inclusion of eye care professionals within stroke care teams would improve the detection of vision conditions, provision of information, short term management strategies and appropriate referral.

Inequities in post-stroke vision care provision between major cities and regional or remote areas of NSW are likely, with results indicating that the greatest discrepancy occurs when trying to access community-based eye care specialist services within regional and remote NSW. The development and implementation of a nationally agreed post-stroke vision pathway will likely help to address these shortcomings in vision care provision for Australian stroke survivors by ensuring clear guidelines for stroke professionals and a standardised approach to care that can be more closely audited.

7 THE EXPERIENCE OF VISION IMPAIRMENT AMONG STROKE SURVIVORS IN NSW: INTERVIEW RESULTS

7.1 INTRODUCTION

This chapter outlines the results of the stroke survivor interviews that were conducted as part of Stage One of the PRECiS Study. The methodology for Stage One of the PRECiS Study has been previously outlined in Chapter 4. The data collected via the surveys described in Chapter 6, provides a descriptive overview of post-stroke vision care practices and pathways within NSW. However, to obtain greater insight into the experience of post-stroke vision impairment for Australian stroke survivors, a series of interviews were conducted with stroke survivors and their carers. Interviews allowed for greater inclusivity for stroke survivors who may not be able to complete an online or written survey. The semi-structured interview approach also provided opportunity for a greater breadth of data to be collected and ensured a wide range of experiences were acknowledged and understood. Through inductive reasoning, these experiences can be considered cumulatively when developing a post-stroke vision care pathway. The inclusion of input from key stakeholder groups is imperative to care pathway development when following the Vanhaecht method.[267]

The interview data revealed five major themes emerging from the overarching topic of stroke-related vision impairment: formal vision care, information, feelings towards care, barriers to vision care, and impact on daily life (Figure 7.1). Formal vision care related to the specifics of assessment, management and referral, the impact of vision impairment on rehabilitation and aspects of care that were either satisfactory or unsatisfactory, as expressed by the participant. The theme of 'information' describes the information about post-stroke vision problems that participants received, how this information was conveyed, and what content and format of information they would have preferred. Feelings towards vision care encompassed both positive and negative emotions surrounding various aspects of stroke survivor's experience of post-stroke vision care. Barriers to vision care involved discussions around access, delayed visual diagnosis, the role of health professionals, and the survivors' own deficits post-stroke. The final theme is impact on daily life, where various physical, recreational, and emotional aspects were discussed as well as the experience of new vision problems in addition to other health issues or physical limitations. Each of these themes are presented and discussed in the present chapter, with supporting quotes provided that best demonstrated the theme or sub-theme throughout the text. Additional supporting quotes relevant to each theme are also provided in Table 7.1

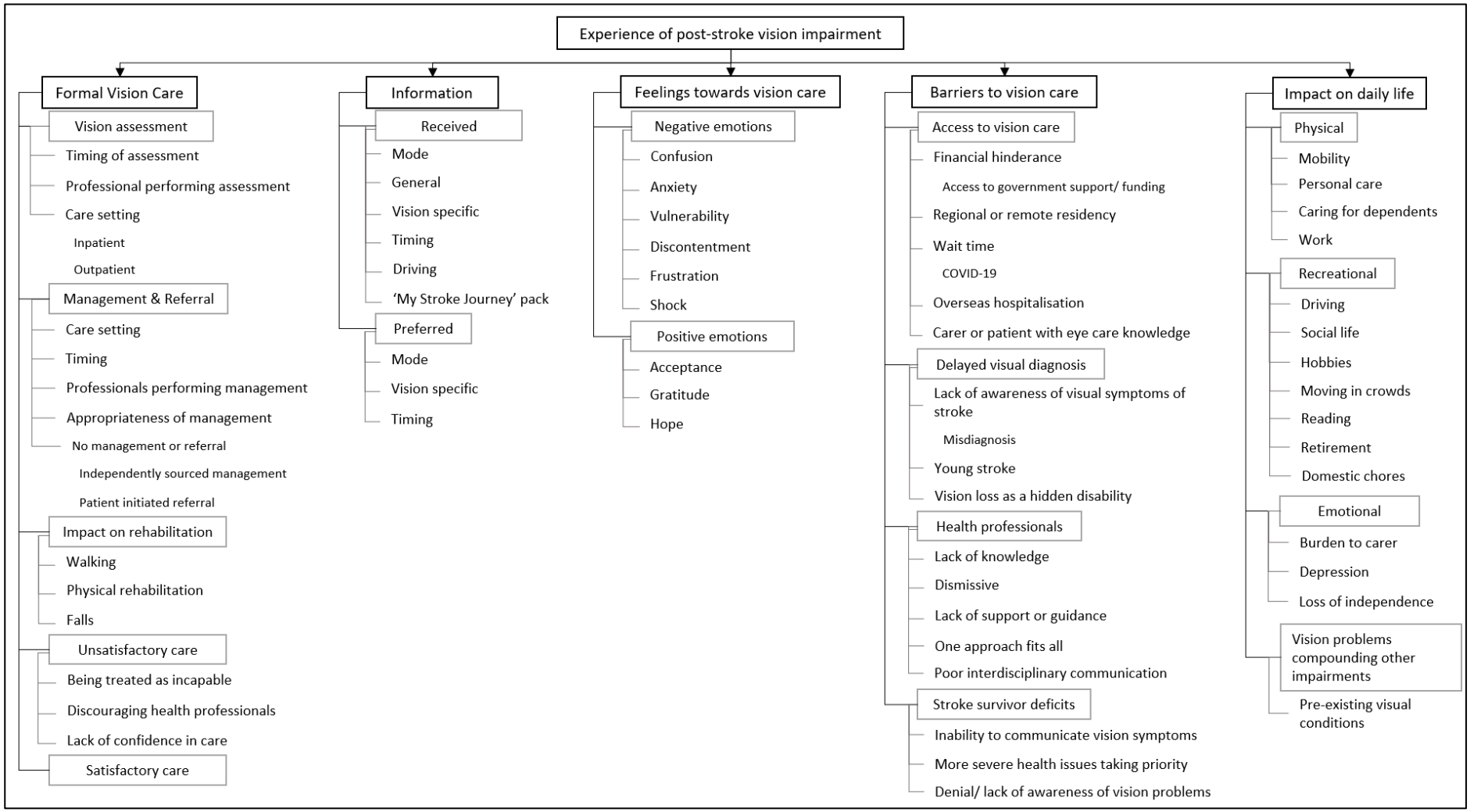


Figure 7.1 Stroke survivor interview data coding schematic showing the five emerging themes of the experience of post-stroke vision impairment.

7.2 INTERVIEWEE DEMOGRAPHICS

Twenty-one stroke survivors were interviewed (11 males and 10 females). Stroke survivors were of mixed ethnicity, residing in NSW, Australia with six living in regional or remote areas and 15 living in major cities. The age of stroke survivors at the time of interview ranged from 35- 85 years, while age at time of last stroke ranged from 17-84 years. Mean duration of time from stroke onset to interview was 4.7 years (SD = 4.1, range= 8 months -18 years). Of the 21 stroke survivors, 12 reported having only one vision problem caused by stroke, of which ten were visual field loss, one was vitreous haemorrhage, and one was double vision. The remaining nine stroke survivors had multiple vision problems caused by stroke. The most common was visual neglect combined with visual field loss. Other visual problems included nystagmus, ptosis, double vision, blurred vision and photophobia. Due to the nature of the study design (interview in participant homes or over telephone/ video conference) visual problems were categorised according to description of symptoms experienced. It was not possible to obtain more specific information regarding visual diagnosis as some participants were unsure of medical terminology or had not yet received formal diagnosis.

7.3 FORMAL CARE

7.3.1 Vision assessment

Most stroke survivors had their first visual assessment as outpatients either within a hospital eye clinic or external private eye clinic (n=14). Of those that had a bedside vision assessment (n=7), this was typically performed by the neurology team and consisted of gross visual field and ocular motility testing:

"Endless assessments. But I don't know how much of the visual was mainly that one that I told you about where she'd say he can't see my fingers. Yeah" – Stroke Survivor

Initial assessment typically took place during the rehabilitation stage of care or after discharge from a rehabilitation facility. For many, they recall vision concerns not being prioritised by treating health professionals because of more urgent or more severe stroke-related deficits requiring treatment:

"Neglect definitely, neglect from every neuro-registrar to resident or whatever was also doing the side vision, because it's a neurological check. Um, specifically vision, no. Um I think they were more concerned about keeping him alive at the time and keeping him fed."
– Carer of stroke survivor

The timing of initial vision assessment from stroke onset varied from 2 days post stroke to up to 1 year post stroke. For those who did not receive any vision assessment as an inpatient, initial vision assessment took place at least one month post-stroke, but for many occurred more than six months after stroke onset. Those who had their first vision assessment during their rehabilitation or later said that they would have liked a formal vision assessment earlier as this would help to reduce anxiety about their visual condition and help to initiate the process of attaining vision care sooner.

"*And that, in a way, makes me almost angrier. It was easily resolved. You know, it was day surgery. And all the anxiety and the stress and trying to work out what I could do or not do, could have, you know, could easily have been resolved by a proper consultation and conversation, you know, the way that it happened afterwards, but it took a while."*
– Stroke Survivor

In most cases, stroke survivors or their family member(s) reported suspected vision problems to their treating health professionals, which then prompted vision assessment by the treating hospital:

*"so I was on the neuro ward by that time at *****, and they, after I complained because the eye was swelled up I could hardly see out of it, um and I was like I don't know what this is so then that's why they did the ophthalmology appointment." – Stroke Survivor*

However, several stroke survivors were still not provided any form of vision assessment despite reporting visual symptoms or were told that inpatient vision assessment wasn't available:

"I think from a visual perspective, I don't think it exists, even though there is an eye department in the hospital there. I did ask when we were there if the registrars do a visit to the stroke ward, and they said no, only upon request of the consultant or the doctor he was under, should they feel the need for a ward visit. And it wasn't requested so it was never done and that's when we…'cause I was sort of sitting there thinking look maybe it will happen one day. But then when it didn't we just thought ok, let's go down the hall and have it assessed."
- Carer of stroke survivor

This often led to patients and their carers feelings as if it was their responsibility to seek vision care independently and resulted in further delay in receiving care as no assistance was provided in setting up appointments or organising transport to and from an eye care specialist service.

"We didn't do a formal assessment until you could get me in a car, and that was obviously our wanting to do it." – Stroke Survivor

7.3.2 Diagnosis and short-term management

In most cases (n=12) stroke survivors experienced a delay in formal visual diagnosis.

"No formal diagnosis, not the eyes. Yea they just said it was some peripheral vision but it's not concerning enough to be a problem." – Stroke Survivor

Six received some form of short-term management for their vision problems in acute care and/or during rehabilitation. This consisted primarily of incidental visual scanning and attention prompts during occupational or physiotherapy or patching for diplopia:

"they were less, not less concerned, less focused, on the vision itself and more concerned with trying to get me to cope with the whole neglect. I was being trained to scan and orient myself in the room to maximize my vision." – Stroke Survivor

Two participants received patching and in one case, Fresnel prisms were provided to a stroke survivor with visual neglect, which was prompted by a family member who was an eye care professional:

"So he had about a month of Fresnel prisms that I put on some plano glasses, which intrigued the physio and OT specifically. But other than that, he doesn't prefer to wear them because it does blur his vision. It sort of helps a little bit, but I think it's just the persistence of wearing them that prevents him getting the full benefit. They helped, I provided the glasses, and they had the Fresnel at the hospital. But I helped them facilitate it."
- Carer of stroke survivor

Those who didn't receive any sort of short-term management for their vision problems felt that this increased the burden of their vision problems during their recovery. One stroke survivor explains their self-discovery of patching to relieve double vision and how this would have improved their experience in hospital:

"If they'd just try and give you like patches and things like that, that would've been really helpful because the patch has been fantastic for me. If I don't wear it, I just get really tired and it's all blurry on one side and it's just too much." – Stroke Survivor

7.3.3 Long term management

Upon discharge, eight stroke survivors stated that they received no care plan at all, while ten received a care plan that did not include any vision management suggestions. One stroke

survivor even found the concept humorous after their experience where no care plan or referrals were provided, demonstrating the stark absence of vision related care:

*"Ha! What long term plan? There was no short-, medium- or long-term care plan *laughing*" – Stroke Survivor*

Ten of the 21 stroke survivors were not provided with a referral to an eye care professional of any kind by either the acute care hospital or rehabilitation facility. Of the ten who were not provided any referral or management options, eight had visual field loss as their main visual problem, and two had double vision. For many this experience was highly disenfranchising, as they felt this meant that nothing could be done for their vision problems and that they would have to live with this deficit, without help, for the rest of their lives:

"When it's vision, I think it's so oh, like I, I remember I was, you know, that year, that first year after I was just sort of begging in myself, Oh, geez, I wish it was a physical. I wish it was…I wish I'd lost my arm movement and my leg movement, because in my mind, I thought I could get that back with rehab." – Stroke Survivor

No offer of management or referral often led to patient initiated referral or independently sourced vision care which again frequently resulted in indirect referral pathways and a delay in access to vision care:

"The other thing that we did of our own volition is that sometime in September, I personally contacted somebody who worked at a neighbourhood sector and she got in touch with a registered nurse and contacted an occupational therapist who came from Vision Australia. And she basically looked at things that we might be able to…we weren't in our home, we were still looking for a home and we were in a rental place so there was no point her doing an assessment at that place. And she just pointed out a few things that might help me like magnifiers and stuff like that. And that's all that happened. But everything that was done was basically done because I instigated it." – Stroke Survivor

For most this consisted of seeking out private ophthalmology care or going to see an optometrist. At this stage, vision problems such as vitreous haemorrhage and double vision were treated promptly with surgical interventions or prisms. Those with visual field loss and/or visual neglect were often told that nothing could be done for them, or were referred to low vision services without any explanation of the services available.

"When we talked about rehab. He and his registrar, both said, oh we can give you lots of help with rehab about everything except specific vision problems. We don't have anything for that. And we were a little bit surprised by that. And said does anyone else? But they said not really." – Stroke Survivor

When low vision services were recommended without any explanation, this was often met with reluctance from stroke survivors as they believed they would only be offered a guide dog or low vision cane. There was a generalised stigma amongst stroke survivors regarding low vision services as they associated this with being completely blind and were of the opinion that these services would not have anything beneficial to offer them. The below accounts of two stroke survivors and a carer exemplify the implications of a lack of information or education about low vision services:

"I went to see the eye doctor that I saw initially... he gave me the number for Guide Dogs and said, my vision will never come back. Go, here's the number for Guide Dogs, get a cane. Basically." – Stroke Survivor

*"They didn't seem to know of anywhere else to suggest. Now the people of ******* rehab did suggest several other things including, they suggested using the Blind Society and the Guide Dogs people. But my impression is that that's really helpful for people whose eye damage is much worse than mine. I can manage around the house." – Stroke Survivor*

"And we rang Vision Australia to arrange an appointment for him, to purchase or, give him a blind stick…he was absolutely no, no, I don't want to walk around with blind stick and I want to walk independently with me (wife). I said it will be much safer because other people can see that you haven't got full sight." – Carer of stroke survivor

This experience for most stroke survivors prompted pursuit of other vision care through independent research or recommendations from friends or other health professionals. In most cases, stroke survivors without referral upon discharge ended up in the care of behavioural/ specialised optometrists or neuro-ophthalmologists. A few continued to pursue support from low vision services such as Vision Australia and Guide Dogs NSW and were provided with mobility training, low vision canes and/or low vision aids.

"No, but my optician, who I've seen for years since I've been wearing glasses, had said, this hasn't been proven, but we do have a lady here, who works with people who have had vision loss such as yours, and assist them with seeing. And it could be possible that your brain could learn how to get the vision back." – Stroke Survivor

One stroke survivor did not pursue any further vision care independently and said they have learnt to manage their vision problem through self-made adaptations such as using a large computer screen to read, scanning and employing the help of others.

*"my sister was very good, actually. She's a clinical psychologist. She wrote a list to help my friends with me. Oh, yeah. ***** will have an orange bag with her. If you put that over your shoulder. Then she'll search for that orange bag if she loses you. Which was very good."*
– Stroke Survivor

"It was, you know, an old fella that was across from me in the stroke unit. He actually lost his sight from a stroke, but he was well in his 60s at that stage, and he said, after his first one with his eyesight what he did to get it back was read books. He said, just read as much as you can. Just to keep your eyes scanning to strengthen them. And that really did help."
– Stroke Survivor

Younger stroke patients also expressed a want for alternate means of care such as acupuncture, yoga, and eye exercises. They felt these options should be made available in the early stages of recovery because they felt it helped them adapt and provided hope for improvement.

"Or even like, saying, you know, like, why don't you try Pilates or something like that, like, I know, it's alternative and they don't like that kind of stuff. But um, you know, I was really anxious. Very, very, like, psychologically stressed out."
– Stroke Survivor

"It's that after care, especially for vision that is just lacking. And I was so jealous of, when you Google chat rooms and stuff, and what happens in America, for instance, but there was so much more on offer." – Stroke Survivor

Some form of vision management was provided to majority of stroke survivors between two weeks and twelve months post-stroke with most remaining under the care of an eye-care professional for regular check-ups or management of eye conditions unrelated to stroke.

7.3.4 Impact of vision impairment on stroke recovery

Many stroke survivors felt that their vision problems had an impact on their overall recovery and rehabilitation from stroke. These issues related primarily to falls during recovery, issues stemming from fear of becoming mobile with reduced vision and added difficulty during physical rehabilitation. In the acute stages of recovery, stroke survivors mostly felt that their vision problems were less problematic or less noticeable because they were bed bound and

not as cognisant as they were in later stages of recovery. For some, they did not become aware of their vision problem(s) at all until weeks or months after their stroke. This carer describes when her husband first noticed issues with his vision following stroke:

"Probably much later on. Because he didn't really do anything. Probably 6-weeks laying in the bed and they did they did everything in the beds. Washed him and... they never really... would have been good six weeks before that actually stood him. Started transferring him, dressed him." – Carer of stroke survivor

"No. I mean, and when I was walking around, because I had been in bed for two weeks. I hadn't lost the use of any of my limbs. But I was a bit wobbly when I was walking. So someone was always walking with me. So yes, I'd have to say I really wasn't aware of how bad my vision loss was." – Stroke Survivor

Rehabilitation activities such as physiotherapy and occupational therapy were often complicated by visual problems. In particular, stroke survivors describe struggling to navigate their environment while trying to learn to walk again:

"When I was going through physical therapy and having to learn how to walk, um, can't see properly and you are unsure on how close things are, even how far away the floor is. I - when I come off a walker, which was about October, November last year, um even walking down steps um where it looked like I was on the last step, I was still two or three steps up."
– Stroke Survivor

Falls following discharge from hospital were a recurring issue amongst interviewees, with some having sustained serious injuries from falls in the twelve months following stroke.

"Yeah, he's had a lot of falls. Several fractures in his spine. They were going to fly him to Sydney to operate. They had the plane ready. It must have been about six or seven (pm), he had a big fall. He fell on those tiles at the front door and he said, 'give me his medical history'. He said because he's had a stroke, I will not put him under anaesthetic." – Carer of stroke survivor

*"apparently the other thing that happened while I was an inpatient was that I fell and I don't know if that had anything to do with the fall. Which they also didn't tell my husband about. We only found out because one of my colleagues who's also at **** came to see me and he said he was sitting, when he came in they were manipulating my foot and I was screaming and he said to them; 'why she screaming?' And they said oh she fell and you know, broke a bone in her foot." – Stroke Survivor*

Once returned to the community, stroke survivors felt that their vision impairment(s) became even more apparent. Many describe an increased dependence on their family members and/or carers as a result of their vision problems preventing them from going out alone and/or driving.

"Oh walking, I couldn't walk outside without hanging onto my partner. I didn't know where I was because this was a brand-new town. So I had no mental map of what to do, I couldn't read, I couldn't…put it this way, the only thing I could do, and I was exhausted, was lay in bed and look out the window. And I couldn't even see properly out of the window. It impacted everything. It still does. You know, I'm still not able to do many things, and never will be able to." – Stroke Survivor

7.3.5 Satisfactory vision care

Six stroke survivors stated that they were satisfied with the vision care they received, often expressing that they felt health professionals did the best they could even if they were not offered any management options for their vision problems. One stroke survivor provided an example of a consultation with one of their treating stroke professionals where they felt appropriate care was taken despite not having the outcome they desired:

*"I've got this haze of colours in my vision, and he took that absolutely seriously. Quizzed me about it in detail. I think sent me back to Dr. ******, or I went back to myself, I forget which now. But essentially, what he said was yeah this can happen. In other words, he's reassured me that this is within the range of normal, but there's nothing specific that he's been able to suggest." – Stroke Survivor*

One participant was under the age of 18 when they had their stroke and so was treated in a paediatric hospital. They spoke highly of the vision care that was provided and felt that the primary strength of the treating health professionals they encountered was the way in which they provided detailed and relevant information throughout the recovery process:

"I would recommend them as a good place to go if you have to go through that sort of thing as kid, or really any other condition, because they have a great ethos and they have a good education side of things, which is so important. To get people to understand their conditions, whatever they may be." – Stroke Survivor

For most, the vision care they received privately or following discharge was viewed as satisfactory and provided some relief in terms of providing a formal diagnosis and information on management strategies or services available.

“went to see the ophthalmologist and then I said to him, 'why, if you need an ophthalmologist to find all these things out, why don't they send them to one soon as they have a stroke? if they get these problems from the stroke?’ He said, he could ask me a lot of questions why doctors did this and that. He said what they should do and what they do - that's completely different.” - Carer of stroke survivor

7.3.6 Unsatisfactory vision care

Unsatisfactory vision care was primarily discussed by interviewees in relation to their inpatient stroke care. Most described their vision care as absent or lacking during their hospital stay and felt that this resulted from a lack of awareness of post-stroke vision problems or lack of attention paid to them:

“Well he said even if you had top medical cover, you may not have been sent to an ophthalmologist. Yeah, it's really got nothing to do with like, you know, the, the insurance or the money. It's purely just lack of awareness. And sometimes, yeah, they just don't know.” – Stroke Survivor

Several stroke survivors felt that more should have been done for them in terms of their visual difficulties, but accepted that this was just not an ordinary part of stroke care:

“No I think there should have been a lot more, because it was the only symptom I had. Apart from a bit of ataxia on the right side, which definitely passed off very quickly. I think, there should have been more, but I could accept that there wasn’t.” – Stroke Survivor

Unsatisfactory vision care was also discussed by stroke survivors with specific mention of discouraging health professionals, whereby the health professionals responsible for their care made it seem as if there was no chance of improvement or that pursuing further vision care was pointless.

“the bedside manner of that second Doctor wasn't real crash. I was worried about my eyesight, it was really blurry, and she said that it will never come back. And she said, you'll probably never work again.” – Stroke Survivor

“Look I know that they don't want to give you too much hope, because they want to manage your expectations. Yeah, but I mean, what makes it worse is, if when they say oh look, it's been three months, it's not going to get any better. That's far worse.” – Stroke Survivor

Some stroke survivors also felt that they were treated as incapable by treating health professionals and/or lacked confidence in the quality of vision care they were provided. One stroke survivor and their partner discuss the difficulties encountered in trying to seek vision care while dealing with aphasia:

"Stroke survivor: I can understand if people tell me what they are talking…

*Partner: Yes, he can understand everything that's spoken to him. This is what's so frustrating for ******* because some people that have come to the home, an occupational therapist, treat him as if he's Ga-ga.*

Stroke survivor: Yeah, and that's purely like what I can, what I can or can't see that is the problem. But if talk to me..."

- Stroke survivor and their spouse/ carer

Another stroke survivor explains how they were not completely convinced that they had received the most appropriate vision care for their condition, but was hesitant to place blame on their treating health professionals:

*"I don't honestly know, because if they've done all that there is that can be done, then they've done the best they can. Yeah, but I'm not absolutely sure that there isn't somebody else who I just haven't come across. Who knows, and who says, Oh, goodness, you should be doing x and y. Dr. *****, the people in ***** said, we don't think there's anywhere else we can recommend to you. I didn't know whether that was just their furlough?" – Stroke Survivor*

7.4 FEELINGS TOWARDS CARE

7.4.1 Positive emotions

Interviewee's feelings towards vision care encompassed a number of positive and negative emotions. Positive emotions primarily related to gratitude for the care provided and for the health professionals providing that care as they felt that they did the best they could. Stroke survivors and carers often empathised with healthcare professionals as they thought of them as being very busy and having highly demanding jobs. Despite many feeling that their vision care could have been better, they were grateful for the overall stroke care that they received:

"This hospital was fantastic. And I'm not putting them down now. They got me from a bit of jelly to walking in three and a half months." – Stroke Survivor

Gratitude was also expressed in reference to the individual outcome of stroke, noting that they are lucky to be alive and know of other stroke survivors with much more severe deficits than themselves.

"Even now, it's probably not as bad as what it what it could be. It's I'm not like the poor fellow next to me who has hooked his eye with the fishing rod. That's totally blind. So, but it's not like that, I can still walk with, and sometimes I don't have any glasses on at all."
– Stroke Survivor

Hope was also expressed in reference to improvement of vision problems and how current or future vision care may assist stroke survivors with this.

"Well see, I would have loved any kind of therapy, to at least try it. And that's where, that machine that I got, I mean, that was the first thing I had. I did that religiously every day because it was actually finally something to help me. "
– Stroke Survivor

Several stroke survivors discuss the importance of having baseline measures of their visual deficits in order to track their progress, as this gave them hope for further improvement. Some also mentioned that being given exercises or some form of management helped them to feel they were actively doing something to help their vision, even if significant objective improvements weren't made.

*"You know, and in that visual field, you know, to go from 80 to 140, 145. It just, you know…and the way it looked in my visual field was that there was a couple of gaps right down in the corner, where it was still evident that there was a bit of vision. Yeah. And ***** was of the belief that eventually they should join up, and that gave me so much positivity finding him."*
– Stroke Survivor

One stroke survivor also made reference to believing in medical advances whereby there might be something to help their vision in the future.

"So yeah, I just I hope, as I have, that they come up with something quick before I pass this mortal coil. And that if it doesn't happen, well then, what I've got at the moment is probably not too bad." – Stroke Survivor

Other stroke survivors describe acceptance of their visual impairment and/or the fact that there was no cure for their vision problems.

*“I mean, she just looks at me and says, ‘there’s no change *******’ and you know, she can’t do more. And I just say ‘well, that’s ok then’. “ – Stroke Survivor*

Interviewees discuss how they are able to ‘get on with life’ and continue to perform certain activities despite their visual deficits, or acknowledge that the outcome of their stroke could have been much worse and hence are able to accept their current circumstances.

“I don't need a cane. You know, and I've been able to travel around the world and still doing fine.” – Stroke Survivor

7.4.2 Negative emotions

The negative emotions towards vision care were often expressed in relation to early experiences post-stroke. The most widely discussed feeling towards vision care was confusion. Confusion stemmed from a lack of information about their visual condition as well as a lack of guidance and support throughout their vision care journey.

“I was trying to work out ways, if I could drive, whether I’d be able to drive with one eye? Would I be able to teach? You know, all of those things.” – Stroke Survivor

Many felt that even when vision care was provided, that they as the patient or carer were not fully involved in the process, but more of a passive bystander.

“They did offer me training and this is where I got angry with them because of the brain damage, and my memory then affected so badly, they would be trying to teach me how to use the cane, for example, going up and down stairs. Every week, I would not remember. Like Groundhog Day, and I would end up in tears every time. And I said to them, I don't think I can do this because it's just too upsetting for me. Their response was, it doesn't matter, we can come and see you every week. I kind of said, it does matter to me because it's not improving me, just upsetting me more.” – Stroke Survivor

Discontentment with vision care was also commonly expressed, where the vision care provided was felt to be limited, delayed or not treated as a priority by health professionals.

*“It's so important, and it really doesn't get the attention that I think it deserves. And certainly not in the way that you know, it’s one of the largest hospitals in Sydney. It wasn't just a small hospital where they were doing their best and, you know, didn't have people. And even the rehab hospital was ******. So it's quite big rehab hospital and they actually had people on staff who could at least do the assessment. But they just didn't see that it was important.” – Stroke Survivor*

Stroke survivors also discussed being in shock after told that there was no treatment available for their vision problems. Anxiety was also felt by several interviewees, particularly when vision care was not provided or delayed for a period of time. Uncertainty about the prognosis of their vision problems in terms of likely recovery, impact and course of action caused stroke survivors stress that they felt could have been avoided or alleviated with more targeted or timely care provision.

"And that, in a way makes me almost angrier. It was easily resolved. You know, it was day surgery and all the anxiety and the stress and trying to work out what I could do or not do, could easily have been resolved by a proper consultation and conversation…the way that it happened afterwards, but it took a while."
– Stroke Survivor

Stroke survivors described feeling frustrated when their visual complaints were not listened to or their condition not understood by their treating health professionals. Frustration was also expressed in relation to receiving management or referral for their vision problems that was not appropriate.

"Look, I think it's, it's, like I said before, it's, sight is one of those things that, you know, loss of sight is terrifying. Whatever you are, and not knowing that you're… not getting people to listen, was really frustrating." – Stroke Survivor

Stroke survivors also felt vulnerable in circumstances where care was provided but not explained, or assessments were performed without feeding back information to the patient or carer.

"Um and its quite funny because with the ophthalmology side of things, I never got anything written down for me, or anything so it's quite confusing when you're in that state about what's happening and you can't really understand it." – Stroke Survivor

"When they took me to the ophthalmology appointment I was quite frightened because they just wheeled me down in a wheelchair because I was paralysed on my left side, and um they like, it's no one's fault or anything, I do understand it's the public system and it's busy, but they sort of just left me in the hallway waiting for the ophthalmologist." – Stroke Survivor

7.5 INFORMATION

7.5.1 Information received

The majority of stroke survivors received general information about their stroke and were advised not to drive during the acute stages of recovery through verbal discussion with their stroke physician or neurologist.

*"***** had said to us that once you've had brain surgery you can't drive for 3 months after anyway. Uh and we knew that after 3 months that he wasn't up to driving anyway, that wasn't going to happen. So that was 6 months. But no, even in the rehab hospital, nobody said anything about eye sight." – Carer of stroke survivor*

"They gave me four or five standard stroke brochures. But these are two sides of A4. And they don't have a lot of information. And it's basically, yes, you can expect this. And it will get better over time in most cases, but we're not saying how much." – Stroke Survivor

The Stroke Foundation 'My Stroke Journey' pack was received by one of the 21 stroke survivors and had a health professional discuss the information in the pack with them.

"So it was and now that I recall it, and I had a little booklet, foolscap booklet that was all about having a stroke and some of that was filled in and some of it you had to do yourself. And some of that was sighted." – Stroke Survivor

Few received information that was specific to post stroke vision problems or their specific vision problem and stated that this made it much easier for themselves and their families to understand and anticipate the challenges of their vision loss post-discharge.

"I think, we were told what hemianopia was. In the sense that we were told that I lost approximately half the vision in both of my eyes. There was, it might have been to my school, I'm not sure, my team went and spoke to my school and my teachers, and they took a pair of glasses where they blacked out - the left half both eyes to give people a sense of what I wasn't seeing." – Stroke Survivor

Those who sought out more information said that there are lots of resources available in the stroke ward for other stroke related deficits but none relating to vision.

"There is no information. No sort of written information, I mean there is a whole wall full of everything else that stroke affects, bar vision, so nothing written, but there was a discussion about making sure that we kept the diabetes under control and that was it."
- Carer of stroke survivor

7.5.2 Preferred information

When information was discussed, stroke survivors and their carers repeatedly emphasised the importance of having information specifically about their vision loss made available to them with regard to what impact the stroke has had on their eyes, what to expect as a result of this and what management or support options are available.

"I had mum there with me, and she found it hard to understand what was going on or what our next step was for recovery. Um, my GP is pretty good but it's like ok we will do this and we will do that, but there was no future explanation. Like um, with my eyesight and my dizziness and my balance, there wasn't 'oh well if this doesn't improve we can do this or we can do this or this'." – Stroke Survivor

"Probably would have been helpful, particularly, for me to have someone who could sit down with you and go through you know, like the whole discharge plan that you get, so I got the paperwork in front of me with all the medical notes, but it would have would have been handy to have had someone sit down and say, ok, your wife had a stroke. Blah, blah, blah, blah, blah. Now the impact on her eyes is x y z. This is what you could possibly expect."
- Carer of stroke survivor

Many also expressed that they would have liked clear and specific guidance on what to do or what professionals to see after discharge to address their vision problems, as well as where to go for guidance on driving requirements and assessment. This was a reoccurring unmet need amongst the majority of stroke survivors interviewed, as they often stated feeling overwhelmed or lost when trying to seek out vision care without guidance, often leading to a delay in attaining appropriate vision care.

"Yes, it would have made me feel a lot better to know that there was some pathway that I could follow. Even if I didn't follow it completely rigidly, I had some skeleton of a framework that I could work with. I turned up at my GP and she knew nothing, and we knew nothing. It was all just, everybody just went into a panic." – Stroke Survivor

"It was just all of my own doing, a lot of my own research. I would have loved to have seen a pack or something given, you know, not just to me, but to anyone else with vision problems. Just to say, you know, 'call Guide Dogs' and that sort of thing is not really an after-care package." – Stroke Survivor

Some variability in preference for timing of information provision was evident, typically depending on the general wellness of the stroke survivor. Most expressed that too much

information during the acute stages of care would be too overwhelming or difficult to understand, while those who had vision problems as their primary impairment would like this information immediately.

"I think its really important to include the carers in that vision care experience because I couldn't really, pieces of memory were coming and going and the brain was switching back on. So it's a really tough time, it's a really odd time, you can't just, you can't really take in a lot of information. I can use bits of it but I'm sure not all of it, so I just sort of go on what I can remember." – Stroke Survivor

"We saw something on TV about prismatic lenses and the training that they were doing with that. That was when we went and saw the optometrists that mum had been working at that time, because we thought something like that might have the potential to help, but of course, by then it was probably too late. The plasticity in my brain was not really there anymore."
– Stroke Survivor

It was suggested that having this information provided in writing and/or discussed with the carer would be helpful in negating the impact of confusion during the acute stages of stroke recovery. All stroke survivors and carers agreed that some repetition or follow up of this information prior to discharge or during early rehabilitation would be particularly useful and make them feel better supported.

"I thought back to that and I thought, wow, I wish I was in there again, because what I would've said to that is: because of the operation your likely to get cataracts, but can I get that cataracts treated or is there damage to the eye where I can't get that treated? So that would've been something that I would've like to have asked. Or you know, been able to call back at a later point and just ask some questions that might have come up for me."
– Stroke Survivor

One stroke survivor included themselves in a 'lucky draw' for 12 months of post-stroke support as a part of an independent research study and was chosen. The stroke survivor and carer felt that this was an invaluable service that helped them both to better navigate the long-term rehabilitation administratively and emotionally.

*"We got it for one year, over a year. We had someone ringing me once a month to see how we were traveling to find out whether **** had any falls, any difference in his vision. Thorough investigation, and we even had a diary we used to keep. The help we received that once a month phone call was invaluable. Kept me sane." – Carer of stroke survivor*

7.6 BARRIERS TO VISION CARE

7.6.1 Access to vision care

A number of barriers to attaining appropriate vision care were discussed in relation to access to vision care, delayed diagnosis of vision problems, knowledge of the treating health professionals and the stroke survivor's own physical and cognitive deficits. Difficulty accessing vision care was highlighted by stroke survivors in regard to location, with several living in regional or remote areas of NSW and one person having their stroke overseas and receiving initial acute care in Indonesia before returning to NSW. Those living in regional areas of NSW discussed issues such as their vision problems being dismissed or misdiagnosed during their hospital stay, information pertaining to their stroke and/or vision problems not being carried over during several hospital transfers and what they felt was a lack of knowledge or training amongst health professionals specific to post-stroke vision problems.

*"And then being in an area where it was a regional hospital, I was appalled. The way the ******** Hospital treated us. Or didn't. They were so dismissive of it, as I told you, and I haven't written a report to them to say that I thought it was bad. I just thought it's not their fault. They're understaffed and overworked. We just need more doctors in the country."*
- Carer of stroke survivor

Another issue discussed in relation to regional residency related to difficulty accessing vision care after discharge due to the physical distance to these services and not being able to drive or access public transport. Due to the limited amount of services available in regional and remote NSW, stroke survivors also found that wait times were longer due to increased demand on the few services available.

"I got a letter this year, I think it was in February, saying that I am on the waiting list and they will ring me with the appointment, if they get a cancellation, and they will let me know...the GP said she was going to ring them up again and keep pushing to try and get that appointment to come up. But other than that, that's all it was." – Stroke Survivor

However, wait time was also an issue for stroke survivors living in major cities, with the onset of the COVID-19 pandemic adding to this issue.

*"the only barriers were the normal sort of; how long will it take to get an appointment? While COVID is like it is? And I was lucky there a couple of times, because Professor ****** couldn't see me for three months, and then there was a cancellation, and she could see me within two weeks." – Stroke Survivor*

"But, um, you know, and I would have liked to have known, I guess, one way or the other earlier, but Corona happened. Yeah, you know, no one can go anywhere anyway."
– Stroke Survivor

The financial burden of accessing vision care was also discussed by some stroke survivors, stating that they chose not to pursue vision care due to cost, or discontinued because they did not feel the cost was justified in regard to private vision care. Three stroke survivors were able to access vision care through the NDIS, two through their private health insurance and one through their DVA entitlements. Those that had this added support expressed said they felt very fortunate as they would not have been able to afford the same level of care without this financial support.

"Because my balance had come back, and I could walk better, although not brilliantly, that I would be able to figure out the new house myself. And my partner was quite helpful with that. So yea, I was told I would have to pay for everything because I wasn't on a pension and I wasn't eligible for a pension." – Stroke Survivor

7.6.2 Delayed visual diagnosis

Delayed visual diagnosis was another barrier to care that stroke survivors related to a lack of awareness of post-stroke vision problems, being a young stroke survivor and the fact that vision impairment is a 'hidden' disability. Lack of awareness of post-stroke vision problems was expressed as an issue amongst both stroke survivors themselves, their families and health professionals. Stroke survivors and carers describe not 'picking up' on the stroke because they did not associate vision problems with stroke.

"The other thing that was negligent of me, but I have no education, I woke up and could not see, I should have called the ambulance because that is a strong symptom of stroke…and I think there needs to be a lot more awareness campaigns. There aren't just four things that cause you to be demonstrating the existence of a possible stroke."
– Stroke Survivor

Many also experienced this when presenting to front line care such as general practitioners and emergency department staff with vision loss as their primary symptom of stroke. Six stroke survivors presented to the emergency department with visual complaints as their primary symptom or in combination with headache or nausea. All but one of these stroke survivors had a delayed stroke diagnosis of three days or more. Delayed stroke diagnosis was caused by inconclusive CT scan or misdiagnosis. One stroke survivor presented to an ophthalmologist with double vision, two presented to their general practitioner, and one to

their treating endocrinologist with loss of vision. Delayed diagnosis of stroke by more than one week was experienced by five stroke survivors, of which all had visual disturbance as their primary symptom.

Twelve stroke survivors experienced delayed visual diagnosis and the timing of visual diagnosis ranged from 1 week to 12 months post-stroke. Stroke survivors who experienced delayed stroke diagnosis felt their deficits could have been significantly reduced had they been diagnosed sooner, while all stroke survivors expressed the importance of increased awareness of stroke-related vision problems amongst the general public and health professionals.

"There were two big barriers, one was the relocation, and one was that I didn't present like a normal stroke victim. I turned up and yes, I was agitated, and I couldn't walk straight, but all my limbs, I had grip strength and everything I could smile, I was talking I was coherent. So, I don't think they took me on board fully as a stroke patient." – Stroke Survivor

Those who were under the age of 45 at the time of stroke seemed to be more likely to experience delayed diagnosis of stroke if they were conscious at presentation, with all three stroke survivors in this group experiencing misdiagnosis and a delay in stroke diagnosis of more than 3 days. Misdiagnosis was typically migraine or drug overdose, with one stroke survivor having history of migraine with visual aura who had a delayed stroke diagnosis of seven days.

"And then they come back the next morning to see me, by this stage I had a splitting headache. My vision wasn't great at all. It was very blurry and hazy. And I had lost peripheral vision. So homonymous hemianopia… he then still was on the drug path. And he had medical students there. And he said, this is what happens to people that OD" – Stroke Survivor

Stroke survivors often expressed frustration due to the fact that their vision problems could not be seen or recognised by others and felt that this 'hidden disability' often inhibited their ability to attain timely and appropriate vision care.

"Because, but because I look normal, and I sound normal. Um, it was really difficult because I do actually have a lot of deficits." – Stroke Survivor

7.6.3 Health professionals

Barriers in relation to healthcare professionals were discussed with reference to health professionals having a lack of knowledge about stroke related vision problems, specifically not being able to offer any management options relating to vision problems, or not being able to appropriately manage vision problems in relation to other aspects of rehabilitation.

“And I remember once that a nurse came in and gave me medication and she’s standing on my left hand side, so I really can't see her. And I said, I'm sorry, I really can't see you. And she huffed. And then she put the tablets down. And she said I've put them on there. I went mad. I said, why don't you look up above the bed? And you'll see that I'm visually impaired.”
– Stroke Survivor

Many interviewees also describe encountering health professionals who were dismissive of their visual complaints. In several instances, stroke survivors or carers would mention their vision problems to staff or request a vision assessment, only to be told that they did not need it, there was nothing that could be done or that their experience was ‘normal’ post-stroke.

“At first I remember, when I was saying “oh my eye is really weird”, I don’t actually know what that was, but I remember one doctor looking at it and saying “oh it’s fine” and I’m going “no it’s not”. So it’s kind of like you kind of have to fight for things some times in those sort of situations.” – Stroke Survivor

A lack of support or guidance in relation to vision problems from health professionals was also a barrier to care with many interviewees expressing that they felt they were given no help in attaining vision care and that seeking it out themselves was overwhelming and confusing. Empathy was expressed for those who did not have support from a carer or family member or did not have the capacity/ education to seek out vision care for themselves as this was not something that was provided by health professionals in stroke care.

*“Absolutely atrocious. But this is not aged care. This is, you know, anyone that's had a stroke. I mean, it's shocking. Just no help out there. If we hadn't found this wonderful ophthalmologist here in *******, I would feel as if I was, excuse the terrible pun, flying blind.”*
- Carer of stroke survivor

Further to this, interviewees felt that stroke health professionals through all stages of care seemed to be ‘ticking boxes’ in relation to the care provided, often not listening to their specific concerns but instead taking a ‘one approach fits all’ to stroke care. Several stroke survivors describe being sent for assessment and rehabilitation with a number of allied health professionals for deficits that they did not have, but had no care provision in response to their visual concerns.

“I think it's a classic thing about, you know, what's important to the patient, as opposed to what's important to the health professionals. You know, as I said, a classic, multidisciplinary team. So everybody was doing their little bit. And nobody was looking at me as a whole person.

And, you know, what my concerns were, which they should do in rehab. That's the whole point of rehab, you know?" – Stroke Survivor

Poor interdisciplinary communication was also noted as a problem during hospital care whereby participants felt that their complaints or conditions were not made known to all health professionals involved in their care.

"I don't know if the OT's and physio's work quite closely together but um, it seemed like the way that its set up is like he has his OT session, then he has his physio session, so I'm not sure how much interdisciplinary communication there is between those professionals. I don't know, I mean obviously they read the notes, they have the hospital notes and that sort of thing, but I think from a visual perspective, I don't think it exists." – Carer of stroke survivor

7.6.4 Other stroke related deficits

Finally, the deficits of the stroke survivors themselves were expressed as a barrier to vision care in several ways. Firstly, many were unable to communicate their vision problems to carers or health professionals due to deficits in speech or cognition caused by the stroke. Others said that they were initially unsure of how to explain their vision problem, or unsure if it were real or imagined. One carer explained how she had to act as an advocate for her husband to receive vision care following his stroke due to aphasia limiting his ability to communicate with health professionals:

"If you can't speak for yourself, as long as you have an advocate who is maybe a little on the pushy side (laughing) you're ok. But if you're old or you have some sort of mental or brain injury, so you can't communicate very well, you are automatically behind the eight-ball in the hospital system." – Carer of stroke survivor

A common theme amongst almost all survivors was that their vision problems were often not seen as a priority initially by themselves or their treating professionals due to more severe or more urgent health issues associated with their stroke. Some even ignored or denied their vision problems out of fear or frustration; preferring to not know or not have to deal with yet another diagnosis.

"what happened was eventually, I went to the GP and I started to tell her that my eye sight was not bothering me, because I was so terrified of all the other things that were happening I started to forget about the eye sight and thought 'well I've just got to live with this'. And I started to negate it I guess". – Stroke Survivor

Also, in cases where there was visual neglect, several stroke survivors were simply unaware of their vision problem and so didn't feel the need to seek out vision care. An interview performed with a stroke survivor and their carer demonstrated the difference in perception between carer and patient regarding the severity and impact of visual neglect:

"Carer: But continuously you say that your vision is not worse?

And he doesn't seem to be affected by it

Stroke survivor: No

Carer: …regardless of what he has been diagnosed with.

Stroke survivor: And I think it's getting better (laughing)"

– Stroke Survivor and their carer

7.7 IMPACT ON DAILY LIFE

7.7.1 Physical impact

Stroke related vision problems had a number of impacts on the daily lives of interviewees, mainly relating to physical, emotional and recreational aspects; however several stroke survivors also noted that this compounded the impact of other impairments. Physical impacts mainly related to issues with mobility whereby stroke survivors felt they now had poor balance, sometimes bumped into things or people, did not feel confident to cross roads on their own or walk in the dark.

"I don't cross roads myself. Doesn't matter how much I scan. I know that you might get halfway across and you're stuck." – Stroke Survivor

*"Once they came over to get ******, he was in the habit before COVID of walking out to the local shops, to the Woolworths the most he could buy is bananas, because nothing is really, not recognizing the labels anymore. But he'd go off independent, then one day I realized when he came back one day, he said somebody's ran a red (traffic light), and nearly ran him down. Quite dangerous." – Carer of stroke survivor*

Issues relating to personal care included eating, which was more of an issue for those with visual neglect, one stroke survivor described issues identifying hygiene products in the shower and others discussed having to move in with their parents again to be cared for.

"Even in the shower, if I don't have the handrail to hold on to, or if I go to grab something and I think oh yea it's there but then it's not really, it's off to the side. So, you sort of um, moving

your hand around trying to find it even though you can sort of see it, but it's not where it should be." – Stroke Survivor

"the depression side of it is pretty high too. A lot of time, like I'm back in my parents' care with my son, so we both had to move back with Mum and Dad so you don't have your own place anymore, and I'm 42 now living with my parents who have to care for me. Yea."
– Stroke Survivor

Some stroke survivors had children that were still dependant and said that they felt their vision problems impacted some aspects of providing care. Most interviewees were retired at the time of their stroke, however those that weren't felt that their vision impairment made performing their job more strenuous and required them to make adaptations to their work environment as well as how they carried out their role. Few stroke survivors also spoke about their need to adopt a particular head posture to compensate for visual field loss or double vision, which in turn caused them neck pain.

"You know, there are things you can laugh at, and then things that I get very, very depressed about like yesterday. You know, I was a seamstress, years ago in London. And so sewing has always been a thing for me. And following very complicated patterns. Now, I cannot work out a complicated pattern." – Stroke Survivor

"I went back to work as a lawyer, about one month, but only on a part time basis. And I'm still part time. Because I get extremely, extremely tired from my eyesight, not, like in scanning and reading and being on the computer." – Stroke Survivor

"We had a physio come to work recently and wanted to change how computers were, where they sat. And I said, I really prefer to have my computer on my right side. Just because if it's on my left, it just makes it that bit harder. To make sure I can see everything…"
– Stroke Survivor

Driving was the most widely discussed activity that was impacted by vision problems. Many associated their inability to drive with a loss of independence and mourned the loss of this entitlement. Several stroke survivors disliked having to rely on other people to drive them to places and said that they participated in less activities because of this.

“Well, the fact that I can't drive. I was such an independent person. I would just pop in the car, go visit friends. Go off to shops. I'm now very nervous and have been ever since, just going to the shops. I mean, I really don't go anywhere on my own.” – Stroke Survivor

7.7.2 Impact on recreation

The social lives of all stroke survivors interviewed were impacted in some way by their vision loss. Many describe impacts on their romantic relationships, as well as difficult social situations where they did not see or recognise an acquaintance in public and have to try to explain their vision loss.

“Well the other funny story I have, I was in a fairly crowded take away. And because I, I don't constantly look down to my left, there was a small, mentally handicapped lady. I must have bumped into and she punched the hell out of me. You know, I didn't know what was going on. It was just very odd. It wasn't her fault I mean. I was the one who wacked into her.” – Stroke Survivor

Others feared going out and tripping or falling in public because this was seen to be embarrassing or struggling to maintain focus/ eye contact during one on one conversations.

“I've very rarely been ill, was always terribly independent. You know, would travel wherever. Now I'm very fearful of going anywhere. Probably because I'm going to miss a step and fall and be really embarrassed that people try to help me. Yeah. But the vision is, is quite devastating.” – Stroke Survivor

Performing hobbies such as sewing, participating in committees, playing an instrument, writing and sports were all provided as examples of activities that interviewees enjoyed doing but now found difficult or impossible as a result of their vision problems.

“I can read I can crochet, watch, watch the television. But the movies it's a lot, I'm a great movies fan, and I went to see Andre Rieu with the big 3D screen. And that made me very very ill.” – Stroke Survivor

Many stroke survivors mentioned that this was particularly an issue because they were recently retired and had hopes of pursuing hobbies at this time in their life that they did not have time for previously. Reading small print or long text was also described as difficult for most stroke survivors.

"I retired at 70 and it happened at 70. But I was very, very active when I, when I retired because my mother had just died. So, I started on the piano again, I was doing exams, and I took up golf and I was very, very active." – Stroke Survivor

"Stroke survivor: As a journalist, I used to read every paper in sight. I don't bother to subscribe to a newspaper anymore.
Spouse: If we were in a coffee shop that's got a newspaper, I will often open it up in front of us and read various sections, but he wouldn't have a hope. So, it has impacted him very much."
– Stroke Survivor and their spouse/ carer

7.7.3 Emotional impact

Depression was widely experienced by stroke survivors, predominantly in the first year post stroke. Many recognised this as a consequence of stroke and were advised by health professionals that this might occur, however, they felt that their vision impairment contributed to this.

"it feels like I'm in a big patch of de-realisation and the whole thing has placed a big strain on my relationship. I get terrible bouts of depression I suppose. I've never had depression but that's what it feels like, I suppose. The social worker that came and saw me in the hospital said that sometimes after a stroke that you can get depressive episodes, uh I didn't know, she didn't tell me what to do about it. And I just battled them and battled them and battled them, until a few weeks ago I just couldn't battle them anymore. So I think that my whole stroke journey, certainly the psychological aspect and the visual aspect, I was not particularly happy with."
– Stroke Survivor

Stroke survivors described feeling disconnected from the world and their loved ones as a result of their vision loss.

"I think a referral to a psychologist would have been extremely beneficial. I've finally done that for myself, I saw my GP about six weeks ago and I said that because I can't see properly, I feel like I am disconnected from everything." – Stroke Survivor

Interviewees also described their loss of independence as a negative impact resulting from their vision problems as they now had to rely on other people to assist them with daily activities such as cooking, shopping, reading mail and getting to places. Many felt as if they were a burden to their carer(s), particularly when it came to driving as this responsibility fell on partners, children or other family members.

"Five months is quite a long time not to be able to drive. And it puts strain on my wife for one thing, because she has to do anything that involves driving." – Stroke Survivor

"I can't drive my kids to sport and I can't like, it's just, it was very, very hard, because I was such an independent person. Yeah. And I would never ask for people like, I never asked for a lift." – Stroke Survivor

7.7.4 Vision problems compounding other impairments

A number of participants mentioned that their visual impairment was of particular concern in their day to day life because of other issues such as hearing loss and general frailty from age which meant that prior to stroke they relied on their sight more heavily.

"vision is extraordinarily important. And particularly, and I've got to say, and I haven't said this before, but particularly for me, also, because I'm deaf in one ear. So if you start taking away my vision, as well as my hearing, it's, it's really scary." – Stroke Survivor

Pre-existing eye conditions were common amongst older participants, particularly diabetic retinopathy, glaucoma and refractive error. Having had reduced vision prior to stroke, additional visual problems generated fear of blindness amongst stroke survivors and added anxiety around worsening of their already compromised vision. One carer explains how diabetic eye disease complicated the post-stroke driving assessment and delayed the stroke survivors return to driving:

*"she couldn't OK the driving at that time, and then the next time we went there was some macula swelling from his diabetes, which can be a result of changes in his insulin and sugars through the hospital stay. So that has settled, so I think the last time we went to ********, the swelling was getting better, so it was just a matter of time of re-establishing that normal blood sugar level for the body, the new normal." – Carer of stroke survivor*

Table 7.1 Additional participant quotes correlating to the five major themes identified through analysis of interview data.

Formal care
a) Vision assessment
i. Yeah, they sent me to, they have people there (rehab) who are, sorry, who are not optometrists but like, technicians? I can't remember what they called them. They didn't call them optometrists and then weren't ophthalmologists. But they were basically people who could do that. So they did an assessment of me and looked at all of that.

b) Management & Referral
i. It was kind of incidental. They were always trying to get me to think about scanning and so it wasn't specifically, you know, practice turning my eyes on my head whenever we practiced making me choose the right place in the room to sit. At uni for example, that sort of thing but it wasn't like now we're going to sit down and do some visual training. It was just incidental along with everything else.
*ii. You know, with the vision. ****** gave me this machine with cellophane in it. And, you know, I in the dark, I had to look at that, for 40 minutes. I think that helped, and I got into a whole heap of... Um, there's a company up in ******* that do natural vision exercises and stuff.*
*iii. This is my daughter helping me, she said someone (in vision care) that understood the cognitive deficits that I've got. And that's I think what I said to you earlier, that ****** were not getting the neurological side of it.*
iv. If I am going to read, I need to keep my mind active. But I do most of my reading on the computer in a large screen now.
c) Impact on rehabilitation
i. When I went to my GP um, I had my glasses that I picked up, my balance had improved a little bit but it's still out, I still have a lot of falls and bumping into door frames.
d) Unsatisfactory care
i. Because they were treating me for stroke and all that sort of thing. And then I heard this... I heard them saying oh, I think somethings wrong with your vision or something like that? And looking not, not exactly guilty, but realizing that they hadn't picked it up.
e) Satisfactory care
i. Which was prism glasses or surgery. We ended up having surgery. There's not much more. I don't think the general nursing staff in the ICU could have done much.
Information
f) Received
i. She did tell me, I remember the lady in the ophthalmology department did tell me that, you know she went through 'this is what we think you've got' and she did go through all the dangers of the operation but she just listed them really quickly and I didn't really get any information from her. I know I should've asked but you know it is really difficult when your mind sort of is hard to focus on one thing.
*ii. I said to my next of kin, ******, I said I can't believe, you're the one that's told me everything that's happened, they're not telling me anything. They did try but you know I*

wasn't remembering anything for a long time. And I guess they don't really know what the time is that you're going to remember.
iii. But he just said they do the visual fields. They tell you what the deficit is. And then they send that to the RTA and the RTA stamps and says, yes, you can drive or no you can't depending on the actual range of loss.
g) Preferred
i. Yea so what I want to see is, if you have a stroke you are impaired in different parts of the body, if your vision is impaired then you know straight away. But even if your vision is not impaired, it would be good to know how does stroke affect the vision? So that when you go out the hospital you can look for the signs. Because according to my understanding, you can be having a lot of mini strokes even after you leave the hospital. And that mini stroke, how does that affect the vision?
ii. And being in a hospital, you know, yes, some information should be given, but there should be some follow up, because you're so overwhelmed in hospital. To be honest, I wanted to get the hell out of there, I had no sleep.
Feelings towards care
h) Negative emotions
i. So I was in overnight, and I don't think I slept at all, at all. Um, because I was just absolutely freaking out and catastrophizing everything.
ii. She also recommended the brain training quote unquote, app called Lumosity as being worth you having a go. But nothing else. And we've been I guess quite surprised that there was nothing else. Particularly for people with occipital strokes where eyes are the biggest problem.
iii. And I sat in shock in the surgery after this, he said you've had a mini stroke that has affected your, your eye and your eye is, how do I call it? The visual potentials…?
i) Positive emotions
i. Uh, I think they did all that was possible at the time and I consider myself very lucky that I can still see and get around and that sort of thing.
ii. I think it's I mean, it's to me, a lot of it's about letting patients know that there's a positive side. Because the mental battle so hard. And if they can, if there can just be this effort to try and keep them positive that's gonna help so much in their recovery, because I found the more I was positive the better the vision was.
Barriers to care
j) Access to vision care

i. *Between those two, we're presuming I'm not having another stroke. Or if I am, it's extremely unlucky. But all of this took a while. Because like I said it was at the height of COVID. For quite a while they weren't doing any of these procedures, because they were elective surgery.*
ii. *I'm not sure if it is because I wasn't in hospital here and it has been much slower but outpatients certainly you don't know where you stand and the time frame to get that assistance is too long to keep progressing.*
iii. *So when they rolled me into the ER yeah I was able to, they probably thought who was this smart arse telling me he's got a left lower quadrantanopia? Well, that's all I picked up. I've got a bit of upper field loss here. But it's not so bad.*
k) Delayed visual diagnosis
i. *No, no, I just, to me I just needed to get him into bed, and he'd be okay. Did not for one second think he had the stroke. To me old people had strokes. So, I tried to get him into bed. And I couldn't.*
l) Stroke survivor deficits
i. *Interviewer: And did he himself ever say to you that 'my vision is not good'?* *He probably did. But he couldn't, get it out. And once we found the ophthalmologist, he would talk to us and he would say 'I told you'.*
ii. *And he really didn't want to go, he didn't want to go to the eye specialist because if it was some other thing and it was going to be big, and affect another part of his life, he didn't want it to happen.*
Impact on daily life
m) Physical
i. *But it was really hard, like, I remember, because I couldn't drive. And I've got kids. I remember walking down to like the yoga studio, and walking back in the dark, and it's really disconcerting and scary when you don't have that vision.*
n) Recreational
i. *Which was devastating. I mean, he was so upset about that. But later, as times gone on, so 12 months down the track, he said, I'm so glad you're driving, to me, because he said I just wouldn't be able to find my way around anymore.*
ii. *And this is a thing that affects me, because I love people. But socially, if I'm sitting talking to people, concentrating, my eye goes really strange. And I get really funny feeling. And it's the concentration with my eyes with the people. And I've even had very, very bad attacks.*

iii. *Well at this point I'm not able to do any of my hobbies, I'm not able to read… I can't cook, I can't drive, basically I can't really…I can do personal care which I wasn't able to in the beginning so I've made some improvement there. I can't go shopping, there is no way I can go shopping. I can't um, yea I can't do what most people, well I can't do what I considered was normal life.*

iv. *Anything, and especially when there's a lot of visual processing involved, it just feels harder. And it quickly leaves me quite mentally tired. Now, this is deeply frustrating to me, because I'm a newly retired academic, wanting to do lots of reading and writing and learning, what I do. And it's just not easy.*

v. *Because I am a pharmacist by profession, and I just retired and after I work I had the stroke, how good is that? Try to relax and I have a stroke!*

o) Emotional

iii. *I was such an independent person. I would just pop in the car, go visit friends. Yeah. Go off to shops. I'm now very nervous and have been ever since, just going to the shops. I mean, I, I really don't go anywhere on my own.*

7.8 DISCUSSION

This qualitative research study explored the experience of vision impairment and of vision care following stroke, for residents of NSW, Australia. It aimed to provide insight into the experience of post-stroke vision impairment for those living and receiving care in NSW and to better understand whether current care practices are meeting the needs of these patients. Overall, the experiences of the visually impaired stroke survivors indicated unmet care needs across all stages of stroke recovery. However, reports of sub-par vision care were often coupled with positive recounts of other aspects of stroke care or vision care at different time points. Interviewees often expressed gratitude and refrained from directing criticism to specific health professionals or aspects of care practice, but rather resolved that issues of resourcing and overall systematic practices were responsible. Five overarching themes emerged from discussion of post-stroke vision impairment during the semi-structured interviews (Figure 7.1). These themes covered aspects specific to the experience of vision care provision following stroke; 'formal vision care', 'information' and 'barriers to care', as well as the personal experience of vision impairment during stroke recovery; 'feelings towards care', 'impact on daily life'.

Biographical narrative interviews provide detailed information about the experiences and perceptions of the interviewee.[268] This was important in order to gain greater depth of understanding of current post-stroke vision care provision in NSW, and of stroke survivor views on the vision care they received. It also allowed for greater insight into the experience of vision impairment after stroke and it's impacts on short- and long-term recovery. However, this research method has potential limitations that should be considered during the interpretation and application of the data. Firstly, such interviews may be prone to bias both from the interviewer and interviewee.

Both parties may wish to highlight or diminish certain issues and so direct the narrative of the interview accordingly. Bias may also stem from the interviewees through the voluntary nature of participation. For example, those who had a particularly negative experience may be more likely to participate in order to get their complaints heard. To mitigate this, separate independent analysis and coding of interview data was conducted for five transcripts (>20%). This helped to ensure validity in the coding process and of the codes themselves.[268] It is also of note that the majority of interviewees also recounted positive experiences in relation to their stroke and vision care, balancing the negativity of some aspects of care with positive recounts of others. Another potential limitation of interview data is that it may not be broadly generalisable due to the small sample size. To counter this, we continued to conduct interviews until the point of data saturation. In line with this methodology, no quantitative target sample size was set, but rather recruitment was to continue until saturation was reached.

Discussion of formal vision care provision made evident issues around the timing of initial vision assessment. For many stroke survivors, assessment came much later than preferred, which exacerbated feelings of anxiety regarding their visual condition. This delay in vision assessment echoes reports from the previously conducted stroke survivor survey (described in Chapter 6) where the majority of respondents indicated having their first vision assessment more than six months post-stroke. The location and timing of initial vision assessment reported by interviewees also coincides with reports by health professionals regarding access to specialist eye care staff, and low numbers of eye care professionals included in stroke care teams. The importance of early vision assessment is reinforced by the interview data, whereby stroke survivors and their carers report feeling that having a vision assessment sooner would have aided earlier access to treatment and potentially reduced the long-term impacts of their vision impairment. In several cases, stroke survivors or their loved ones had reported vision problems to their treating health professionals early in their stroke recovery but were

dismissed or were told that this was 'normal' following a stroke. This lack of attention paid to vision problems on stroke units is an issue reported by stroke survivors in other countries such as the UK[36,111] and Norway[220] whereby similar delays in assessment were experienced.

Management of vision problems was a key area of disappointment for the vast majority of stroke survivors and their carers due to a lack of management options provided, and no onward referral to an eye care professional or support service. A small number of interviewees received inpatient vision rehabilitation or management which was provided upon the request of a family member, or in combination with other rehabilitative treatment. The lack of visual rehabilitation described again supports the reports provided within the stroke survivor survey (see Chapter 6). A qualitative study of stroke survivors with vision impairment in Norway also describes the concerns of stroke patients discharged from hospital without offer of any visual rehabilitation or referral,[220] highlighting inequalities that exist in stroke care for those with vision impairment as an issue that is not unique to Australian healthcare. The lack of management provided for vision problems had a significant impact on overall stroke rehabilitation for most participants, specifically by adding complexity to walking and physical rehabilitation as well as increased fear and occurrence of falls. It is well documented that vision impairment, particularly visual field defects, increases likelihood of falls[123] and impacts gait[37] in older people. Evidence also indicates that fear of falling reduces the likelihood of individuals participating in physical activity[269] and hence causes long-term reduced physical capacity. If vision impairment impacts physical fitness in a general population of older people, it is reasonable to assume that impact is far greater when compounded by stroke. It then stands to reason, that visual rehabilitation should be considered of equal importance and given equal attention as physical rehabilitation by stroke care providers.

Unsatisfactory care was often described by interviewees in relation to health professionals perpetuating the power imbalance between patient and care provider. Examples of this included health professionals treating stroke survivors with vision impairment as incapable of understanding information about their condition or relating to their management. Another example provided described how treating health professionals were discouraging about vision problems improving, suggesting that there was nothing that could be done to help manage the condition, or providing misinformation regarding potential recovery of the condition. Occurrences like these are of great concern, as health professionals should be aware of the existing power imbalance between themselves and their patients and aim to provide care or advice where they requisite knowledge and refer onwards where they don't. Similar accounts have been made by other stroke survivors where they were told nothing more could be done

for them, which in turn reduced their confidence in their treating health professionals.[220] In contrast, a UK study describes the empowerment felt by stroke survivors who were provided patient-centred care,[111] where they were able to set goals during their rehabilitation, based on their concerns and priorities.

Another area of stroke care in NSW regarding the provision of appropriate information requires improvement. Most stroke survivors were provided general information about stroke and were advised not to drive if vision problems were identified. Several interviewees with unidentified or undiagnosed vision problems, did not receive this advice and continued to drive once discharged. A lack of adequate and appropriately delivered information can be harmful to the individual and the community but was also reported to cause undue confusion and distress to stroke survivors and their loved ones. In other studies of stroke survivors with vision impairment where stroke survivors were given no or inadequate information specific to their visual condition,[27,36,220] this was identified as an unmet care need and occurred more frequently in hospitals with non-eye trained staff.[111] Information provided verbally was described as difficult to retain and placed greater reliance on family members, further reducing the stroke survivor's sense of independence. It is suggested that stroke health professionals seek to provide information specific to the individual's visual condition, give patient-centred strategies to manage and adapt, and direct appropriately to available support services. This information should be provided in a format that best enables the stroke survivor's understanding and that allows them to refer back to this information as needed.

When expressing feelings experienced about the vision care they received, recounting of negative emotions outweighed that of positive emotions. Stroke survivors and their carers describe feelings of confusion and anxiety in relation to the unknowns of their visual condition and how to obtain help. Interviewees often reported feeling vulnerable during health assessments following their stroke – particularly when there was poor or mis-targeted communication. Feelings of discontentment and/or frustration were also expressed in relation to experienced vision care practices and/or treating health professionals, as a result of repeated unmet needs. These feelings seem to be a common experience amongst these stroke survivors with vision impairment during their recovery, as other qualitative studies of similar populations have indicated generalised feelings of worry, distress and anxiousness.[36,111,220] This is often followed by feelings of acceptance and/or apathy in the later stages of stroke recovery, as has been indicated both by the stroke survivors in this study and in others conducted in Norway[220] and the UK.[111] These emotions are seemingly expressed when

reflecting back from their current understanding and adaption to their visual condition and changes in sensory capabilities.

Several barriers to successful vision care were identified through the personal experiences of participants. Access to vision care was limited by a number of factors including cost of vision care, living in regional or remote areas of NSW, wait times for appointments and the onset of the COVID-19 pandemic. Cost of vision care was viewed as an issue by stroke survivors when they were not given appropriate direction or referral and had to pay for consultations with several health professionals before finding the most suitable to assist with their condition. Cost was also an issue for those who were not provided any visual rehabilitation as an inpatient and so had to seek private eye care. Studies estimate that Australians with vision impairment incur a personal cost of approximately AUD$5,300 per annum as a result of their vision problems.[270] For those that could not afford to seek private eye care, wait times for public ophthalmology services caused significant delays in access to vision care, and was an issue for those both in major cities and in regional or remote areas.

Major Sydney hospitals providing public ophthalmology services currently report wait times for first appointment between 386[271] and 124[272] days for an initial appointment. As post-stroke visual conditions are generally considered non-urgent by the time stroke survivors are returned to the community, and also receive even less priority when there is no pharmaceutical or surgical intervention available, these patients are likely put at the end of waitlists during triage. While this issue is evident in major cities of Australia, limited specialist health services in regional and remote Australia is also a well-known issue.[273] With the onset of the COVID-19 pandemic, wait times for public ophthalmology services in NSW have further increased, with procedures such as cataract extraction having an average wait time of 330 days (98 days longer than in 2019).[274] The COVID-19 pandemic further contributed to extended wait times in access to specialist care, as non-urgent services were completed stopped for extended periods of time during strict lockdowns in 2020 and 2021. Until the removal of all COVID-19 restrictions to NSW public health services in early 2022, services such ophthalmology clinics were running at reduced capacity, again exacerbating the wait times experienced by patients. Improved public eye care service delivery across both major cities and rural areas of Australia should be a key area of focus for the Commonwealth Department of Health and Aged Care moving forward. While this is not an issue that can be addressed in a short time frame, improved provision of inpatient vision care and appropriately targeted referrals provided to stroke survivors prior to discharge, may help to improve timely access to services for these patients.

Delayed diagnosis of stroke was also a barrier to care for those with visual problems as their only or primary symptom, often stemming from a lack of awareness of stroke related visual symptoms among stroke survivors, their families and treating health professionals. These trends have been made evident in other populations of occipital lobe stroke patients, resulting in delayed stroke diagnosis and limiting eligibility for thrombolysis therapy.[245] Delayed diagnosis and misdiagnosis of stroke appeared to be more common among young stroke survivors with stroke related visual symptoms. Misdiagnosis of stroke as a possible migraine with aura or drug overdose, presents as a common theme amongst young stroke survivors in this study and in others,[220,235] again highlighting a significant gap in awareness amongst the general population and health professionals alike. Delayed visual diagnosis was also a common barrier to accessing vision care, often described in the present study and in other international studies[111,220] as a result of vision impairment being a 'hidden disability'.

The other stroke related deficits experienced by interviewees also acted as a barrier to vision care, particularly in the earlier stages of stroke recovery. Understandably, more urgent or more severe health issues took precedence over visual problems during the stroke recovery journey for many participants. For others, their vision problems were a key priority or concern, but they were unable to communicate this to their treating professionals due to the stroke affecting their communication skills and/ or cognition. Standardised vision screening for all stroke patients would help to mitigate this issue, as assessment and subsequent provision of care would not be dependent on patient reported concerns, but rather investigated by health professionals as a normal part of stroke care.

7.9 CONCLUSIONS

The data gathered from these interviews collectively indicates a large unmet need for stroke survivors with vision impairment. The experience of post-stroke vision care in NSW for participants in PRECiS: Stage One is littered with gaps in care practices and barriers to care across all stages. This prevents appropriate and timely diagnosis, provision of management and information, as well as long-term support and follow-up. The impact of vision impairment on stroke recovery and daily life is profound, affecting both the physical and emotional wellbeing of stroke survivors. The variable nature of care across different stroke care facilities, highlights the inequality of post-stroke vision care at present in NSW and further emphasises the need for a standardised vision care framework for stroke survivors. A framework rather than a single protocol is needed due to the diversity of care settings, visual conditions and stroke severity experienced by stroke survivors. Such a framework would ensure that current

gaps at all stages of post-stroke vision care are corrected and help address the challenges inherent in the delivery of equitable healthcare in Australia. The framework should include the introduction of evidence-based strategies to improve screening and diagnosis of stroke-related eye conditions, improving knowledge of eye conditions within the stroke team, while also enhancing accessibility to specialist eye care staff. This should be accompanied by a program to increase general awareness of stroke related visual symptoms, while providing adequate resources for service delivery in regional and remote areas. Finally, better delivery of information regarding long-term care and support for eye conditions is important to assist stroke survivors in their day-to-day living and quality of life post-stroke.

8 DEVELOPMENT OF A POST-STROKE VISION CARE FRAMEWORK FOR USE IN NSW (PRECIS: STAGE TWO): METHODOLOGY

8.1 INTRODUCTION

Stroke care in Australia is largely guided by the Stroke Foundation Clinical Guidelines for Stroke Management.[52] These guidelines claim to 'cover the most critical topics for effective management of stroke, relevant to the Australian context, and include aspects of stroke management across the continuum of care'. Within these guidelines, brief mention is made regarding vision, including the recommendation that all stroke survivors should have an assessment of visual acuity, the presence of visual field deficits, and eye movement disorders. It is also recommended that during this assessment, health professionals should aim to establish the patient's eye health history and previous time spent doing vision intensive activities. No recommendations are made regarding management or interventions for post-stroke vision problems, apart from installation of solar shades for those with light sensitivity, and user training on motorised wheelchair use for stroke survivors with visual field loss. The guidelines also indicate that specialist optometry or ophthalmology services are available to provide rehabilitation for eye impairments prior to stroke survivors recommencing driving. Of the Australian states and territories, only Western Australia[246] and South Australia[247] have their own set of stroke guidelines. Again, mention of post-stroke vision problems within these guidelines is minimal and does not cover all relevant aspects of post-stroke vision care (see Chapter 3).

The lack of guidance specific to this area of stroke care indicates that the provision of post-stroke vision care in Australia is not standardised and is unlikely to be given the same level of attention and resources as other stroke related deficits. Recommendations from the Stroke Foundation Acute Stroke Services Framework[16] neglects eye care specialists in their proposed multidisciplinary stroke team composition. At present the framework recommends that the stroke team consist of medical, nursing, occupational therapy, physiotherapy, speech pathology, social work and dietetics.[16] The presence of eye care specialists in Australian stroke care or rehabilitation facilities is undocumented. However, data from the Orthoptics Australia 2017 Workforce survey[275] showed that of 136 respondents working in NSW at the time, 21 worked in rehabilitation in some capacity, while 38 identified neuro-ophthalmology to be the clinical area of their main employment. Of these, only 12 worked in regional or rural areas of NSW. More recently NSW health reported that there were 37 full time orthoptists employed in 2020, working across only 9 local health districts out of the 15.[276] This would suggest that

unlike other countries with locally trained orthoptists, like the UK, orthoptists are not typically part of the core stroke multi-disciplinary team in Australia.

Findings from PRECiS: Stage One (Chapters 6 and 7) confirm the data regarding coverage for post-stroke eye care, as the majority of NSW stroke survivors report that existing post-stroke vision care practices did not meet their vision care needs. Reports from both stroke health professionals and stroke survivors in NSW (Chapter 6) indicate large amounts of variability in current post-stroke vision care practices, specifically with regard to the timing and method of vision assessment, and the provision of interventions, visual rehabilitation and referrals. Both groups indicated that a lack of specialist eye care staff and/or services is a primary barrier to appropriate post-stroke vision care. Health professionals also indicated that the absence of a post-stroke vision care protocol or guidelines was a barrier to effective identification and management of stroke related visual conditions. The stroke survivor interviews, presented in Chapter 7, also brought to light a number of pitfalls in current vision care provision relating to delayed and misdiagnosis of visual conditions and absence of appropriate, targeted information pertaining to stroke-related visual conditions. The results from PRECiS: Stage One further indicated that while accessibility to vision care services is an issue across the board, those living in regional and remote areas of NSW may be disproportionately disadvantaged due to the limited number of services available.

In keeping with the Vanhaecht 7-phase method for care pathway design,[267] PRECiS: Stage Two follows the guidelines and objectives of the 'development' phase. In this stage, we aimed to create and evaluate a post-stroke vision care pathway based on the existing evidence relevant to this area of care provision, as well as the objective information collected in PRECiS: Stage One. In developing this pathway in consultation with the key stakeholders, we aim to address the unmet care needs identified, and hence improve existing care practices in post-stroke vision care within NSW. This chapter describes the methodology used in PRECiS: Stage Two, whereby a set of best practice statements (BPS) were developed based on the findings of PRECiS: Stage One as well as other existing evidence. These BPS were then revised and validated by an expert panel of stroke health professionals over two rounds of survey and a final panel meeting. The final output was then reviewed by a sub-sample of stroke survivors via web-survey. The results of PRECiS: Stage Two are presented in Chapter 9.

8.2 METHODOLOGY

8.2.1 Study Design

Stage two of the PRECiS study utilised the RAND/University of California at Los Angeles (UCLA) Appropriateness Method (RAM)[277] to develop and evaluate the NSW Post-stroke Vision Care Pathway (Figure 8.1). The RAM consists of a literature review to synthesise available evidence relevant to the topic or practice. The review is then used to form a list of indications or 'best practice statements' (BPS). Due to the expansive nature of this topic, literature relevant to methods of post-stroke vision assessment and management is presented in Chapters 1, and the literature relevant to existing post-stroke vision care pathways and practices is presented in Chapter 3 of this thesis. Chapter 3 also revealed a lack of evidence available specific to Australian post-stroke vision care practices. As such, PRECiS: Stage One was conducted to further evaluate the current care practices and identify barriers to care and unmet care needs. PRECiS: Stage One is presented in Chapters 4-7, of which the results were also used to inform development of the BPS.

The BPS are then rated for their degree of appropriateness by an expert panel over two rounds, using a modified Delphi process. This approach was chosen as it has previously produced results that have been shown to be valid and reliable.[277,278] The RAM was developed as a result of the "increasing complexity of medical care, resulting in some patients not undergoing procedures that they needed, and others undergoing procedures that they did not need" (Brooke, 1994).[277] The preceding chapters of this thesis have shown that the provision of stroke care is complex and that it has continued to be problematic almost 30 years after the RAM's development. The ability of the RAM to "combine the best available scientific evidence with the collective judgement of experts" to inform clinical practice that is patient-specific and aims to provide the best possible outcome for the individual, makes it the most suitable approach to guide post-stroke vision care provision.[277] Traditionally, the first round of rating of BPS takes place by way of survey and the second round during a face-to-face panel meeting. As PRECiS: Stage Two took place in Sydney, NSW in 2021 during the second wave of the COVID-19 pandemic, both rounds took place via electronic survey.

The nature of stroke care involves the timely coordination of multiple medical disciplines. Stroke-related vision problems while diverse in their presentation and often complex in their management requirements, also require timely intervention. There is evidence to indicate that the development and implementation of care pathways can greatly improve care organisation,[279] reduce risk of complications for patients[280] and improve collaboration within

multidisciplinary healthcare teams.[281] As such, it was decided that the BPS developed through PRECiS: Stage Two should be translated into a diagrammatic pathway to better aid their implementation and applicability to varied stroke care settings across NSW. To do this, a third round of evaluation was added to the RAM in form of a video-conference panel meeting. The panel meeting component of the RAM is thought to be essential to ensure rigour within the evaluation process by allowing live discussion amongst panel members. During this round of evaluation, panellists were directed to review the draft diagrammatic pathway, which was based on the previously rated BPS. Panellists again discussed appropriateness of the content of each item within the pathway and corresponding BPS, with the additional consideration to the structure and flow of the diagrammatic pathway. Following discussion of each item, changes were proposed as deemed necessary by the majority and a final rating was provided. An overview of the process involved in developing and validating the BPS and pathway, as well as the chronology of events is provided in Figure 8.1.

8.2.2 Ethics and Consent

Ethical approval was obtained from the University of Technology Sydney Human Research Ethics Committee on the 16th of November 2020 (ETH20-5446). Informed consent was obtained from all participants using an electronic survey form on RedCap (Appendix 11.9). Participants consented to participating in all three rounds of the consensus process and to video recording of round three. Participants were permitted to drop out of the study at any given time, regardless of their participation in any preceding rounds.

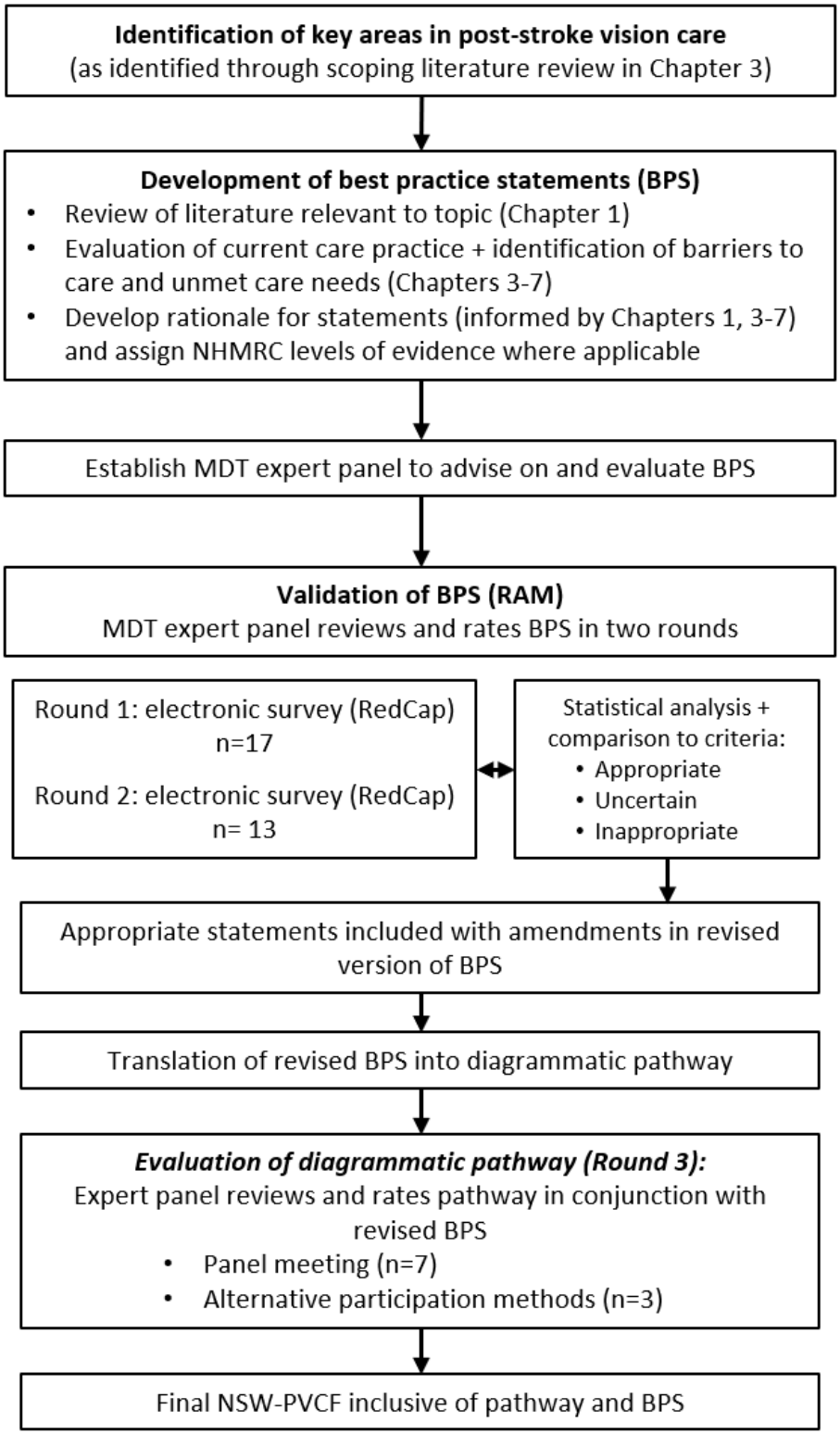


Figure 8.1 The RAND/UCLA appropriateness method (RAM) as applied to the development of the NSW Post-stroke vision care pathway and best practice statements (BPS) in PRECiS: Stage Two. NHMRC, National Health and Medical Research Council; MDT, multidisciplinary team.

8.2.3 Development of NSW Post-Stroke Vision Care Pathway

Development of Best Practice Statements

The development and organisation of the BPS was guided by the conceptual framework of post-stroke vision care developed through the scoping review conducted in Chapter 3, whereby the provision of such care includes: Pre-hospital Pathways, Screening and Assessment, Management and Referral, and Education and Information. All components of the framework were found to be influenced by timing, while specificity was relevant to all components except Pre-hospital Pathways. Specificity related to the health professionals involved in care and the services they provided relevant to Screening and Assessment, and Management and Referral. However, for Education and Information, specificity pertained primarily to the relevance of information to the individual patient and specialisation of health professional training. This framework allowed the evidence synthesised in Chapters 1-3 to be organised into logical stages of care relevant to stroke-related vision problems.

The scoping review (Chapter 3) also highlighted a significant gap in information specific to post-stroke vision care practices within Australian healthcare. In response to this, Stage One of the PRECiS Study (Chapters 4-7) sought to gather evidence regarding existing post-stroke vision care pathways and practices in NSW, as well as identify perceived barriers and unmet care needs within them. The results of PRECiS: Stage One further informed the development of the BPS by providing evidence of successful post-stroke vision care practices already in use, as well as highlighting barriers to care provision and how they could potentially be overcome. Using the sources of evidence described, the candidate identified the evidence available that was applicable to post-stroke vision care practice and categorised this according to each stage of care as indicated by the conceptual framework. Through the identification of well supported recommendations, existing gaps and unmet care needs from the literature reviews (Chapters 1-3) and Stage One results (Chapters 6-7), the evidence was then translated into statements regarding best practice, with accompanying rationale, relevant evidence cited, and respective grades according to the NHMRC Levels of evidence and grades for recommendations for developers of guidelines[282]. This grading system was chosen because it aligns with the Australian Clinical Guidelines for Stroke Management and is endorsed by the Australian NHMRC peak body. As the NHMRC levels of evidence do not include a grading for every type of study design, mixed methods studies and qualitative studies, when used to support a BPS, were labelled “NA”.

There is also a lack of consensus at present regarding the grading of qualitative studies, and so an alternative grading system was deemed not appropriate. The research study grades were provided as a means of assisting panellists to evaluate the evidence. However, as the topic of post-stroke vision care practice is a somewhat emerging area of study, there was limited literature applicable to Australian healthcare and so panellists were encouraged to review and rate BPS in relation to the evidence, as well as their own expert knowledge and experience. For this reason, only NHMRC levels of evidence were indicated (I, II, III) and not the grade (A,B,C,D), as grades take into account other, largely non-applicable aspects, such as quantity of evidence, consistency, clinical impact, and generalisability. The BPS were then reviewed by the supervisory team and revised where needed to improve clarity of wording and presentation (see Appendix 11.10). The final document contained 40 BPS across four stages of care.

Multidisciplinary Expert Panel

The expert panel was purposively recruited in order to ensure its composition included representatives from all disciplines relevant to stroke care where possible. This was in order to ensure that the pathway and accompanying BPS were holistic in their approach and feasible to implement within the multiplicity of deficits requiring care post-stroke. It was also designed to include experts working in stroke care within both metropolitan and rural areas of NSW, as well as those working in both clinical (both acute and rehabilitative) and research roles. The investigative team identified the primary disciplines involved in stroke care within Australia to be: stroke physicians and nurses, physiotherapists, occupational therapists, speech pathologists, general practitioners, paramedics, and social workers. As the topic of interest was specific to post-stroke vision problems, we also sought to include ophthalmologists, orthoptists and optometrists. Experts were invited to participate if they worked in one of the aforementioned roles within stroke care in NSW, within the last five years. Participants were excluded if their role in stroke care was outside of NSW or they had not worked in this role within the last five years.

The RAM indicates that typically nine experts should be recruited to the panel as sufficient to permit a diverse sample and also permit panellists to participate in group discussion during the panel meeting. However, the panel can be greater in number if appropriate for the topic or procedure being reviewed. In this instance, it was considered preferable to recruit a larger number of experts (up to 20), given the diverse range of disciplines and clinical/ geographical contexts within which stroke care takes place in NSW. This would allow for inclusion of a diverse range of perspectives and expertise in the development of the pathway and BPS.

Experts were identified and recruited through direct invitation (via phone call or email) to NSW members of professional organisations as well as NSW hospitals with known stroke units who admit 75 or more stroke patients per year (as listed on the Stroke Foundation website: https://strokefoundation.org.au/About-Stroke/Learn/Treatment-for-stroke/Stroke-Care-Units) (Table 8.1). Researchers with publications relevant to stroke care, who have affiliations with organisations and/or universities within NSW were also contacted directly and invited to participate. Recruitment of health professionals working with stroke patients in either acute or rehabilitative settings were also recruited through Twitter and Facebook via relevant organisational and community health pages/ groups.

Table 8.1 Professional organisations (NSW members) and NSW hospitals with known stroke units admitting 75 or more stroke patients per year who were contacted during recruitment of expert panellists.

Professional Organisations	NSW Hospitals with Stroke Units
• Acute Stroke Nurses Network • Agency for Clinical Innovation (Stroke Network) • Stroke Society of Australasia • Australian Physiotherapy Association • Speech Pathology Australia • Occupational Therapy Australia • Orthoptics Australia • Optometry Australia • Royal Australian and New Zealand College of Ophthalmology • Australian and New Zealand Association of Neurologists • NSW Nurses and Midwives Association • Australian Association of Social Workers	• Bankstown Hospital • Bathurst Base hospital • Blacktown Hospital • Calvary Mater Hospital Newcastle • Campbelltown Hospital • Coffs Harbour Health Campus • Concord Hospital • Dubbo Base Hospital • Gosford Hospital • Hornsby Ku-ring-Gai Hospital • John Hunter Hospital • Lismore Hospital • Liverpool Hospital • Manning Rural Referral Hospital • Orange Base Hospital • Port Macquarie Base Hospital • Prince of Wales Hospital • St Vincent's Hospital • Sutherland Hospital • Ryde Hospital

	• Shoalhaven Hospital • St George Public Hospital • Tamworth Base Hospital • The Tweed Hospital • Westmead Public Hospital • Wagga Wagga Base Hospital • Royal Prince Alfred Hospital • Royal North Shore Hospital • Nepean Hospital • Lismore Hospital • Wollongong Hospital • Wyong Hospital

8.2.4 Validation of Best Practice Statements (Round 1 & 2)

Rounds one and two involved individual ratings of statements via electronic survey (RedCap) that were distributed to panel members through email. The facilitator (SS) contacted each panellist to explain the RAM procedure and clarify any questions. The panellists were then emailed: a copy of the BPS complete with a summary of the evidence and NHMRC level of evidence; instructions on how to perform the ratings according to the definition of appropriateness provided in the RAM manual; a summary of the available evidence relating to post-stroke vision care (see Appendix 11.11) and a Dropbox link complete with full texts of every reference. The facilitator's contact details were provided so that any queries in regard to how to perform the ratings could be answered. The panellists rated the 'appropriateness' of each statement on a scale of one to nine, with nine being the most 'appropriate'. They were also able to record comments to explain their scores and make suggestions for revisions. Panel members were then able to download a copy of their completed survey with their scores and comments to aid in participation in the following round(s). The scores and comments were stored in the RedCap database accessible by the investigative team and downloaded as an Excel file for analysis. Following analysis of the results of round one, the same process was followed for round two using the revised BPS according to panellist feedback. A summary of the scores provided by the panel in round one, as well as their own score, median score and measures of agreement for each statement (see Appendix 11.12) was also provided to each panel member to assist in their ratings during round two.

Analysis

Following the RAM guidelines, median scores were calculated for each statement and the number of panellists rating outside the median tertile was recorded. Statements were classified and agreed as valid, based on the median rating of appropriateness and the degree of panel agreement (dispersion). Statements with a median panel score in the top tertile (7–9) without disagreement were classified as 'appropriate', median ratings in the bottom tertile (1–3) without disagreement were classified as 'inappropriate', and median scores between 4 and 6, or any median with disagreement, were classified as neither appropriate or appropriate but as 'uncertain'. Agreement was calculated using both the median and inter-percentile range (IPR) methods. The median method is the standard approach for analysing agreement (or disagreement) within a panel that has member numbers that are a multiple of three. This follows the definition that the minimum number of panellists permitted to rate outside the region containing the median score, must be one less than the number of panellists rating in the extremes for disagreement. Agreement was indicated when no more than two panellists rated the statement outside the three point region (1–3; 4–6; 7–9) containing the median score. Disagreement was indicated when at least three panellists rated the statement in the lower third region (1–3) and at least three panellists rated it in the top third region (7–9).

Given that the recruitment method for panellists allowed for a number of members that may not be a multiple of three, it was decided to also measure agreement using the IPR method for comparison where appropriate. The IPR method was developed as a means of addressing bias in the measure of disagreement and agreement in panels, with a number that is not a multiple of three.[277] It was found that an IPR of 0.3 – 0.7 produced results closest to that of the classic median method in such cases. Additionally, it was found that when ratings were symmetric, the IPR required to label an indication as disagreement is smaller than when they were asymmetric.[277] As such, an additional measure was also used, the Interpercentile Range Adjusted for Asymmetry (IPRAS). Asymmetry is defined as "the distance between the central point of the IPR and the central point of the 1-9 scale, i.e. 5." Since the more asymmetric the ratings are, the larger is the IPR required to say that there is disagreement, the following mathematical function was developed:

IPRAS = IPRr + (AI * CFA), where

IPRAS = Interpercentile Range Adjusted for Symmetry required for disagreement;

IPRr = Interpercentile Range required for disagreement when perfect symmetry exists;

AI = Asymmetry Index

CFA = Correction Factor for Asymmetry.

Thus, each indication requires a different IPRAS to be classified as disagreement, depending on its internal symmetry. The values that best reproduce the "classic" definitions in the data sets applied are: IPRr = 2.35, CFA = 1.5. Thus, the final formula is:

IPRAS = 2.35 + (AI * 1.5)

Consequently, indication *'i'* is rated with disagreement if IPR> IPRAS.

Content analysis on the comments was performed by the facilitator (SS) to provide an understanding of the nature of any issues panel members may have had with the statements and the way in which the majority saw best to address these. Analysis also sought to identify whether statements were deemed appropriate because of supporting evidence, expert experience or both. This process was undertaken following rounds one and two.

8.2.5 Development and Validation of Diagrammatic Pathway

Following round two of the validation process, the revised BPS were used to construct a diagrammatic post-stroke vision care pathway (Appendix 11.13). The content of the BPS were consolidated and translated into a flowchart format, organised under the same categories as the BPS, with the aim of creating a quick reference that could be easily utilised by health professionals working with stroke patients. The diagrammatic pathway aimed to create clarity as to how the BPS should be implemented and make the information more accessible for all stroke health professionals and members of the general public alike. The diagrammatic pathway was then divided into sections and labelled numerically (1-11) for the purpose of review at the panel meeting (round three).

Panel meeting

Due to the stay-at-home orders occurring during the COVID-19 outbreak in NSW, Australia during July-October 2021, the panel meeting took place via Zoom video conference. Prior to the meeting, panellists were sent an email containing a copy of the draft diagrammatic pathway, a summary of the scores provided by the panel in round two, as well as their own score, median score and measures of agreement for each statement (see Appendix 11.14). A Doodle Poll link was also sent to determine the most suitable date and time for the meeting to take place, allowing members to select up to three options. Seven of the 13 panellists who participated in Round two were able to attend the panel meeting. Three panellists were

unable to attend the panel meeting but wished to participate and were offered alternative methods to do so (see 8.2.5, *Alternative participation methods*). The remaining three panellists did not offer a response to our request to participate in the final round of evaluation. Of the seven who attended the panel meeting, three were orthoptists, one a neuro-ophthalmologist, one a stroke nurse and researcher, one an occupational therapist and one a physiotherapist and researcher. The candidate led the panel meeting as the facilitator and a member of the supervisory panel (AF) was present to support and advise, if necessary, as well as take minutes.

During the panel meeting, the facilitator (SS) provided an overview of the meeting purpose and aims, instructions on how to provide feedback and ratings, and ground rules for engaging in discussion (see Appendix 11.15). The screen share function on Zoom was used to display the pathway document to help facilitate discussion amongst the panel. The facilitator directed panellists to focus on one section of the pathway at a time, while the note taker live documented major points of discussion and suggested revisions for each respective section as comments and/or annotations on the pathway document. Panellists were directed to focus discussion on the appropriateness of the pathway content, structure and flow. At the end of discussion of each section, the live polling function on Zoom was used for panellists to provide their ratings using the same definition and scale of appropriateness as in previous rounds. The facilitator was able to identify individual panellist's ratings, however, such individual ratings were anonymous to other panellists. A summary of the de-identified ratings was then shared with the group. If agreement was reached, discussion moved to the next section. The panel meeting was recorded through Zoom with consent of the participating panellists. A summary of the ratings provided by panellists in each poll was then downloaded from Zoom for analysis following the meeting.

Alternative participation methods

Panellists who wished to participate in the final round of evaluation but were unable to attend the panel meeting were offered the option of providing their ratings and feedback via a 1:1 interview or electronic survey. Two of the 13 panellists who participated in round two opted for a 1:1 interview (one speech pathologist and one social worker) and one (occupational therapist) opted to participate via survey. The interviews and survey were intentionally conducted following the panel meeting, so that the panellists participating through these alternate methods could be provided with a summary of the discussion points, revisions and ratings from the Zoom panel meeting. Interviews took place via Zoom and followed a semi-structured interview format in reviewing the pathway by the same sections (1-11) used in the

panel meeting. Prior to the interview taking place, interviewees were sent a written summary of the panel meeting discussion and ratings organised according to the numbered sections of the pathway (see Appendix 11.16). During the interview, the interviewer (SS) provided a brief verbal summary of this same information, then invited the interviewee to share their thoughts and suggestions. Following this, the interview provided their rating for each respective section. This was done using the live polling function on Zoom for the purpose of accurate data recording. Interviews were recorded through Zoom with consent of the panellists. A record of the panellists ratings was downloaded from Zoom following each interview.

The same written summary of the panel discussion (Appendix 11.16) was used to construct the survey with the addition of scoring panel at the end of each section which panellists could use to indicate their rating. Instructions were provided as a preface to the survey with a reminder of appropriateness definitions, rating scale and aims of the study. The survey was sent via email as a PDF form and participants were requested to return the completed survey via email within two weeks. The ratings provided via survey were recorded on a master Excel spreadsheet where they were pooled with the ratings provided through the Zoom polling function during both the panel meeting and individual interviews for collective analysis.

Analysis

The pooled ratings of panellists were again analysed following the RAM guidelines, whereby median scores were calculated for each section and the number of panellists rating outside the median tertile was recorded. Sections were classified and agreed to as valid based on the median rating of appropriateness and the degree of panel agreement (dispersion). Sections with a median panel score in the top tertile (7–9) without disagreement were classified as 'appropriate', median ratings in the bottom tertile (1–3) without disagreement were classified as 'inappropriate', and median scores between 4 and 6 or any median with disagreement was classified as neither appropriate or appropriate but as 'uncertain'. As the number of panellists in the round three did not confirm to a multiple of three, the IPR method was again used to measure agreement.

Recordings of the panel meeting and interviews were transcribed verbatim. The transcripts of the panel meeting and interviews, as well as the comments from the survey were analysed thematically using NVivo 12. The results of the thematic analysis were used to inform any final revisions of the pathway, identify areas of strong agreement, disagreement or uncertainty among the panel, and suggestions that conflict with the existing evidence base.

Stroke survivor feedback

No stroke survivors were recruited as part of the expert panel in PRECiS: Stage Two. This was decided because significant input from stroke survivors was collected in PRECiS: Stage One through the stroke survivor interviews, and that informed the initial development of the BPS. However, as Australian stroke survivors are arguably the greatest stakeholders in the area of care for which the BPS and pathway were developed, a final consultation process with a small sub-sample of stroke survivors was conducted. Of the stroke survivors who participated in PRECiS: Stage One, 10 consented to being contacted again for further participation. These participants were contacted via email and invited to complete a short, six-question, free text response survey distributed as a PDF form (Appendix 11.17). Participants were provided with a copy of the finalised BPS and diagrammatic pathway, and a summary of the study aims and evaluation process used in their development. This was followed by questions that asked about the specific areas of the BPS and pathway that retained some level of uncertainty or disagreement amongst the expert panel, as indicated by the qualitative analysis of round three discussion and feedback. These areas were: modes of presentation, indication of time cut-off for reperfusion therapies, the inclusion of eye care specialists in stroke teams, and the use short term management strategies. Stroke survivors were also asked to provide general feedback on the BPS and pathway overall. Survey responses were imported to NVivo 12 and a simple content analysis undertaken.

8.3 CONCLUSION

PRECiS: Stage Two forms phase four of Vanhaecht's method for pathway development and utilises a modified RAND/UCLA appropriateness method. Adaptations to the methodology such as utlisation of web surveys and conducting the panel meeting via Zoom were necessitated by COVID-19 restrictions in place in NSW during the data collection period. The three rounds of validation enabled an iterative feedback process whereby the BPS were revised based on the ratings and comments provided by the expert panel in round one and recirculated for further review. Following the same process, further revisions were made to the BPS based on the ratings and comments provided in round two. This second revision of the BPS was then translated into a diagrammatic pathway to be used as a supplementary visual aid and quick reference guide to the BPS. This diagrammatic pathway and second revision BPS underwent further review in round three via the panel meeting and alternate participation methods. The combined framework comprising the third revision BPS and diagrammatic pathway was then put to review with a sub-sample of stroke survivors to ensure adequate and

equal input for both groups of key stakeholders throughout the development process. The results of PRECiS: Stage Two and contents of the framework are presented in Chapter 9.

9 DEVELOPMENT OF A NSW POST-STROKE VISION CARE FRAMEWORK: RESULTS

This chapter outlines the results of Stage Two of the PRECiS study which aimed to develop an evidence-based post-stroke vision care framework, appropriate for use in Australia. The framework was intended to address the issues and/or pitfalls of current post-stroke vision care provision that were identified in Stage One of the PRECiS Study (see Chapters 6 and 7).

9.1 MULTIDISCIPLINARY PANELLISTS

A total of 17 stroke health professionals in NSW formed the multidisciplinary expert panel (MEP). The majority of these stroke health professionals worked specifically in a stroke care setting at the time of recruitment into PRECiS: Stage Two (n=10), worked in another clinical or hospital setting where they provided care to stroke survivors (n=4), or were experts in stroke care research relevant to their discipline with prior experience in stroke care provision (n=3). The multidisciplinary composition of the panel included: four occupational therapists (hospital and community based), three orthoptists, three nurses (stroke nurse educator, stroke care coordinator, and an academic), two speech pathologists, a physiotherapist, an orientation and mobility specialist, a social worker (vision sector), a neurologist, and a neuro-ophthalmologist. All panel members had extensive experience in stroke care provision within the Australian health system and worked in NSW at the time of recruitment.

9.2 VALIDATION OF BEST PRACTICE STATEMENTS

9.2.1 Round One

Forty best practice statements (BPS) were rated across four areas of post-stroke vision care (see Table 9.1). At the end of Round One, all 40 BPS were rated as appropriate with agreement amongst the panel according to both the median and IPRAS methods. Of these 40 statements, 14 (35%) had more than two ratings below seven (outside the median tertile), indicating that there were some discrepancies between panellists in this round. One of these BPS (BPS 2.3) had five ratings outside the median tertile, making it the statement with the widest dispersion of scores. All but one panellist provided comments regarding justification of their score and suggested revisions to the statements and/or the BPS overall. Content analysis of these comments revealed that panellists deemed a BPS to be appropriate when the evidence base aligned with their clinical experience of post-stroke vision care provision. Justification of a score between nine and seven often referenced a process or pathway within their own workplace that was relevant to the respective BPS. The panellist's experience of the success or

failure of this process hence provided them with knowledge of a known benefit or identified unmet care need in support of the BPS. Where revisions of the BPS were suggested, this mainly centred on statement wording and specificity pertaining to time frames, context, and role delineation. Panellists also reported several perceived problems regarding the BPS that related to the feasibility of implementation. These concerns related primarily to current limitations within the health system, such as the need for further training of stroke health professionals and access to specialist eye care services/professionals. As these concerns did not pertain to the appropriateness of the BPS as per the RAND/UCLA definition, they were not reflected in panellists scores. Based on panellist feedback, 31 of the 40 BPS underwent revisions that were either minor changes to wording or the inclusion of additional details (see Appendix 11.18).

9.2.2 Round Two

As none of the BPS were rated as inappropriate in Round One, all 40 statements were retained and the revised versions (Appendix 11.18) rated again in Round Two. Three occupational therapists and one speech pathologist were unable to participate in Round Two, making a panel of 13 members. All of the BPS were rated as appropriate according to both the median and IPRAS method with strong agreement amongst the panel (see Table 9.2). Of the 40 BPS, six (15%) had one or two ratings outside the median tertile. This indicates that the revisions to wording and increased specificity of the statements made based on feedback from Round One reduced the discrepancies between panellists. Approximately half of the panellists provided comments regarding further suggested revisions to the statements. These comments related primarily to minor wording revisions and naming of additional disciplines and/or services in certain areas of care provision. Overall feedback on the BPS was positive and reaffirmed the appropriateness of the statements collectively. Based on the comments provided, 12 of the 40 BPS underwent minor revisions relating to wording or inclusion of additional disciplines/services where recommended (see Appendix 11.19).

Table 9.1 Best Practice Statements (BPS) for each area of care (n=40) presented with median panel score, number of panellists that scored outside the median tertile, Interpercentile range (IPR) and Interpercentile range adjusted for symmetry (IPRAS).

BPS No.	Round 1 NSW Post-Stroke Vision Care BPS 2021	Median Score/9	No. outside median tertile	IPR	IPRAS
1	**PRE-HOSPITAL PATHWAYS**				
	Community Awareness				
1.1	Orthoptists, optometrists and ophthalmologists should endeavour to raise community awareness of visual stroke symptoms.	9	1	1	7.6
1.2	Orthoptists and ophthalmologists should provide training to general practitioners, accident and emergency personnel and other 'first point of care' professionals regarding differentiating diagnosis of migraine with visual aura, drug overdose and stroke, particularly in younger people.	8	4	2	6.9
	Referral Process				
1.3	Patients that present to their general practitioner, community vision service, or hospital outpatient clinic with sudden onset of visual symptoms (onset < 4 hours) indicative of stroke (e.g. double vision, field loss, loss of vision) and unexplained by identifiable pathology should be referred to nearest emergency department.	9	0	0.2	8.2
1.4	Patients presenting to emergency services (emergency department, ambulance) with sudden onset of visual symptoms (onset < 4 hours) indicative of stroke (e.g. double vision, field loss, loss of vision) should be investigated for stroke/ TIA.	9	0	1	7.6

BPS No.	Round 1 NSW Post-Stroke Vision Care BPS 2021	Median Score/9	No. outside median tertile	IPR	IPRAS
2	**SCREENING AND ASSESSMENT**				
	Timing of assessment				
2.1	Vision screening, including objective measures, should be provided to all stroke patients within 4 weeks of regained consciousness, OR before rehabilitation activities begin.	9	0	1	7.6
2.2	Where vision screening indicates the need for further vision assessment, this should take place before rehabilitation activities begin or in the early stages of rehabilitation.	8	2	1	7.6
2.3	All stroke survivors should be encouraged to have an optometry assessment within 3 months of discharge.	9	5	2.2	6.7
	Health professional(s) performing assessment				
2.4	Where an orthoptist is not available, the use of a suitable, validated vision screening tool(s) for stroke survivors (e.g. VISA, V-DISST) by non-eye care specialists should be supplemented with appropriate training and education around how to administer and interpret results of the tool.	8	3	2	6.9
2.5	Stroke survivors suspected of having visual deficits, who report visual deficits, or show potential visual deficits as a result of screening should be referred for assessment by an orthoptist or ophthalmologist.	9	0	0	8.4
	Execution of assessment				
2.6	All stroke survivors should have an assessment of visual acuity wearing the appropriate glasses, to check their ability to read newspaper text and see distant objects clearly.	9	0	0.2	8.2
2.7	All stroke survivors should have an examination for the presence of visual field deficit (e.g. hemianopia) and eye movement disorders (e.g. strabismus and motility deficits).	9	0	0	8.4

BPS No.	Round 1 NSW Post-Stroke Vision Care BPS 2021	Median Score/9	No. outside median tertile	IPR	IPRAS
2.8	All stroke survivors should be assessed for visual neglect and visual perception disorders at the time of vision assessment or perceptual assessment.	9	1	0.2	8.2
2.9	Vision screening should include vision history (with carer present if necessary) to identify any pre-existing vision conditions.	9	0	0	8.4
3	**MANAGEMENT AND REFERRAL**				
	Timing of management and referral				
3.1	Orthoptists should initiate management and referrals for visual deficits based on the patient's needs, readiness for information and capacity for participation in these services based on discussion with the stroke survivor and their family.	9	2	1	7.6
3.2	Where a visual deficit is found through screening, or by report of the patient/ carer/ other health professional, there should be immediate referral to an orthoptist.	9	1	1	7.6
3.3	Where short-term management (e.g. advice, patching, Fresnel prisms) is appropriate and available, this should be provided as soon as it becomes beneficial for the stroke survivor.	9	1	0	8.4
3.4	If a visual deficit is found that has a known treatment/ intervention available, referral to the appropriate health professional should be made immediately.	9	0	0	8.4
3.5	If a visual deficit is found that does not have a known treatment/ intervention available, but can be managed through therapy/ training, there should be a referral provided at the time the stroke survivor is physically and cognitively able to participate in said management OR on discharge.	9	1	1	7.6

BPS No.	Round 1 NSW Post-Stroke Vision Care BPS 2021	Median Score/9	No. outside median tertile	IPR	IPRAS
3.6	If a visual deficit is found that does not have any known treatment/ intervention or therapy/ training that is appropriate, referral to a vision support service and/or social worker should be provided on discharge.	9	1	0.2	8.2
	Appropriateness of referral				
3.7	Where pharmacological or surgical intervention is available/ recommended for their visual deficit, stroke survivors should be referred to an ophthalmologist.	9	1	0.2	8.2
3.8	Where therapeutic training and/or compensatory management options are available/ recommended for their visual deficit, stroke survivors should be referred to an orthoptist and/or trained occupational therapist.	9	0	0.2	8.2
3.9	Where optical correction (such as glasses and/ or long term prisms) is available/ recommended for their visual deficit, stroke survivors should be referred to an optometrist.	9	0	0	8.4
3.10	Visual perceptual deficits should be referred to a neuro-ophthalmologist.	9	3	1	7.6
3.11	Where no treatment or therapy is available/ recommended for their visual deficit, stroke survivors should be referred to a vision support service (e.g. Vision Australia, Guide Dogs NSW) and social worker to discuss available services and entitlements.	9	0	0	8.4
3.12	Discussions with the stroke survivor/ carer should be had to determine if referral to a social worker, stroke or vision support service, or access to a case manager (where available) would aid in managing their vision care and assist in accessing funding for disability support.	9	0	0	8.4
3.13	Referrals to non-eye care specialists, namely occupational therapists and social workers, should be provided in the same instance as eye-specific referrals.	9	4	0.2	8.2

BPS No.	Round 1 NSW Post-Stroke Vision Care BPS 2021	Median Score/9	No. outside median tertile	IPR	IPRAS
	Appropriateness of management				
3.14	Management of visual field loss should include promoting awareness of the field loss and compensatory strategies (e.g. visual scanning training, reading strategies, discussion and referral for assistive technology) by an eye care professional as well as environmental adaptations and mobility training guided by an occupational therapist or appropriate healthcare professional. Other options such as restitutive treatment should also be discussed with the patient with advice on effectiveness so they can make an informed decision should they wish to pursue.	9	1	0	8.4
3.15	Where double vision is the primary complaint of a strabismus or ocular motility issue, occlusion of one eye or Fresnel prisms should be suggested as a short term solution to aid rehabilitation. Long term management should be through referral to an ophthalmologist, neuro-ophthalmologist or orthoptist.	9	2	1	7.6
3.16	Reduced central vision should be referred to an optometrist to ensure refractive error is fully corrected AND ophthalmologist to investigate/ manage potential pathology.	9	2	1	7.6
3.17	Management of visual neglect should include promoting awareness of the area of neglect and cognitive rehabilitation (e.g. visual scanning training, reading strategies) by an eye care professional as well as environmental adaptations and mobility/ activity training guided by an occupational therapist. Other options should also be discussed with the patient with advice on effectiveness so that they can make an informed decision should they wish to pursue.	9	2	1	7.6

BPS No.	Round 1 NSW Post-Stroke Vision Care BPS 2021	Median Score/9	No. outside median tertile	IPR	IPRAS
4	**EDUCATION AND INFORMATION**				
	Timing of information				
4.1	All stroke survivors should be provided general information about stroke related symptoms/ conditions prior to discharge.	9	1	0	8.4
4.2	Where a visual deficit is identified, information should be provided at the time of diagnosis and prior to discharge.	9	0	0	8.4
	Specificity of information				
4.3	General information about how stroke can impact the eyes and vision should be provided to all stroke survivors in written form (e.g. pamphlet or fact sheet).	9	4	2	6.9
4.4	Stroke survivors with a visual deficit should be provided information about what their condition is, what area of the brain and visual system it relates to, the expected implications on functional vision, expected recovery, available management options, resources and support services. This should be included in writing in the patient's discharge summary or in the form of a take home report.	9	3	0.2	8.2
4.5	Referrals should be explained in regards to what condition is to be managed or what service provided by each professional the stroke survivor is referred to.	9	2	0.2	8.2

BPS No.	Round 1 NSW Post-Stroke Vision Care BPS 2021	Median Score/9	No. outside median tertile	IPR	IPRAS
	Education/training of stroke health professionals				
4.6	Non-eye specific health professionals should receive training relating to commonly used vision terminology, and visual conditions relating to stroke.	9	1	0	8.4
4.7	Post-stroke vision assessment should be included in existing stroke pathways and/or protocols for all acute and rehabilitation services.	9	1	1	7.6
4.8	Trained eye care professionals (e.g. orthoptists) should be included in the multi-disciplinary team of all stroke care facilities (acute and rehabilitation).	9	2	1.2	7.5
4.9	Information regarding the visual condition of a stroke survivor, the implications and how to best manage these should be documented in the patients file and in discharge papers/ referrals for shared access between the multi-disciplinary team.	9	1	0	8.4

Table 9.2 Round 2 median panel scores of the best practice statements (BPS) and measures of agreement.

BPS No.	Median Score/9	No. outside median tertile	IPR[a]	IPRAS[b]
1.1	9	0	0.4	8.05
1.2	8	0	1	7.60
1.3	9	0	0	8.35
1.4	9	0	0	8.35
2.1	9	1	0.4	8.05
2.2	9	0	1	7.60
2.3	9	1	1	7.60
2.4	9	1	0.4	8.05
2.5	9	0	0	8.35
2.6	9	0	0	8.35
2.7	9	0	0	8.35
2.8	9	0	0	8.35
2.9	9	0	0	8.35
3.1	9	0	0	8.35
3.2	9	0	0	8.35
3.3	9	1	0	8.35
3.4	9	0	0	8.35
3.5	9	0	0	8.35
3.6	9	0	0.4	8.05
3.7	9	0	0	8.35
3.8	9	0	0.4	8.05
3.9	9	0	0	8.35
3.10	9	2	1.4	7.30
3.11	9	1	0	8.35
3.12	9	0	0	8.35
3.13	9	0	0	8.35
3.14	9	0	0.4	8.05
3.15	9	0	0.4	8.05
3.16	9	0	0	8.35
3.17	9	0	0.4	8.05

BPS No.	Median Score/9	No. outside median tertile	IPR[a]	IPRAS[b]
4.1	9	0	0	8.35
4.2	9	0	0	8.35
4.3	9	0	0	8.35
4.4	9	0	0	8.35
4.5	9	0	0	8.35
4.6	9	0	0	8.35
4.7	9	0	0	8.35
4.8	9	0	0.4	8.05
4.9	9	0	0	8.35
4.10	9	0	0	8.35

[a] Interpercentile range

[b] Interpercentile range adjusted for symmetry

9.3 Development and Validation of Diagrammatic Care Pathway

The revised BPS based on Round Two feedback (see Appendix 11.19) were translated into a visual pathway (see Appendix 11.13) that extended across three areas of care (pre-hospital pathways, assessment, management and referral) intended to assist in the application of the BPS in practice within NSW. The pathway sections were assigned numerical labels (1-11) to provide structure for discussion and scoring in the video-conference panel meeting (see Figure 9.1).

The panel meeting took place on the 27th August, 2021 via Zoom video conference. During this time, a public health order was in place in NSW that required all residents to stay at home with the exception of essential workers. As a result, many panellists experienced significant schedule disruptions and increased work demands as essential health workers. Several attempts were made to coordinate a time suitable for all panel members to attend, however due to the larger than usual number of panellists and the impact of delta variant outbreak in NSW, only seven of the 13 panellists who participated in Round Two were able to attend. Alternative options for participation were offered to the remaining seven panellists in the form of an individual interview at their preferred time or by survey response.

Of those able to attend the panel meeting, there were three orthoptists, one physiotherapist, one occupational therapist, one nurse and one neuro-ophthalmologist. Of the remaining six panellists offered alternative participation methods, two participated in individual interviews

and one provided their scores and feedback via survey. These panellists were from the disciplines of social work, speech pathology and occupational therapy.

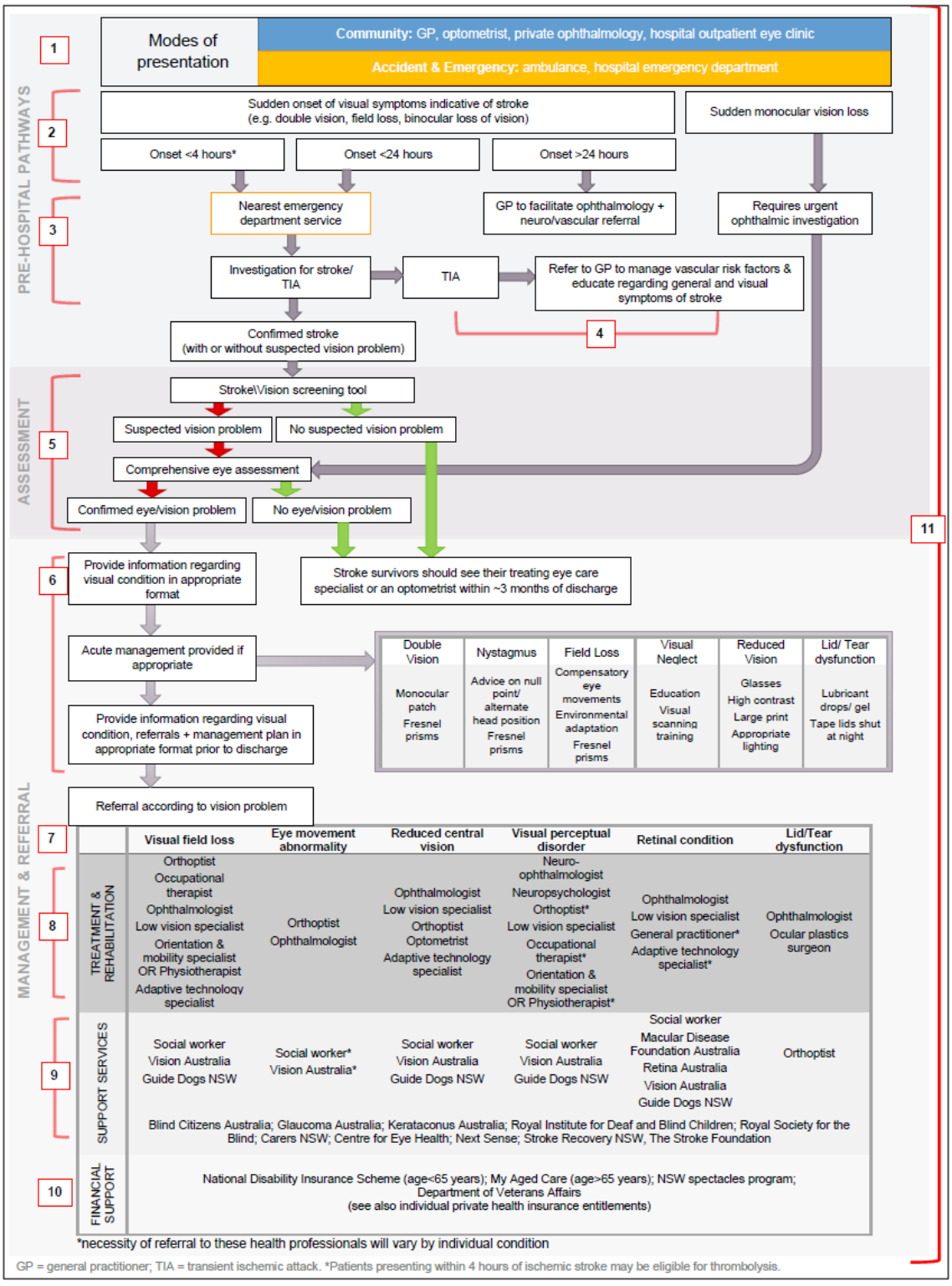


Figure 9.1 Diagrammatic pathway developed from the best practice statements, divided and labelled into 11 sections for the purpose of rating and discussion in the panel meeting.

9.3.1 Combined Feedback Outcomes

For the purpose of guiding discussion during the panel meeting and semi-structured interviews the NSW Post-Stroke Vision Care Pathway was divided into 11 sections (see Figure 9.1). The same sections were used in the electronic survey. A summary of the discussion outcomes for each section according to data collection method is provided in Table 9.3. Owing to time constraints, only sections 1-8 were reviewed during the panel meeting, with feedback on the remaining sections provided via electronic survey. Thematic analysis of the panel meeting discussion, interview transcripts and written feedback from surveys was undertaken for each area of care discussed within the pathway.

Pre-Hospital Pathways

When reviewing pre-hospital pathways, the major points of discussion centred on the modes of presentation, presenting symptoms, timing and urgency and transient ischemic attack. Panel members felt that it was important to recognise the diversity of referral pathways for stroke patients with visual symptoms. This included the potential for significantly delayed presentation to stroke services because of lack of awareness of stroke related visual symptoms. Lack of awareness of the relationship between visual symptoms and stroke amongst the general public, may lead to a false perception of the severity of these symptoms and hence delayed presentation to stroke care facilities. The same lack of awareness within community health services can result in long and convoluted referral pathways, again causing a delay in presentation to stroke services. Similarly for patients who experience onset of stroke-related visual symptoms while already under the care of a health professional, such as existing inpatients or nursing home residents, recognition of these symptoms by their carer is necessary for appropriate referral. It was proposed that for patients that are already in a supervised setting such as an existing inpatient, a nursing home resident, or those within a detention centre or prison, their presentation to stroke services would more likely be through a direct patient transfer. Panellists also noted that while the modes of presentation should reflect all possibilities, the pathway to follow should indicate and guide towards the most direct referral process.

When discussing presenting symptoms, panellists recognised that there are other visual symptoms that could be associated with stroke, such as lid dysfunction and generally reduced vision. However, because these symptoms can be caused by several other non-stroke conditions, they were considered too broad for inclusion. This decision was also based on evidence that such visual symptoms, if caused by stroke, would be associated with other

physical and/or cognitive deficits more readily recognised as stroke related, and so were not necessary to include. Panellists felt that more clarity was required regarding the outcomes following investigation of sudden monocular vision loss. Ophthalmic investigation of this symptom could result in confirmation of ocular stroke or a visual condition that was not stroke related, and so both potential outcomes should be indicated in the pathway. It was also agreed that for patients in the category of stroke-related vision loss, early inclusion in the stroke pathway should be made via referral for investigation of stroke/TIA. This would again allow for recognition of all potential causes including stroke/TIA and its mimics.

Discussion regarding timing and urgency of referral was undertaken in relation to the risk of a secondary or escalating stroke, and window of opportunity for stroke interventions such as thrombolysis. The risk of secondary or escalating stroke between 24 hours and 1-2 weeks post onset of symptoms was raised, with specific mention of carotid artery dissections. It was suggested that referral to a general practitioner within this time frame would not be appropriate for neurovascular care as the referral process is too slow. Literature was cited to indicate that referral facilitated by a general practitioner can result a delay in access to specialist care.[283,284] Evidence was also sought regarding the exact timeframe at which patients with carotid artery dissection are at increased risk of escalating stroke, which was determined to be between five and ten days post onset.[285] Based on agreement amongst the group, a new category was included in the pathway specific to those experiencing onset of symptoms for at least 24 hours and up to two weeks. Panellists agreed that these patients should be referred to a stroke/TIA rapid-access centre, while those with onset of symptoms less than 24hours old, should go to the nearest emergency department and those with onset of more than two weeks prior should seek ophthalmology and neurovascular referral from their general practitioner. The categories for patients with onset of symptoms less than 4.5 hours and less than 24 hours should both receive referral to the nearest emergency department, and so it was deemed appropriate and more concise to combine them.

The issue of highlighting time constraints for stroke interventions such as thrombolysis and other reperfusion therapies, was then raised. There were mixed opinions amongst the panellists regarding whether specific mention of this timeframe was appropriate withn the scope of this pathway, as it is specific to vision care. Given the difference in outcome that these interventions can provide for stroke patients, including those with visual symptoms or ocular stroke, it was deemed that this eligibility criteria should remain within the pathway. It was agreed that inclusion of the time frame as a footnote to the urgent referral category would be most appropriate.

Regarding TIA, the decision to differentiate or treat as stroke was discussed at length amongst panellists. It was suggested that TIA patients should follow the same pathway as stroke patients as the conditions require a similar approach to care. This was discussed in reference to the literature, which suggests that the transient nature of TIA means that both the symptoms and cause are temporary, and hence do not require the same management. Current evidence and guidelines also indicate that TIA should be investigated and treated as a stroke until this transient nature can be confirmed. In light of this, it was agreed that the wording should be revised following investigation for stroke and TIA. The outcomes listed were updated to 'confirmed stroke' or 'confirmed TIA'. As TIA patients are still typically admitted into hospital before confirmation of their condition can be provided, the follow-on action for a confirmed TIA was moved out of 'pre-hospital pathways' to better reflect the time frame in which this occurs. The inclusion of referral for neurovascular management of TIA patients was debated with regard to its relevance to this pathway. It was deemed important by the majority of panellists to include some guidance on appropriate community care provision due to the increased risk of stroke for TIA patients. Suggested referral and provision of information for confirmed TIA is detailed in the Clinical Guidelines for Stroke Management, and so these guidelines were referenced. As this pathway is specific to those with visual complications, it was also indicated that these patients be referred to their treating or community eye care specialist to ensure appropriate follow-up of visual symptoms and management of any pre-existing eye conditions.

Screening & Assessment

The assessment section of the pathway was discussed mainly in relation to the delegation of tasks and role differentiation, accounting for variances in the assessment pathway and the appropriateness of involvement of non-eye care professionals. Delegation of tasks was deemed important by all panellists who felt it was necessary to make clear which health professionals were responsible for undertaking vision screening and assessment. This would help to ensure that this step was not missed due to lack of clarity or miscommunication within stroke teams. In keeping with this, there was thought to be a lack of differentiation between vision screening using a validated tool and a comprehensive eye assessment.

Table 9.3 Summary of Round 3 feedback outcomes by pathway section for the panel meeting, individual interviews and online survey formats.

Pathway Section	**Panel Meeting** (n=6)	**Interview** (n=2)	**Online Survey** Section 1-8 (n=1) Section 9-11 (n=7)
1	• Commonality of indirect referral pathways to stroke care facilities for those with primarily visual symptoms (e.g. through GP, optometrist, ophthalmologist) • Indirect referral pathways lead to delayed presentation to stroke care facilities and is likely due to lack of awareness of stroke-related visual symptoms • Guidelines should exemplify the most direct referral pathway while being inclusive of all modes of presentation • Need to include additional category for existing inpatients and those in other care facilities who then experience onset of symptoms = direct patient transfer	• Important to recognise the diversity of referral pathways for stroke survivors with visual symptoms • Revisions made are more reflective of this diversity	• Revisions more inclusive of potential modes of presentation.
2	• The presenting visual symptoms list are of appropriate specificity for stroke investigation • Important to highlight key visual symptoms of concern/ indicative of possible stroke, as many non-eye care health professionals may	• Potential issues with time categories of initial pathway prior to revisions. Changes made reflect more appropriate action for those still at heightened risk without overloading emergency services.	• Agree that revisions made were necessary and may improve awareness among public regarding rapid access centres for stroke/TIA. Allows patients to be better informed.

Pathway Section	Panel Meeting (n=6)	Interview (n=2)	Online Survey Section 1-8 (n=1) Section 9-11 (n=7)
	be unfamiliar with these. This will help to prompt neurological examination sooner • Time cut-off for reperfusion therapies in vision care pathway relevant but appropriate to include as footnote, as onset within 24 hours should still be referred to ED • Risk of secondary or escalating stroke (especially in carotid artery dissection) indicated need for additional time category between 24 hours and 2 weeks post onset		
3	• Following urgent ophthalmic investigation, all outcomes should be included (stroke related vision loss and vision loss not stroke related) • Monocular vision loss deemed to be stroke related should return to stroke pathway at the stage of investigation for stroke/TIA for confirmation	• Revisions account for the possibility that monocular vision loss may not be stroke related, makes clear that not all of these patients will be stroke patients • Re-entering stroke pathway at investigation stage allows for potential identification and exclusion of other stroke mimics	• Important to be inclusive of all potential outcomes.
4	• TIA patients should be investigated and treated as stroke until transient nature of the event can be confirmed	• New evidence indicates some lasting cognitive impact of TIA up to 3 months later, hence appropriate referral	• School of thought regarding TIA is changing and it is important to reflect this/ ensure

Pathway Section	Panel Meeting (n=6)	Interview (n=2)	Online Survey Section 1-8 (n=1) Section 9-11 (n=7)
	• Patients are typically admitted to hospital and spend more than 24 hours there before TIA is confirmed and hence suggested action should be moved down (out of 'pre-hospital' area) • Important to provide information and education on general and visual stroke symptoms as TIA patients at greater risk of stroke, but referral to GP for neurovascular management potentially outside scope of this pathway. • Referral to community eye care should be made for monitoring of visual condition and care provision for pre-existing visual conditions	important. Stroke Foundation Guidelines indicate what general referrals and information should be provided and should be referenced here. This won't change the pathway but is important for wholistic care. • Follow up for visual conditions in the community also important and not included in Stroke Foundation guidelines but is covered in this pathway.	appropriate care provision in the community.
5	• Delegation of tasks needed to ensure responsibility is taken by a member(s) of the team. • Clarification that a 'comprehensive' eye assessment is one performed by a specialised eye care professional. This helps to	• Revisions make clear that the goal is to screen all stroke survivors for vision problems at some point early in their care provision. • Appropriate to add reference to the relevant BPS in this section to provide clarity around who performs vision	• Vision screening by non-eye care professionals is necessary but it is important to highlight the need for appropriate training.

Pathway Section	Panel Meeting (n=6)	Interview (n=2)	Online Survey Section 1-8 (n=1) Section 9-11 (n=7)
	differentiate screening from formal assessment. • Use of a validating screening tool that can be administered by any member of the stroke team is appropriate, particularly in areas of limited access to specialist eye care services. • Formal vision assessment by an ophthalmologist and/or orthoptist is still required and should be specified. • More detail and clarification is included in the BPS, include explicit reference to this section of the BPS to guide users. This will remind users that the pathway is to be used in conjunction with the BPS. • Account for variances in assessment pathway (timing of assessment) to avoid double-up and ensure effective use of resources.	screening. Not all non-eye care professionals will be comfortable performing vision screening hence it is important to reference the need for training.	
6	• Need to make clear that this section is inclusive of pre-existing and acquired visual conditions. Important to address both as each can impact on rehabilitation.	• Suggested driving suspension post-stroke in Australia is 4 weeks for a private license holder (3 months for commercial license). Community eye assessment for	

Pathway Section	Panel Meeting (n=6)	Interview (n=2)	Online Survey Section 1-8 (n=1) Section 9-11 (n=7)
	• Fresnel prisms not appropriate in acute management of visual field loss and nystagmus. • Additional information needed around proper use of glasses. Misinformation amongst patients and health professionals is common.	those without diagnosed vision problem should occur prior to return to driving. • Agreed that clarity around the inclusion of pre-existing eye conditions makes clear that all vision problems should be accounted for during rehabilitation. • Preferable to keep acute management strategies simple with assurance that benefits outweigh disadvantages.	
7	• All categories of vision/eye problems appropriate and reflective of the acquired and pre-existing conditions that may occur.	• Categories of vision/eye conditions seem appropriate based on the literature.	• Categories of vision/eye conditions seem appropriate based on the literature.
8	• Separate physiotherapist and orientation and mobility specialist to indicate differences in speciality/ role • Prioritisation of referrals according to potential benefit to the patient • Not appropriate to include specifics of the management strategies used in this section, but important to reference the relevant BPS to guide users. There is lack of awareness of	• Agreed that benefit to the patient should have most influence on the referrals made. • Issues of feasibility e.g. access are often in conflict with best practice. Important to indicate best practice within the pathway and potentially provide more feasible alternatives within the BPS.	• Revisions better reflect the multidisciplinary nature of management, even for visual conditions.

Pathway Section	Panel Meeting (n=6)	Interview (n=2)	Online Survey Section 1-8 (n=1) Section 9-11 (n=7)
	management strategies, particularly for visual field loss. • Inclusion of additional referrals more accurately reflect multidisciplinary nature of management • Referral to optometrist may be more widely applicable in areas of limited access to specialist eye care services. However, inappropriate referral should not be made based on limited access as there may be no benefit to the patient. • Issues around access conflict with best practice. The pathway should be indicative of best practice and may highlight the need for change/ improvement.		
9	-	1 Early and ongoing linkage/ access to a social worker or case manager important in provision of wholistic care 2 Dynamic and complex nature of support services can make them difficult for patients/ carers to navigate on their own	4 Inclusion of this information within the pathway highly beneficial for stroke health professionals. Allows onflow of information to patients. 5 Inclusion of carer support services important to address.

Pathway Section	**Panel Meeting** (n=6)	**Interview** (n=2)	**Online Survey** Section 1-8 (n=1) Section 9-11 (n=7)
		3 Lack of awareness of the support services available, and requirements for eligibility among patients and health care professionals.	6 Vision specific care pathway that appropriately addresses the multifaceted nature of managing deficits in stroke survivors.
10	-	• Large financial burden on patient and carer following stroke with increased medical expenses and reduced income, necessitates access to financial support. • Lack of awareness of the financial support available, difficulty in navigating systems. Long-term support is required, not just at discharge. • Financial support services are still limited, as out of pocket costs are still incurred e.g. My Aged Care. Patients should be properly informed to manage expectations and plan for expenses.	• Information regarding financial support is highly sort after by patients in rehabilitation but limited in availability. Important to include to increase awareness of options available.
11	-	• Additional details required to more clearly reflect content of the BPS	• Revisions allow for more logical flow and clearer categorisation.

Pathway Section	**Panel Meeting** (n=6)	**Interview** (n=2)	**Online Survey** Section 1-8 (n=1) Section 9-11 (n=7)
		• Revised flow of the pathway based on updates to presenting categories and required actions • Colour coding should be clear and intuitive. Alternative coding required for black and white print option. • Alignment of boxes/ headings, etc within the pathway important to improve aesthetic of the pathway and make it easier to follow/ interpret.	

Although more detail was provided in the BPS regarding the difference between initial vision screening and a comprehensive eye assessment, it was deemed appropriate to alter the wording to 'use of a stroke-vision screening tool' and 'undergo comprehensive orthoptic/ophthalmic assessment'. This was thought to make clear that a comprehensive assessment is one performed by a trained eye care professional, in contrast to vision screening which can be performed by any member of the stroke team using a validated tool.

Panellists recognised the importance of vision screening that could be performed by any member of the stroke team, particularly in areas of limited access to specialist services. It was acknowledged that in the context of current stroke care in NSW, many facilities do not have access to an eye care specialist, and as a result, vision screening by a non-eye care professional may be the only way for stroke survivors to receive early vision assessment. However, the need for provision of appropriate training for stroke health professionals was imperative, as was confirmation of diagnosis through formal ophthalmic assessment. Detail regarding recommendations for training and follow-up assessment is provided in the BPS, and so reference to the relevant statements was seen as an appropriate inclusion in this section. The issue of variances within the assessment pathway was also raised, with specific reference to the timing of assessment. In the clinical experience of panellists, vision screening will sometimes occur during the stroke workup depending on the patient and their presenting symptoms. The pathway should make clear that vision screening is recommended for all stroke survivors as soon as practicable, but may occur during, or after confirmation of stroke. In order to address these potential variances in timing and circumstances, the wording was further revised to include "use of a stroke vision screening tool (if not conducted during stroke workup)".

Management & Referral

The management and referral section was reviewed at length and discussion centred on revisions to management strategies, multidisciplinary management of visual conditions and addressing pre-existing eye conditions. Some discussion also occurred regarding the impact of COVID-19 on management of stroke survivors, lack of awareness of management strategies and prioritisation of referral. The inclusion of support services as part of management provision, included discussion around the importance of holistic care for stroke survivors, updates to available services and perceived limitations of these services. Revisions of management strategies were made for the acute management of visual field defects, nystagmus and reduced vision. While there is some evidence in support of the use of Pelli

prisms for visual field defects, clinical experience of panel members indicated that this was often not appropriate in the acute stages of stroke recovery as they are poorly tolerated and tend to increase confusion, particularly when there is a cognitive deficit present. A similar position was held by panellists regarding the use of Fresnel prisms for the acute management of nystagmus. It was agreed that these strategies be removed from the pathway under the acute management section.

While all panel members felt that it was important for the patient to have their prescribed glasses with them during their stroke recovery, it was noted that there are often issues surrounding this, particularly, where stroke survivors typically use or require glasses but do not have them, or may not have the correct prescription, or are sent for assessment or rehabilitation activities without their glasses or with the wrong glasses. It was suggested that the pathway include the need for education around the use of glasses for both patients and treating health professionals. In order to address this, a footnote was added to the acute management section which states "ensure near and distance glasses are differentiated and appropriate". The respective BPS were also revised to make clear the importance of stroke survivors having the correct glasses, and that they and their treating health professionals know what distance and/or tasks the glasses should be used for. A revision was also made to the long term management and referral of retinal conditions, with the removal of 'general practitioner' from this section. It was acknowledged by the group that retinal conditions often occur as a result of systemic conditions that require management by a general practitioner, such as diabetes and hypertension. However, systemic management of such conditions was deemed outside of the scope of this pathway which is intended to address vision care specifically.

Multidisciplinary management was deemed necessary for almost all visual conditions, both stroke-related and pre-existing. While this was reflected in the pathway, panellists felt that there were some health professionals missing from those listed under the management and referral section. Specifically, discussion was had around the role of physiotherapists and orientation and mobility specialists in the management of balance issues resulting from eye movement abnormalities. It was agreed that this was an essential part of effective management for these conditions and so these professions were added. The differences in the role of physiotherapists and orientation and mobility specialists was also discussed, and it was thought to be most appropriate to separate these professions in the referral list to make clear the distinction. A similar argument was made for the inclusion of optometrists in the management of eye movement abnormalities and lid/tear dysfunction. Acknowledgement was

made that while it may not be appropriate to refer to an optometrist for all eye movement abnormalities, they do hold an important role in the provision of refractive and prism correction.

The issue of access to specialist eye care services in regional and remote areas of NSW was also raised, noting that optometrists are often the most accessible eye care professionals in these areas. It was also noted that care should be taken not to encourage inappropriate referral based on limited access, as this may not be beneficial to the patient. Panellists concluded that best practice and feasible practice can at times be conflicting. In accordance with the intended aim of this pathway, it was decided that decisions should be made based on best practice alone. It was agreed that optometrists be included in the management and referral section for eye movement abnormalities, with a footnote to explain that necessity of referral would depend on the condition. Optometrists were also added to the management and referral of lid/tear dysfunction. As more specific detail was provided in the BPS regarding referral for each condition, and suggestions made for addressing accessibility issues, these were deemed appropriate revisions.

Panel members determined that there was a need to specify that the management and referral section of the pathway was inclusive of both stroke-related and pre-existing visual conditions. It was not deemed necessary to separate these within the pathway as there may be overlap between them, however, the importance of acknowledging the impact of pre-existing eye conditions on rehabilitation and recovery was stressed. While the pathway was already inclusive of treatment for both stroke-related and pre-existing eye conditions, it was agreed to revise the wording at the first stage of this section to indicate that what follows applies to both types of conditions. This was thought to help raise awareness amongst stroke health professionals and the community about the prevalence and impact of pre-existing eye conditions among stroke survivors.

Concern regarding a lack of awareness of eye conditions amongst some health professionals, extended to the management strategies for several vision conditions, including visual field defects and visual perceptual disorders. It was agreed that reference to this in the relevant BPS, be made in this section to guide users to the detail provided in relation to these strategies. Based on discussion within the meeting, the order of professionals listed for referral of each condition was also revised to reflect the priority of each. There was also mention of the changes to management practices experienced by panel members since the onset of the COVID-19 pandemic. In several cases, care provision was greatly limited during mandatory

lockdowns in an attempt to prevent patient and staff contact with many different people. As these were deemed to be exceptional circumstances and not generally applicable to stroke care provision, no revisions were suggested based on this discussion.

Information, Education & Support

The inclusion of information regarding general and vision-specific support services was seen to be highly beneficial for both stroke health professionals and stroke survivors. Panellists stated that there is generalised limited knowledge of and access to information regarding available support services among stroke health professionals. In particular, financial support services and vision-specific support services were mentioned as being highly sort after by stroke survivors. The need for a holistic approach to care provision was a key theme within this area of post-stroke vision care, with support services deemed to be essential in helping to meet the individual goals of stroke survivors' rehabilitation. It was agreed that early and ongoing engagement of a social worker or case manager for stroke survivors would help to facilitate more holistic management. Several support services listed within the pathway were updated throughout the interviews and through survey feedback, highlighting the dynamic nature of support services within NSW.

The panel noted that with frequent changes to service providers, eligibility requirements, and application processes, access to these services can be complicated. It is often difficult for stroke survivors and/or their carers to navigate these systems on their own whilst also trying to manage their recovery. The ongoing support of a social worker or case manager for stroke survivors as inpatients and continuing after discharge would likely improve access to the available services and lessen the burden of post-stroke vision impairment. The limitations of these support services were also acknowledged by panellists, particularly with regard to financial support. Inclusion criteria often limits accessibility for stroke survivors, and some services do not cover the full expense of additional rehabilitation or general support, such as My Aged Care. These services also often impose limits on the time frame in which these services are available or on the number of sessions that will be subsidised. Panellists noted that provision of information on these services should be transparent so that patients know what to expect and can better plan for these expenses.

Overall Structure & Clarity

General discussion and feedback on the pathway overall centred on the clarity of wording, level of detail provided, the structure and flow of the pathway, and visual presentation.

Revisions to wording were made throughout the consultative process based on feedback, to better reflect the intent and content of the BPS. In most cases, to improve clarity and reduce potential issues of misinterpretation, additional detail was included in the pathway (see Appendix 11.20). As revisions were made, the structure and flow of the pathway was also revised to ensure logical progression of care provision. The structure of the pathway was also reviewed to ensure that all possible outcomes of investigation were appropriate. Comments on the visual presentation of the pathway included making colour coding more intuitive and distinctive throughout the pathway. It was also noted that an alternative coding system or legend be developed for a 'black and white' pathway version, so that inability to view or print in colour did not limit the pathway's use. Finally, alignment and consistency of boxes and headings throughout the pathway were deemed important, to improve the overall aesthetic of the pathway, making it easier to follow and interpret.

Throughout all sections of the pathway, there were one or more panellists who felt that a particular topic of discussion was beyond the scope of their expertise. An example of this includes discussion of specific timeframes for acute stroke intervention, where panellists who work primarily in the rehabilitation of stroke survivors felt the need to clarify further, through review of evidence and/or consultation with other panellists working in acute stroke care. Similarly, when discussing the appropriateness of management strategies for specific visual conditions, several non-eye care specialists felt unable to comment beyond the indications of available literature, as this was outside of their area of expertise. The reoccurring nature of this theme throughout the pathway refinement, reinforced the necessary multidisciplinary nature of stroke care and the need for collaborative care provision for stroke survivors.

9.3.2 Final appropriateness ratings

Final appropriateness ratings were provided for each section of the care pathway using the RAND/UCLA definition of appropriateness as in previous rounds (Table 9.4). For those who participated in the panel meeting (n=6), these ratings were provided at the conclusion of discussion for each section and following consensus on revisions (sections 1-8). The remaining sections (9-11) were rated via electronic survey. Remaining panellists provided their scores for each section either during the individual interview (n=2) or via electronic survey (n=1).

All sections of the pathway were deemed appropriate (median score between 7 and 9) with agreement amongst the group (≤2 panellists rating outside the median tertile). For comparison with previous rounds, the IPRAS method of measuring agreement was also used and indicated strong agreement amongst panellists (IPR<IPRAS).

Table 9.4 Median panel score of NSW Post-stroke Vision Care Pathway sections presented with measures of agreement.

Pathway Section	Median Score/9	No. Outside Median Tertile	IPR[a]	IPRAS[b]
1	9.0	0	0.0	8.4
2	8.0	1	0.0	6.9
3	8.0	0	0.0	6.9
4	8.0	0	0.3	7.1
5	8.5	0	1.0	7.6
6	8.5	0	1.0	7.6
7	9.0	0	0.3	8.1
8	8.0	0	1.0	7.6
9	8.5	0	1.0	7.6
10	8.5	0	1.0	7.6
11	8.0	0	0.3	7.1

[a]Interpercentile range

[b]Interpercentile range adjusted for asymmetry

9.3.3 Stroke Survivor Feedback

Of the ten stroke survivors invited to provide feedback on the final care pathway and BPS (Appendix 11.20), seven provided a response. Simple content analysis of the written feedback provided indicated that all stroke survivors felt that the pathway was inclusive of all potential modes of presentation for stroke survivors with visual symptoms. All stroke survivors in this group also felt strongly about the need for inclusion of eye care specialists within acute and rehabilitation stroke teams. Many referenced personal experience of delay in eye care provision and lack of access to specialist consultation. They viewed the inclusion of specialist eye care services in stroke facilities to be of great importance to overall stroke recovery. Most stroke survivors (n=5) felt that use of the pathway and BPS would have helped to meet their post-stroke vision care needs. Of those that did not feel the pathway would have improved their experience of post-stroke vision care (n=2), one stated that this was because they received stroke care within the paediatric system at the time. This meant that they had eye care specialist services available to them during their acute and rehabilitative care and were assigned a case manager who ensure their vision care needs were addressed. The other stroke survivor felt that the pathway needed simplification and suggested some form of regulation process to ensure that all health professionals mentioned in the pathway and/or BPS followed

and implemented these guidelines appropriately. With respect to short-term vision management strategies, all stroke survivors felt that implementation of these strategies would be beneficial to stroke survivors as inpatients. Perceived benefits included a reduced burden of vision problems during rehabilitation exercises and early introduction to management techniques helping to form better long-term adaptation. However, one stroke survivor indicated that long-term management strategies were most important and thought that short-term management should not be provided in place of this. Finally, the inclusion of reperfusion therapy timeframes was viewed to be important and relevant to this pathway by the majority of stroke survivors (n=6). They felt that the time-critical nature of these therapies needed to be clearly communicated as they can greatly impact the outcome of stroke with respect to all types of deficits including vision. One stroke survivor felt that awareness of these timeframes was important, but not relevant to vision care.

9.4 Discussion

Consensus has been reached on the final NSW Post-stroke Vision Care Framework (NSW-PVCF) (Appendix 11.20), inclusive of 43 best practice statements across all stages of post-stroke vision care, using a modified RAM[277] quality indication development and validation process. Development of the NSW-PVCF occurred in response to evidence from stroke health professionals and stroke survivors with vision impairment in Stage One, that there is a need for detailed guidelines and a clear pathway for the provision of post-stroke vision care in Australia. The 43 statements and diagrammatic pathway are a considerable expansion to the current vision related recommendations contained in national and state-based stroke guidelines.[52] While a lack of awareness and guidance pertaining to vision problems is evident across all stages of stroke care in NSW, the greatest burden for stroke survivors' results from an absence of ongoing management and support following discharge.[36,111] This area is addressed extensively in the NSW-PVCF, in order to reduce the burden of vision impairment on stroke survivors by increasing awareness of the management strategies available and encouraging a holistic care approach. Multidisciplinary referral, as well as facilitated access to support services, can aid rehabilitation and reintegration into the community[36] while reducing the psychological, social and financial burdens of post-stroke vision impairment.[111]

Post-stroke vision care is a developing area of research in Australia and overseas. Much of the available evidence on this topic has emerged from countries within the UK and Europe,[21,49,51,124,231,245] with a limited number of Australian studies published on assessment of vision problems in stroke survivors.[28,48,61] As such, many of the BPS were supported by

qualitative evidence or expert opinion. While a lack of high-quality evidence within the context of Australian healthcare is a potential limitation in pathway development, it also highlights these evidence gaps and may help to focus research on these areas of practice. A clear limitation of this pathway, resulting from a lack of available Australian evidence is the inability to identify differences in post-stroke vision care needs of First Nations people. Evidence indicates that Aboriginal and Torres Strait Islander Australians are at greater risk of non-stroke related visual conditions such as diabetic retinopathy and typically develop these conditions at a younger age than non-Indigenous Australians.[169] It is also known that First Nations people are at greater risk of stroke at a younger age when compared to non-Indigenous Australians.[286,287] As young stroke[288] and occipital stroke[289] are risk factors for delayed stroke diagnosis and access to care, and young Aboriginal and Torres Strait Islander Australians are more likely to have pre-existing visual conditions, it is fair to assume that Aboriginal and Torres Strait Islander stroke survivors with vision problems may suffer greater inequities in access to post-stroke vision care. This is compounded further by the fact that a greater proportion of the First Nations population of Australia live in regional and remote regions of the country[290] where healthcare services are more limited. It is then reasonable to assume that First Nations people may have different and potentially more complex post-stroke vision care needs than non-Indigenous Australians. It should be noted that it is unknown whether the views represented in this thesis are representative of any First Nations people, as this data was not collected. Participants in the PRECiS Study were not asked if they identify as Aboriginal and/or Torres Strait Islander, as investigation regarding this population specifically was outside of the scope of this doctoral project. Further research is needed on this topic to ensure that the current care pathway and recommendations are suited to the needs of Aboriginal and Torres Strait Islander populations and encourage culturally appropriate working practices.

Given the limited evidence available on post-stroke vision care pathways and practices in Australia, use of a modified RAM method was ideally suited to the development and validation of the NSW-PVCF, utilising a combination of research evidence and expert opinion.[277] This method offers the advantage of providing panellists the opportunity to provide individual feedback on their BPS ratings, as well as to discuss their underlying opinions and assumptions within the group, in relation to source evidence and appropriateness of the pathway.[291,292] There were very high levels of agreement in all rounds, despite panellists having different disciplinary backgrounds and working in different areas of stroke care. This highlights the obvious benefit of the BPS and pathway to stroke survivors as perceived by health professionals working in stroke care within NSW.

Another strength of PRECiS: Stage Two design is the engagement of a diverse range of stakeholders within the validation process. Panellists encompassed almost all of the main health disciplines who are typically involved in the provision of care to stroke survivors, including neurologists, stroke nurses, physiotherapists, speech pathologists, occupational therapists, social workers, neuro-ophthalmologists, orthoptists, and orientation and mobility specialists. Panellists in PRECiS: Stage Two also worked across several areas of stroke care such as acute and rehabilitative care, inpatient and outpatient services, as well as in research, and were inclusive of services within the private and public sectors and located in both major cities and regional areas of NSW. While the representation of stroke health professionals was extensive, it is possible that the judgements made by a single panel may not be representative of all clinicians, researchers, and policy makers.

Not all panellists were able to attend the video-conference panel meeting and provided their input and ratings via interview or survey after being provided a summary of the panel meeting discussion. While their input was considered cumulatively in the analysis, their absence may have affected the initial discussion that took place. As the panel meeting took place during NSW lockdowns occurring in response to the outbreak of the COVID-19 delta variant, it is possible that the discussion and evaluation of the pathway may have been unintentionally influenced by changes in healthcare practices occurring at the time. As the pandemic continues to place strain on the Australian healthcare system and impose change on the ways that care is provided across all areas of health, implementation strategies may need to be developed that account for accessibility of staff and redirected resources.

According to the RAM definition of appropriateness, a procedure or practice is deemed appropriate if "the potential benefit to the patient outweighs the potential risk by a significant margin, irrespective of financial cost".[277(p30)] Based on this definition, all BPS were deemed appropriate, with minor revisions made to most. Despite this, feedback and discussion amongst panellists repeatedly raised issues around practicality and feasibility regarding access to specialist eye care within stroke services. It is clear that eye care specialists such as ophthalmologists and orthoptists are not included within stroke care teams as a standard within Australia at present, and issues regarding access to specialist staff is likely more apparent in regional and remote areas. There are several potential reasons for this, such as a lack of awareness regarding the need for eye care services as part of stroke care provision, a shortage of appropriately trained eye care specialists available to meet this need, or a lack of opportunity for eye care specialists to work within stroke care settings.

As NSW has ophthalmology, orthoptic and optometry training programs, it seems unlikely that a shortage of appropriately trained eye care specialists is a major cause of these access issues. However, there is an inequality in access to specialist health services between metropolitan and rural areas of Australia,[261] and it is probable that this inequality extends to vision care and more specifically, post-stroke vision care. Further research is needed to quantify this inequality and identify the issue behind a more generalised lack of access to post-stroke vision services, as well as how best to address this through policy and resourcing. By demonstrating the way in which vision care should be provided to stroke survivors and providing a clear indication of the health professionals who should be involved, the pathway may highlight the need for change in stroke care services across NSW. The NSW-PVCF also aims to raise awareness of post-stroke vision care needs and how best to address these in order to reduce the burden of vision impairment during stroke recovery.

While the initial development of the BPS was based on evidence from stroke survivors in NSW regarding their experience and vision care needs (Stage One), the final NSW-PVCF was returned to a group of stroke survivors for further consensus. This is an additional strength of the current study design, as it ensures engagement of stroke survivors as key stakeholders throughout the entirety of the pathway development. Discussion of the pathway and BPS amongst panellists highlighted some potential discrepancies in aspects of care deemed important or relevant by health professionals compared to patients. For example, panellists debated whether inclusion of reperfusion therapy timeframes was within the scope of the pathway and necessary for inclusion. However, when stroke survivors were consulted, the majority felt that this was important information, particularly for stroke survivors with visual symptoms, as the lack of awareness of stroke-related visual symptoms can often result in a delay in access to stroke care and hence exclusion from time-sensitive interventions. This reinforces the need for inclusion and consultation of all stakeholders when developing guidelines, particularly in healthcare, as there can often be differences in value placed on information and/or procedures between the different stakeholder groups.

Competing priorities among health professionals of different disciplines also became apparent at times. Eye care specialists saw benefit in providing vision care prior to the commencement of other rehabilitation therapies to ensure that vision problems could be accounted for during these exercises. However, non-eye care health professionals felt that making vision assessment mandatory before commencing further rehabilitation might in fact delay rehabilitation efforts and be of detriment to the patient. Both arguments were valid with respect to benefit offered to the patient and hence were equally represented in the BPS. This

demonstrates the importance of representation of different perspectives on care provision, particularly in complex, multifaceted conditions such as stroke.

The pathway and majority of the BPS are transferable to all Australian states and territories and should be internationally applicable to countries with similar healthcare systems. The only other Australian state with an orthoptic training program is Victoria, and so access to specialist staff may be a more apparent issue in other parts of the country. However, as in NSW, use of the pathway across Australia will likely bring to light necessary change that is required within stroke care, to ensure vision and eye health is appropriately addressed. While some countries with developed healthcare systems have surpassed Australia in addressing this gap in stroke care, there may be others that face similar issues with regard to geographic complexities and access to specialist staff. This may be an increasing challenge since the onset of the COVID-19 pandemic and the increased pressure placed on healthcare systems globally. Countries such as those within the UK have well established stroke care guidelines that specifically address vision problems and list orthoptists as necessary members of the multidisciplinary stroke team.[182]

Researchers from the UK have also recently developed a post-stroke vision care pathway that further clarifies how such guidelines should be implemented.[231] However, these countries have much larger populations,[293,294] are more densely populated[293,294] and have very different geographic and cultural landscapes, in comparison to Australia. This, along with other considerations for comparison of the NSW-PVCF and similar international research, is presented in Chapter 10. Although Australia can be considered unique in the challenges its healthcare system faces, the strategies used to address these may be transferable. In particular, the challenge of providing equitable, high-quality healthcare in a country where most of the land is sparsely populated,[18] geographically diverse and there is a proportionately small, ageing population, is ongoing.[295] The NSW-PVCF encourages holistic care provision, multidisciplinary collaboration, and the utilisation of advancing technologies to improve quality and access in post-stroke vision care. This approach is widely applicable to vision care provision, however some adaptation may be required for use in other nations, particularly for those recommendations that have been heavily contextualised for practice in NSW, such as those pertaining to support services and driving regulations. Future research may hence look to develop international consensus on applicable aspects of post-stroke vision care pathways in relation to the primary components of care.

The developed BPS for post-stroke vision care, as part of the NSW-PVCF, are evidence based and expert-endorsed. The combined guidelines address the gap in current post-stroke vision

care provision in NSW by providing clear recommendations for best practice in this area, that are suitable for implementation in NSW. The development of the NSW-PVCF is a foundational step for a necessary state-wide and potentially national implementation effort in providing timely and appropriate vision care for stroke survivors.

10 SUMMARY AND CONCLUSIONS

Stroke continues to be a major cause of death and disability within Australia.[6,9] Development of evidence-based stroke care guidelines such as the Stroke Foundation's Australian Clinical Guidelines for Stroke Management[52] strive to improve stroke care practices across the country. Such guidelines help to reduce the burden of stroke on survivors and their families, as well as to the general community, by better facilitating timely rehabilitation and enabling stroke survivors to reintegrate into their community following discharge. Certain aspects of stroke recovery that previously did not receive as much as attention in Australian health care, such as the psychological impacts of stroke, now have a greater focus within Australian stroke guidelines and care practices.[52] Whilst this is a promising step forward in ensuring holistic care for Australian stroke survivor's, there remains an alarming gap in current guidelines and post-stroke care practices with respect to visual rehabilitation.

Visual impairment is a common consequence of stroke, occurring in approximately 60% of stroke survivors.[21] There is also a high prevalence of age-related visual conditions amongst Australians over the age of 65 years,[24,28,29] who are most at risk of stroke.[8] As such, the PRECiS study aimed to determine in detail the current post-stroke vision care pathways and practices in NSW, and whether they are successfully meeting the vision care needs of stroke survivors. This information, combined with the existing evidence-base pertaining to the assessment and management of stroke-related vision problems, as well as input from key stakeholders, was then used to develop a post-stroke vision care framework, suitable for use in Australia. While there is an identified need nationwide, the PRECiS study was confined to NSW due to timing and resource constraints. NSW was chosen as it is the state in which the research team is based and has the highest population of all Australian states and territories, as well as having geographical and demographical diversity. Due to the inclusive nature of the PRECiS study design, it is likely that the findings of this study are applicable nationwide.

Chapter 2 provides an overview of the vast array of visual conditions that can occur within this population, the impacts these conditions may have on functional vision, and how these are best identified and managed. Despite the availability of this information, the Australian Clinical Guidelines for Stroke Management[222] only contain limited guidance regarding post-stroke vision problems. A scoping review of current post-stroke vision care pathways and practices in Australia described in Chapter 3, revealed that there has been very little research performed in Australia on this topic, with no published protocols or pathways to support Australian stroke health professionals in the provision of post-stroke vision care. Much of the available evidence

on this topic has emerged from countries within the UK and Europe,[21,49,51,124,231,245]with a limited number of Australian studies published on assessment of vision problems in stroke survivors.[28,48,61,63] Surveys of stroke health professionals performed in Scotland indicated that only a small proportion (9-12%) of respondent's report having access to protocols for post-stroke vision impairment.[49,124] More recent research has shown improvement in this area across the UK, with 44% of stroke health professionals utilising post-stroke vision care protocols in 2015,[50] and 85% in 2019.[230] This improvement is the likely result of a growing evidence base relating to the provision of post-stroke vision care in this region,[22,36,47,49,62,66,108,124,227,231] as well as the inclusion of vision specific information within UK stroke guidelines,[182] which name orthoptists as necessary members of the multidisciplinary stroke team.

The available evidence worldwide also indicates significant inconsistencies in how vision problems are assessed[50,51,183,228] and managed[49,51,217,227,230] within stroke care settings, as well as a generalised lack of awareness of stroke-related vision problems among health professionals[27,124] and the general public.[220,245] As indicated in Chapter 3, the evidence pertaining to post-stroke vision care practices and pathways in Australia and comparable countries is limited. Only six of the 28 articles identified in the literature review were Australian,[17,48,61,63,112,227] of which the majority investigated the efficacy of vision assessment[61] and screening[63,227] methods in stroke survivors. While research of this nature is essential in informing best practice methods in this area of Australian stroke care, it only provides insight into one aspect of a vast and complex care pathway. Several of these studies were also conducted in a small cohort and confined to services within Sydney,[48,61,63,227] which can limit the applicability of results. Some Australian studies provided information on management and referral practices,[17,112] however, these were either not investigating vision exclusively[17] or were conducted across a select number of services within a single local health district in Sydney,[48,112] and so could not provide generalisable information on referral patterns or typical management practices. When considering the literature available internationally in addition to that in Australia, many of the relevant studies providing information on other areas of post-stroke vision care have similar limitations. With the exception of the studies conducted in the UK [49, 122, 27, 218,225, 228,229,231], those offering information on management and referral were often specific to a single service [51,181] or were qualitative studies conducted with a relatively small number of stroke survivors.[215,218, 230] In addition to the larger sample sizes and broader reach of several UK studies,[47,62, 111,122,182,225,226,228,229,231,238] the strength of the research on this topic

conducted within this region is the collective body of evidence, which provides more in depth and wholistic insight into UK post-stroke vision care practice.

When reviewing the information available on vision care services within NSW stroke care facilities in Chapter 1, it appears that visual rehabilitation is not a well-resourced area of stroke care within Australia. The lack of vision specific protocols, and specialised vision care services, within Australian stroke care facilities and literature, alludes to a large gap in stroke care with respect to vision and a need for detailed, evidence-based guidelines on post-stroke vision care provision specific to Australia. This set the stage for the PRECiS studies reported in this thesis.

10.1 PRECiS Study: Stage One

Stage one of the PRECiS study aimed to establish post-stroke vision care practices in NSW from the perspectives of both the stroke survivors and the health professionals involved in their care. PRECiS: Stage One utilised a mixed methods design to explore current practices and barriers to care, which is detailed in Chapter 4. The results of the PRECiS Study: Stage One (Chapters 6 and 7) provided much needed insight into the success and failures of current post-stroke vision care practices in NSW and was integral to informing the initial development of the NSW Post-stroke vision care framework evaluated in stage two.

10.1.1 Health Professional & Stroke Survivor Surveys

The surveys were piloted and found to be feasible for use in both participant groups (see Chapter 5). The results of the SSS and the HPS detailed in Chapter 6 revealed a number of sub-par vision care practices experienced by respondents. An overwhelming majority of health professionals reported that their workplace did not have a protocol or care plan that included, or was specific to, vision problems following stroke. This supports the findings of the scoping review conducted in Chapter 3 that indicated a lack of formal guidelines for post-stroke vision care in Australia. In their survey, stroke survivors reported that vision assessment often did not occur in a timely fashion following stroke, with over a quarter of them having no vision assessment at all in the six months following their stroke. Only half of stroke survivors report having a vision assessment within six weeks of their stroke, despite evidence indicating that most stroke survivors are able to undergo vision screening within 3 days of their stroke.[171] Health professionals reported highly variable practice relating to the timing and routine implementation of vision assessment, with some indicating that this occurred on admission or first visit and others assessing vision only if vision problems were reported/suspected. The variation in timing of initial vision assessment of stroke survivors is unsurprising, as respondents worked in a variety of health care settings including acute stroke wards, mixed

stroke wards, rehabilitation facilities and ophthalmology clinics, but still indicates a lack of recommended practice.

According to the SSS, when vision assessment was provided, very few assessments occurred on the stroke ward, with most taking place in an eye clinic external to the treating hospital. This indicates a lack of collaborative vision-stroke services available in NSW hospitals and likely contributes to a delay in the identification of vision problems in stroke survivors. The data also shows that a large proportion of vision assessments are conducted by non-eye-care health professionals, increasingly so when looking at vision assessments performed on the stroke ward only. This would indicate that specialist eye care professionals are not typically part of the multidisciplinary stroke team in NSW facilities. The health professional performing initial vision assessment, according to the HPS, was often an orthoptist or ophthalmologist, with the remaining reporting a variety of non-eye-care health professionals as the person responsible for vision assessment in their workplace. This supports the results of the stroke survivor survey and reinforces a suspected lack of eye care specialists in stroke services within NSW. Somewhat contradictory to this is the proportion of health professionals reporting having orthoptists (38%) and ophthalmologists (33%) as part of their stroke multidisciplinary team. A possible explanation for this is that eye care specialists within the multidisciplinary team do not conduct initial vision assessment but are involved in follow-up and management of suspected visual conditions. An even more likely explanation is that eye-care professionals are over-represented within this sample and hence involvement of eye care professionals in stroke care is over-estimated by this survey.

The lack of available eye care professionals in stroke care settings may necessitate the use of a screening tool developed specifically for stroke-related vision defects, coupled with education for non-eye-care stroke health professionals, to better support them in the accurate identification of vision problems. Such screening tools have been developed specifically for use in stroke populations,[28,47,63] with the SVDST freely available for use by NSW health professionals.[266] Of concern is the extremely low proportions of health professionals reporting use of these vision screening tools (7%). The failure to routinely use such tools indicates a lack of awareness of the vision care resources available to NSW stroke health professionals and reaffirms the need for a standardised set of guidelines to improve this.

More than half of stroke survivors were not provided a care plan on discharge from their treating hospital. Of those who were provided a care plan, the vast majority did not include any management options for their vision problems. Most stroke survivors did not receive any

assistance or short-term management for their vision problems as an inpatient and did not receive an eye care referral prior to discharge. Similar trends in management and referral were also reported in relation to rehabilitation facilities. This suggests that management of vision problems is often overlooked in current NSW stroke care, possibly because stroke care facilities are not equipped to provide this and a lack of awareness and education in this area of stroke rehabilitation. The HPS indicated that some visual conditions, such as visual field loss and visual neglect, were more likely to be treated internally than referred for treatment. This may be due to a greater awareness of these conditions and their management strategies amongst stroke health professionals. This greater awareness of these specific conditions is likely, as they are the only visual conditions mentioned in the Australian Clinical Guidelines for Stroke Management.[52]

Health professionals identified a lack of protocol or management plan as the primary barrier they experienced in providing appropriate post-stroke vision care, while stroke survivors found provision of information about their post-stroke visual impairment was lacking and inconsistent between stroke care facilities. A large proportion of stroke survivors also felt that their vision care needs were not successfully met by the treating hospital, or the care plan/ referrals provided. Reported reasons for this primarily related to a general absence of vision care during their stroke recovery, or provision of care that was non-specific or inappropriate for their visual condition. Worryingly, most stroke survivors felt that their vision impairment had a moderate to severe impact on their daily lives. It can be assumed that appropriate and timely information and referral for management of stroke-related vision problems would reduce the impact of these conditions on the lives of Australian stroke survivors, both during their recovery and in the long-term.

10.1.2 Stroke survivor interviews

In Chapter 7, the pitfalls in post-stroke vision care practices identified through the health professional and stroke survivor surveys were strongly reaffirmed through the stroke survivor interviews. The interview data provided much needed insight into how these pitfalls impacted stroke survivors in their recovery. It also allowed understanding of what aspects of post-stroke vision care stroke survivors felt were most important and why. For example, the surveys indicated that vision assessment for stroke survivors in NSW often doesn't occur in a timely manner. For stroke survivors who did not have timely vision assessment, this created additional anxiety caused by the uncertainty of the existence and/or diagnosis of their vision problem and the likely prognosis. Stroke survivors also felt that an early vision assessment

would have allowed them to begin management sooner and perhaps improved their chance of recovery or better facilitated adaptation to their vision loss.

Similarly, the lack of vision specific information provided to stroke survivors identified in the survey was reinforced by the recounts of stroke survivors and carers during the interviews. This lack of appropriate and timely information made them feel uncertain and unsupported in their visual rehabilitation journey. The interview data also revealed the importance of delivering information in a format that is appropriate and tailored to the individual needs of the stroke survivor. For those who did receive information, this was often only provided verbally and therefore often not retained or understood due to cognitive deficits caused by the stroke, or caused stroke survivors to be overwhelmed during the early stages of acute stroke.

Stroke survivors reported increased difficulty and discomfort during their recovery and rehabilitation from a lack of short-term management accessed while they were inpatients, again echoing the survey data that inpatient management of vision problems was often not provided. The stroke survivor interviews also revealed that many stroke survivors had to seek out vision care themselves following discharge from their treating hospital, which was often an overwhelming and lengthy exercise involving multiple referrals before arriving at an appropriate care provider. This caused delays in receiving appropriate management and increased financial expense for many.

The interview data also provided novel and detailed information regarding the barriers to vision care experienced by stoke survivors. Some of the barriers, such as the stroke survivor having serious health issues requiring urgent attention thus preventing participation in vision care activities, are not able to be overcome. There were, however, a number of barriers identified that highlighted areas of vision care provision that can be improved. Importantly, improving access to specialist eye care personnel and services in metropolitan and rural areas of NSW appears key. This suggests that greater collaboration between eye care services and stroke teams is needed across all stroke care facilities. In addition to this, the interview data strongly indicated a need for improved education and training on post-stroke vision problems amongst stroke health professionals.

Many stroke survivors and carers were unaware of the visual symptoms of stroke and delayed contact with healthcare services as a result. Public awareness campaigns on visual stroke symptoms are likely to aid more timely presentation. For some stroke survivors who did present to healthcare services immediately, their visual symptoms were dismissed or misdiagnosed by misinformed health professionals. Education on the presentation and

identification of stroke-related vision problems for general medical staff (general practitioners, nurses, paramedics and emergency department staff) as well as for the public, is essential in avoiding delayed presentation to hospital, misdiagnosis and consequent delayed treatment of stroke and associated visual conditions.

The interview data also provided unique insight into the impacts of vision impairment on the daily lives and long-term rehabilitation of stroke survivors. For many, vision impairment significantly impacted independence through reduced mobility, and inability to work and/or drive. Furthermore, there was a strong emotional impact noted by stroke survivors, that again reinforces the importance of timely provision of vision care for stroke survivors that is holistic in nature. Specifically, in addition to managing the visual condition, vision care should be inclusive of social workers and support services to better equip stroke survivors and their carers to deal with the financial, emotional, and functional implications of the stroke survivor's vision impairment.

10.1.3 Comparison of Surveys and Interviews

The survey results presented in Chapter 6 report the different perspectives and experiences of post-stroke vision care provision of stroke survivors (SSS) and stroke health professionals (HPS). Differences between the results of the two surveys were found (see 6.3.7), particularly in relation to the timing of assessment and provision of information and support. However, it should be noted that these differences in reports from the two groups may not be indicative of true disagreement, but rather may be reflective of the differed perspectives held. Despite this, there were oftentimes strong agreement between the two groups, specifically in relation to the perceived barriers to care. Interestingly, similar trends in agreement and disagreement occur when comparing the results of the surveys to the interview data.

The surveys show that stroke survivors and health professionals alike report a generalised delay in initial vision assessment, although seemingly more significant when comparing the delay reported by health professionals (2-6 weeks post-stroke) and stroke survivors (approximately one third being assessed within 6 weeks of stroke). Stroke survivor interviews (Chapter 7) also indicate that the majority did not have their vision assessed within 6 weeks of their stroke, and often not within 6 months of their stroke. The interviews revealed that the consequence of this was often heightened feels of anxiety and distress about the unknowns of their visual condition. The location and timing of initial vision assessment reported by interviewees also coincides with survey reports by health professionals regarding access to specialist eye care staff. The majority of health professionals report that initial vision

assessment takes place in an eye clinic external to their stroke service, as was the case for most of the interviewees. The HPS also reported low numbers of eye care professionals included in stroke care teams which was supported by stroke survivors in their interviews whose vision was often initially examined by their treating neurologist or an occupational therapist.

Greater discrepancy is noted between the groups when reporting on management of poststroke vision problems. The data from the HPS indicates that management (unspecified) is typically provided to stroke patients if an eye condition is identified, however, it may only be provided as a one-off service and it is not possible to ascertain if it is the most appropriate form of management for the stroke survivor's condition. In contrast, the vast majority of stroke survivor interviewees report not receiving any form of eye care management as inpatients and most did not receive a referral to an eye care professional. While the disagreement in reports regarding provision of management may in part be accounted for by vision problems not initially being identified by health professionals, interview participants also reported a lack of vision management options provided and no onward referral to an eye care professional following a visual diagnosis. Stroke survivors frequently reported increased difficulty and discomfort during their recovery and rehabilitation from a lack of short-term management accessed while they were inpatients. This lack of inpatient vision management is supported by the HPS data which shows that 'inhouse' management was only a frequent occurrence for certain visual conditions (visual field loss and visual neglect).

Similarly, when reporting on the provision of information pertaining to stroke-related eye conditions, results from both the HPS and SSS indicate that this is not uniformly provided to stroke survivors in NSW, and often does not include crucial information on management and support services. In the interviews, most stroke survivors were provided general information about stroke and were advised not to drive if vision problems were identified. Most were not provided information specific to their visual condition and were not provided with information in an appropriate and accessible format, which caused undue confusion and distress to stroke survivors and their loved ones. While a direct relationship cannot be concluded from the data in this study, it may be speculated that appropriate and specific vision information is not routinely provided within NSW stroke services because: 1) the majority of stroke services do not have access to specialist eye care staff, 2) non-eye care health professionals are not aware of or provided appropriate training on vision problems, and/or 3) the relevant information is not easily accessible to stroke health professionals.

For stroke survivors, a lack of information, management options and appropriate referral were the primary barriers they reported in the SSS, preventing successful provision of vision care. In the interviews, stroke survivors often discussed barriers pertaining to their treating health professionals being seemingly dismissive or inattentive to their vision problems, providing misinformation about their visual condition, and/or not being able to provide them with appropriate management or support for their vision problems. In the HPS data there is some evidence in support of this when comparing the barriers that health professionals encounter in providing post-stroke vision care. Health professionals reported a lack of clear, evidence-based guidelines in conjunction with limited access to specialist staff, as primary barriers to the provision of appropriate post-stroke vision care. Secondary barriers identified by health professionals were a lack of timely referral to appropriate vision services, limited time to perform assessment or treatment, and insufficient skills or experience to confidently provide vision care. When comparing the results of the surveys and interviews, it becomes clear that the barriers identified by the health professional group could lead to those identified and experienced by stroke survivors.

10.2 PRECiS Study Stage Two

The final output of PRECiS: Stage Two and the consultative process described in Chapter 8, was the NSW Post-stroke Vision Care Framework (NSW-PVCF) consisting of 43 best practice statements and a diagrammatic care pathway (Chapter 9). The newly developed pathway begins at presentation to health services, with suggested actions categorised by the type of visual symptom and the length of time since onset. Different possible outcomes are then stated and addressed in the pre-hospital stage. Following confirmation of stroke, the pathway suggests use of a vision screening tool for all stroke patients within two weeks of regained consciousness or prior to commencement of rehabilitation activities with further detail provided in the accompanying best practice statements. Those who are suspected of having a vision problem based on well-designed screening are then recommended for a comprehensive ophthalmic or orthoptic assessment as soon as practicable. This provides a uniform standard for post-stroke vision assessment that is not evident in current clinical practice.

Those who have a confirmed vision problem should then be provided information on their diagnosis in an appropriate format and given short-term management strategies appropriate for their condition. Prior to discharge from a treatment facility, stroke survivors should again be provided information about their visual condition, as well as any necessary and relevant referrals and management plans. These are categorised as referrals for treatment or

rehabilitation, for support services and for financial support. This section addresses the repeatedly reported issue of a lack of vision rehabilitation offered to stroke patients. It also ensures that a more holistic approach is taken in forming vision management plans by the inclusion of community support services and information on available financial aid.

A sub-sample of stroke survivors from PRECiS: Stage One were contacted via email and invited to complete a short, free text response survey in relation to the framework. The questions asked about specific areas of the framework that retained some level of uncertainty amongst the panel, as indicated by the qualitative analysis of round three discussion. The feedback from stroke survivors was uniformly positive with regard to potential modes of presentation (e.g. first presentation was to optometrist, general practitioner, emergency department) in the pathway, the inclusion of eye care specialists within stroke teams, the use of short term vision management strategies for stroke inpatients and the inclusion of reperfusion therapy timeframes. Most stroke survivors felt that use of the framework would have helped to meet their post-stroke vision care needs.

The 43 statements and diagrammatic pathway are a considerable expansion to the current vision related recommendations contained in national and state-based stroke guidelines.[52,224,225] There were very high levels of agreement between panellists in all rounds, despite their diversity in disciplinary background and differences in the stroke care setting in which they worked. This highlights the obvious benefit of the BPS and pathway to stroke survivors, as perceived by health professionals working in stroke care within NSW. Studies investigating the implementation of stroke clinical care pathways have shown improvement in multidisciplinary coordination in stroke care provision, reduction in length of hospital stays, and overall health costs.[241]

A similar post-stroke vision care pathway was recently developed by researchers in the UK,[231] and is the only other known, published, post-stroke vision care pathway to have been developed. This pathway provides similar information with regard to the differing modes of presentation for stroke survivors with vision problems, and the suggested referral pathways. There are notable differences between the pathway developed by Rowe et al. (2020)[231] and the pathway presented in the current study. These relate primarily to the differences in stroke and vision care services available within the UK versus Australia. In particular, the UK pathway specifically mentions referral to hospital-based optometry, orthoptic, and low vision services, which are often absent in Australian hospitals. There are also notable differences in community-based support services, and financial support services between the UK and

Australia, and hence between the pathways. The NSW PSVCF also includes a greater level of detail with regard to vision screening methods, timing, and management strategies. This level of detail was deemed necessary during the development of the NSW PSVCF due to a lack of Australian-based information and guidelines in this area of stroke care available elsewhere. In contrast to this, there is greater availability to vision specific information in UK stroke guidelines[182] and through organisations such as the British and Irish Orthoptic Society (BIOS).[296] It is also of importance to note that countries within the UK generally have much larger populations,[293,294] are more densely populated[293,294] and have very different geographic and cultural landscapes in comparison to Australia. As such, the NSW-PSCVF was developed in consideration of the unique characteristics and challenges presented within the context of Australian healthcare. However, the strategies employed in this framework may be transferrable to other countries looking to overcome challenges in delivering equitable, high-quality healthcare in a country where most of the land is sparsely populated,[18] is geographically diverse, and/or has a proportionately small, ageing population.[295]

10.3 Strengths and limitations

The stroke survivor's survey distributed as part of Stage One of the PRECiS Study, was designed to be as broadly inclusive as possible, with simplified language, adjustable text size, text-to-speech functionality, and the option to save responses so that the survey could be completed in stages to account for fatigue. The time taken to complete the survey was also found to be feasible (Chapter 5) and of a similar length to other surveys conducted with stroke survivors.[249] Similarly, the length of the health professional survey may have affected the number of responses obtained. Health professionals working with stroke patients are typically in a patient-facing role for the entirety of their workday and hence time poor. This was considered carefully during the survey design, and attempts were made to reduce the length of the survey while preserving the ability to capture all relevant data. The feasibility study (Chapter 5) demonstrated that the average completion time was approximately 15 minutes, which is similar to other surveys conducted with stroke health professionals.[124,228]

The primary limitation of PRECiS: Stage One was the lower-than-expected response rate to both the health professional and stroke survivor survey (Chapter 6). Unfortunately, we were unable to reach the recruitment target for either group despite extensive recruitment efforts and varied survey dissemination strategies. There are several potential reasons for the low response rate amongst the two groups. It is possible that the target of 100 stroke survivors did not account for the number of stroke survivors within the eligible time frame who were still

suffering from physical and/or cognitive deficits that prevented them from participating. While the design of PRECiS: Stage One did allow for carers to complete the survey on their behalf, the survey did require carers to be able to communicate with and receive input from the stroke survivor in order to provide an accurate response.

The initial outbreak of COVID-19 also occurred during the time of PRECiS: Stage One recruitment, which undoubtedly impacted the response rate for both surveys. While survey completion did not require face-to-face interaction with participants, the public health orders in place at the time limited face to face opportunities for recruitment, which are more effective means of recruiting in older populations. This reduced access to the age group most affected by stroke may have had implications for awareness of the study within this population. As older people were also amongst the most vulnerable to the COVID-19 virus, heightened psychological stress may have reduced willingness to voluntarily participate in research. The same might be said for health professionals during the pandemic, as the health system was under immense strain due to reduced staff numbers, heightened risk for staff and the introduction of many new safety protocols.

As the intention of the surveys was to describe the post-stroke vision care pathways and practices in NSW at the time of the survey, and the data captured was descriptive in nature, statistical estimations of appropriate sample size were not applicable. Instead, we used sampling error as a measure to guide recruitment targets. In doing so, we intentionally over-estimated potential sampling error, by basing this calculation on the least sensitive form of measurement in a survey ('yes'/'no' responses) and the highest possible sampling error response split (50/50). As the vast majority of questions asked in both surveys were not 'Yes'/'No' questions, this greatly reduces the potential sampling error, despite the below-target sample size. Also, there were no data points that demonstrated an exactly equal response, hence further reducing the sampling error within the survey data. As such, it can be assumed that low response rates have not dramatically impacted the quality or validity of the data. We were also able to obtain responses from varied participant groups, ensuring that a broad range of experiences and perspectives were represented. For example, the stroke survivor group contained an equal mix of men and women, as well as a mix of those living in major cities, regional, and remote areas, proportional to the overall population of NSW. Similarly, the health professional group contained respondents from a wide range of health disciplines relevant to stroke care, as well as roughly equal numbers of eye-care specialists and non-eye-care specific professionals.

Another limitation of PRECiS: Stage One is the potential for recall bias, which may be more likely to occur in a stroke survivor population and hence may be relevant to both the survey (Chapter 6) and interview data (Chapter 7). The inclusion and exclusion criteria for the sample population of this survey aimed to reduce recall bias by ensuring that stroke survivors were at least 3 months post-stroke and were excluded if their stroke was more than 10 years ago. To obtain a more accurate representation of the vision care received by stroke survivors in NSW, a retrospective audit of patient files could be performed. However, this information would need to be collected from the first point of care, treating hospital, rehabilitation facility and community-based care services for all patients in order to provide an overview of entire post-stroke vision care journey. Unfortunately, this was not possible with the resources available to this study. Such a study design also does not allow for insight to be gained into the human experience, which is essential in understanding the reasons for certain limitations in practice, the relative importance of particular aspects of care to patients and their implications. The ability to capture and explain these facets of post-stroke vision care is a strength of PRECiS: Stage One and provides an invaluable contribution to the knowledge base in this area of healthcare.

PRECiS: Stage Two (Chapters 8 and 9) continued to be impacted by the COVID-19 pandemic in similar ways, as the outbreak of the delta variant occurred during the time of recruitment and data collection. Strict stay-at-home orders were enforced within NSW during this time and the strain on hospitals and healthcare facilities had reached a peak. This again made accessing healthcare professionals difficult and resulted in a significant drop-out rate as we progressed through each round of evaluation. However, according to the RAM guidelines used to inform PRECiS: Stage Two design, only nine panellists were needed in order to evaluate the appropriateness of healthcare guidelines. Following difficulty with recruitment in Stage One, we intentionally recruited a number of health professionals well over this target in the first round of evaluation to account for potential dropouts.

We were also able to maintain a diverse panel of healthcare professionals who represented the key disciplines involved in stroke care: neurologists, stroke nurses, physiotherapists, speech pathologists, occupational therapists, social workers, neuro-ophthalmologists, orthoptists, and orientation and mobility specialists. Panellists worked across several areas of stroke care such as acute and rehabilitative care, inpatient and outpatient services, as well as in research, and were inclusive of services within the private and public sectors, located in both major cities and regional areas of NSW. There were very high levels of agreement in all rounds, despite panellists having different disciplinary backgrounds and working in different

areas of stroke care. This demonstrates the obvious benefit of the NSW Post-stroke Vision Care Framework to stroke survivors as perceived by health professionals. The NSW-PVCF encourages holistic care provision, multidisciplinary collaboration, and the utilisation of advancing technologies to improve quality and access in post-stroke vision care. As the primary output of this research, it covers a large gap in Australian stroke care that ensures a contemporary and feasible approach to vision care provision.

10.4 DIRECTIONS FOR FUTURE RESEARCH

As discussed, the PRECiS study overall has several limitations that can be in part attributable to the time and resource constraints of a PhD as well as the impact of COVID related public health orders. Continued research in this area of stroke care in Australia may help address these limitations. Scoping of current practice in post-stroke vision care across all Australian states and territories, and hence, across a larger sample, will help to further evaluate and clarify trends presented in Stage One of this study. Specifically, the differences in care between stroke survivors living in rural vs metropolitan areas of Australia should be investigated within the different stages of post-stroke vision care provision (pre-hospital pathways, screening and assessment, information and education, management and referral). Also, the differences in practice, education levels and confidence in providing vision care between eye-care health professionals and non-eye-care health professionals working with stroke patients. Further investigation into current post-stroke vision care practices and pathways across the country may also potentially bring to light other issues or barriers that were not identified in the present study, conducted only within NSW.

Further to this, the lack of high-quality evidence within the context of Australian healthcare posed limitations in our pathway development. However, it also highlighted crucial gaps in the evidence base, which should be the focus of future research. In particular, the lack of available Australian evidence to identify differences in post-stroke vision care need of Indigenous Australians. Evidence indicates that Indigenous Australians are at greater risk of non-stroke related visual conditions such as diabetic retinopathy and typically develop these conditions at a younger age than non-Indigenous Australians.[8] It is also known that Indigenous Australians are at greater risk of stroke at a younger age when compared to non-Indigenous Australians.[9,10] As young stroke[288] and occipital stroke[289] are risk factors for delayed stroke diagnosis and access to care, and young Indigenous Australians are more likely to have pre-existing visual conditions, it is fair to assume that Indigenous stroke survivors with vision problems may suffer greater inequities in access to post-stroke vision care. This is

compounded further by the fact that a greater proportion of the Indigenous population of Australia live in regional and remote regions of the country[290] where healthcare services are more limited. It is then reasonable to assume that Indigenous Australians may have different and potentially more complex post-stroke vision care needs than non-Indigenous Australians. Further research is needed in this area to ensure that the current care pathway and recommendations are suited to the needs of Aboriginal and Torres Strait Islander populations and encourage culturally appropriate working practices.

Future research should also focus on implementation and ongoing evaluation of the newly developed NSW-PVCF, in keeping with steps five-seven of Vanhaecht's method.[267] Implementation and evaluation of the framework should be performed and compared within NSW and other Australian states and territories to investigate the breadth of applicability and identify potential needs for redirected or increased resourcing. This is of even greater importance in a post-coronavirus context, as the impact of the pandemic continues to impose change on the ways that care is provided across all areas of health within Australia. There is a need for implementation strategies to be developed that account for accessibility of staff and resources within primary and community care facilities. Implementation of the framework will need to involve consultation and collaboration with core organisations in Australian stroke and vision care, such as the Stroke Foundation, Vision Australia, Guide Dogs and other relevant professional organisations, to ensure appropriate dissemination and awareness of the framework.

Awareness of the framework and its contents should be supplemented by the development of education packages and campaigns tailored to both stroke health professionals and the Australian public. For health professionals, this may include freely accessible online training programs to familiarise them with the framework and its importance, as well as connecting them with relevant resources such as stroke-vision screening tools, patient information materials, and vision support services. Public awareness campaigns should focus on promoting awareness of visual stroke symptoms and directing patients to appropriate health care services. Following initial implementation of the framework, collaboration with the aforementioned organisations, as well as governing bodies within Australian public health, will also allow for more widespread, coordinated feedback on the framework. Ongoing and iterative evaluation of the framework is essential in ensuring it remains current in relation to the evidence available, as well as in relation to changes in the healthcare landscape of Australia.

10.5 CONCLUSIONS

The data gathered from PRECiS: Stage One (Chapters 4-7) indicated that the vast majority of health professionals working with stroke patients are attempting to provide vision care without any clear guidelines or protocols as to how they should be best implementing such care. This means that post-stroke vision care in NSW is non-standardized and extremely variable between different hospitals and care facilities. Inequality in care provision exists regardless of location however those living in regional or remote areas may be at greater risk due to reduced access to specialist vision services. While a lack of protocols may be largely responsible for this, health professionals also identified a lack of specialist eye care staff in stroke teams and a lack of resources or appropriate training, as major contributing factors. The other message that has come across strongly through PRECiS: Stage One is that the majority of stroke survivors with vision impairment feel as though their vision care needs are not adequately met as part of their stroke recovery and are disproportionately burdened by this as a result. Reports from the stroke survivors and health professionals show some contradiction in terms of the timing of vision assessment, as well as the provision of vision management or rehabilitation strategies and referrals. However, these two participant groups seemed to be aligned in regard to perceived barriers to successful vision care, with most indicating that post-stroke vision problems often go unidentified and that there is a need for a clear protocol or guidelines for post-stroke vision care provision.

In response to this, the NSW Post-stroke Vision Care framework was developed (Chapters 8 and 9), consisting of a list of best practice statements and a diagrammatic care pathway covering all stages of care. Consensus was reached on the final NSW-PVCF, inclusive of the care pathway and 43 best practice statements. Development of this framework was based on evidence gathered from key stakeholders that had indicated a need for change in the current practices and pathways used in the provision of post-stroke vision care in Australia. The results of the PRECiS study are a significant and novel addition to the Australian evidence-base regarding post-stroke vision care provision. In keeping with Vanhaecht's method for care pathway development,[267] subsequent studies will involve investigating the implementation of the framework in a sample of stroke patients within NSW-based stroke care facilities. Larger implementation studies to follow should include multiple stroke-care facilities within metropolitan and rural NSW, as well as interstate, to assess the applicability of the framework nationally. The pathway should then continue to be evaluated and revised regularly, to ensure information is kept up to date in relation to new evidence and changes within the healthcare

system. It would be hoped, however, that the outcomes of this research form an important step in the provision of better eye health care for Australian stroke survivors.

This pathway should be used in conjunction with the best practice statements for post-stroke vision care in NSW (Section 2).

PRE-HOSPITAL PATHWAYS (BPS SECTION 1)

Modes of presentation

- **Community:** GP, optometrist, private ophthalmology, hospital outpatient eye clinic
- **Accident & Emergency:** ambulance, hospital emergency department
- **Direct patient transfer:** existing inpatients, secondary facility, nursing home, detention centre, correctional facility

Sudden monocular vision loss

- Requires urgent ophthalmic investigation
  - Vision loss not stroke related
  - Stroke related vision loss

Sudden onset of visual symptoms indicative of stroke (e.g. double vision, field loss, binocular loss of vision)

- Onset <24 hours[a] → Nearest emergency department service
- Onset 24hours – 2 weeks → Stroke/ TIA rapid-access centre or equivalent
- Onset >2 weeks → GP to facilitate ophthalmology + neuro/vascular referral

Investigation for stroke/ TIA

- Confirmed stroke (with or without suspected vision problem)
- Other condition: requires further investigation/ referral as appropriate
- Confirmed TIA[b] → Refer to treating/community eye care specialist & provide referral/ information according to SF Clinical Guidelines for Stroke Management

ASSESSMENT (BPS SECTION 2)

Use of a stroke vision screening tool (if not conducted during stroke workup)

- Suspected vision problem → Undergo comprehensive ophthalmic/orthoptic assessment
  - Confirmed eye/vision problem
  - No eye/vision problem
- No suspected vision problem

MANAGEMENT & REFERRAL (BPS SECTION 3)

Provide information regarding visual condition (acquired and/or pre-existing) in appropriate format

Acute management provided if appropriate (professionals providing treatment: see BPS 3.3)

Provide information regarding visual condition, referrals + management plan in appropriate format prior to discharge

Referral according to vision problem (management strategies: see BPS 3.15-3.19)

Stroke survivors should see their treating eye care specialist or an optometrist within ~4 weeks of discharge (or prior to return to driving if sooner than 4 weeks post-discharge)

Double Vision	Nystagmus	Field Loss	Visual Neglect	Reduced Vision	Lid/ Tear dysfunction
Monocular patch Fresnel prisms	Advice on null point/ alternate head position	Compensatory eye movements Environmental adaptation	Education Visual scanning training	Glasses[c] High contrast Large print Appropriate lighting	Lubricant drops/ gel Tape lids shut at night

[c]Ensure near & distance glasses are differentiated and appropriate

	Visual field loss	Eye movement abnormality	Reduced central vision	Visual perceptual disorder	Retinal condition	Lid/Tear dysfunction
TREATMENT & REHABILITATION	Orientation & mobility specialist Occupational therapist Physiotherapist Orthoptist Ophthalmologist Low vision specialist Adaptive technology specialist	Orthoptist Ophthalmologist Optometrist* Orientation & mobility specialist* Physiotherapist*	Ophthalmologist Low vision specialist Orthoptist Optometrist Adaptive technology specialist	Neuro-ophthalmologist Neuropsychologist Orthoptist* Low vision specialist Occupational therapist* Orientation & mobility specialist* Physiotherapist*	Ophthalmologist Low vision specialist Adaptive technology specialist*	Ophthalmologist Ocular plastics surgeon Optometrist Orthoptist
SUPPORT SERVICES	Social worker Vision Australia Guide Dogs NSW	Social worker* Vision Australia*	Social worker Vision Australia Guide Dogs NSW	Social worker Vision Australia Guide Dogs NSW	Social worker Macular Disease Foundation Australia Retina Australia Vision Australia Guide Dogs NSW	General practitioner
	Blind Citizens Australia; Glaucoma Australia; Kerataconus Australia; Royal Society for the Blind; Centre for Eye Health; Next Sense; Stroke Recovery NSW, The Stroke Foundation; Carer Gateway; Disability Gateway; Indigenous Liaison Officer					
FINANCIAL SUPPORT	National Disability Insurance Scheme (age<65 years); My Aged Care (age>65 years); NSW spectacles program; Department of Veterans Affairs; Centrelink (carer payment/ allowance, disability support pension); Vision impaired persons travel pass; Taxi transport subsidy scheme (see also individual private health insurance entitlements)					

*Necessity of referral to these health professionals will vary by individual condition

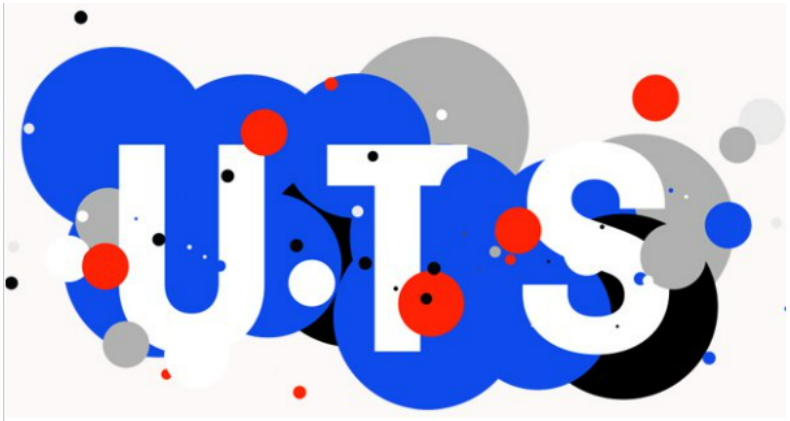
[a]Patients presenting within 4.5 hours of ischemic stroke may be eligible for thrombolysis and/or other reperfusion therapies up to 24hours post onset.
[b]TIA is confirmed if symptoms are fully resolved within 24 hours
GP = general practitioner; TIA = transient ischemic attack, SF = Stroke Foundation.

Figure 10.1 The NSW Post-stroke Vision Care Pathway developed as part of the NSW Post-stroke vision care framework.

11 APPENDICES

11.1 STROKE SURVIVOR SURVEY - FINAL VERSION USED IN PRECIS: STAGE ONE

11.1.1 SSS Pre-text/ Participant Information Sheet



Returning?

AAA

Stroke Survivor Survey

NSW Stroke Survivor Visual Rehabilitation Study

Please ensure that you read and understand the following information.

This study is being conducted by a team of researchers from the University of Technology Sydney. The goal of the study is to determine the nature of care pathways for stroke survivors with visual impairment in NSW. It aims to find out how vision is tested post-stroke and when the testing happened. We will also examine how you were referred for therapy and what kind of vision management/ rehabilitation you have had. From the information you give us, coupled with the perspectives of stroke health professionals, we aim to identify gaps in the eye care pathway and potential barriers to successful management and rehabilitation for visual conditions.

You are invited to participate in this study because you are a stroke survivor or carer of a stroke survivor who live in NSW. You have expressed to a healthcare professional, interest in participating in this survey OR you have sought out this survey via an advertisement. Please note that there is no financial remuneration provided to participants.

If you decide to participate, you will be asked to complete a series of questions about your experiences and perspectives on the vision care you received following your stroke. The questions are aimed at gathering information about the following:

- The timing and nature of your stroke
- The impact of your stroke on your eyes and vision
- Your experience of any vision tests and treatment you might have received as an inpatient
- The long term vision care plan provided to you and your perspective on how this affected your overall rehabilitation
- Whether you feel you had any unmet care needs and if you had any barriers to receiving eye care.

The survey takes approximately 30 minutes to complete. If completing the survey online, you may save your responses at any point and resume the survey at a later time. Completing the survey does not obligate you to further participate in any additional aspects of the study.

ARE THERE ANY INCONVENIENCE OR RISKS?

Yes, the time given (30 minutes) to complete the survey may be an inconvenience. You might also feel some uncomfortable emotions when recalling experiences of your stroke and the recovery process. If so, you can stop the survey at any time without giving a reason.

You don't have to say yes. Participation in this study is voluntary. It is completely up to you whether or not you decide to take part. Your decision to participate, or not participate, will not affect your relationship with the researchers, UTS or your health care professionals.

WHAT WILL HAPPEN IF I SAY NO?
Nothing, I will thank you for your time and won't contact you about this research again. If you decide not to participate in the survey, we will not collect additional personal information from you and destroy existing personal information and contact details. If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason, by contacting Dr Amanda French - E: Amanda.French@uts.edu.au PH: (02) 9514 7238 or Shanelle Sorbello - E: Shanelle.Sorbello@student.uts.edu.au PH: (02) 9514 4106.

CONFIDENTIALITY
By submitting this survey you consent to the research team collecting and using the information provided in this survey for this research project. All this information will be treated confidentially. Your data will be de-identified and securely stored on a UTS internal server, which is accessible only via an authenticated UTS system login and only available to the researchers involved in the study. Your information will only be used for the purpose of this research project. It can only be disclosed with your permission, except as required by law. We plan to publish the results of the study in scientific journals and present results at relevant scientific conferences. In any publication, information will be provided in such a way that **you cannot be identified.**

WHAT IF I HAVE CONCERNS OR A COMPLAINT?
If you have concerns about the research that you think I can help you with, please feel free to contact Dr Amanda French - E: Amanda.French@uts.edu.au PH: (02) 9514 7238 or Shanelle Sorbello - E: Shanelle.Sorbello@student.uts.edu.au PH: (02) 9514 4106.

NOTE:
This study has been approved by the University of Technology Sydney Human Research Ethics Committee. If you have any concerns or complaints about any aspect of the conduct of this research, please contact the Ethics Secretariat on ph.: +61 2 9514 2478 or email: [Research.Ethics@uts.edu.au], and quote the UTS HREC reference number [ETH18-2675]. Any matter raised will be treated confidentially, investigated and you will be informed of the outcome.

By completing and submitting this survey you are indicating your consent to participate.

Please complete the survey below.

11.1.2 SSS used in PRECiS: Stage One

Please complete the survey below.

Reference to withdraw:

* must provide value

1001

As all surveys are completely anonymous, we cannot identify which response belongs to you. If you wish to withdraw your responses, please quote this reference number when contacting the researchers. Please take note of this reference as you will not have access to it again after submitting the survey.

This portion of the survey is to demonstrate that you are cognitively able to provide consent to participate.

What is the purpose of this study as described to you in the participant information form?

* must provide value

- ○ To test your vision
- ○ Investigate vision care after stroke
- ○ Investigate the impact of diabetes on eyes

reset

Do you have to answer this survey if you do not want to participate?

* must provide value

- ○ Yes
- ○ No
- ○ I don't know

reset

If you withdraw from this study, will it affect your relationship with the researchers or UTS?

* must provide value

- ○ Yes
- ○ No
- ○ I don't know

reset

Which of the following is a risk or discomfort that you may experience as a result of answering the survey (as described in the participant information above)?

* must provide value

- ○ Uncomfortable emotions from recalling the time after your stroke event
- ○ Headaches
- ○ Psychological trauma

reset

Will you receive any financial remuneration for participating in this study?

* must provide value

- ○ Yes
- ○ No
- ○ I don't know

reset

Survey Questions
This section marks the beginning of the survey questions.

Please indicate whether you are:
* must provide value

- ○ The stroke survivor
- ○ The primary carer of a stroke survivor (all answers must relate to the experience of the stroke survivor)

reset

Age in years (of stroke survivor):
* must provide value

Sex:
* must provide value

- ○ Male
- ○ Female
- ○ Other

reset

Which of the following best describes the type of area you lived in at the time of stroke:

(please see image below if you are unsure which category your area fits into)
* must provide value

- ○ Major city
- ○ Inner Regional
- ○ Outer Regional
- ○ Remote
- ○ Very Remote

reset

Remoteness area map

What type of stroke did you have?
* must provide value

- ○ Haemorrhagic (bleed)
- ○ Ischemic (clot)
- ○ I don't know

reset

Where in the brain did your stroke occur?
* must provide value

How long ago was your stroke?
(if you have had multiple strokes, when was the most recent stroke?)

Prior to having a stroke, did you have any eye conditions/ visual symptoms?

* must provide value

- (●) Yes
- ( ) No

reset

Which of the below best describe the visual diagnosis/ visual symptoms you had PRIOR to stroke?
(please select all that apply)

* must provide value

- [ ] Refractive error (long or short sighted)
- [ ] Astigmatism
- [ ] Glaucoma
- [ ] Macular Degeneration
- [ ] Cataract
- [ ] Retinal tear/ retinal hole/ retinal detachment
- [ ] Retinal bleed/ hemorrhage
- [ ] Dry eye
- [ ] Eyelid droop or dysfunction
- [ ] Corneal issue
- [ ] Unexplained blurred vision
- [ ] Loss of peripheral (side) vision
- [ ] Double vision
- [ ] Flashes and/or floaters
- [ ] Other

Did you experience any new visual symptoms that you feel were related to your stroke?

* must provide value

- (●) Yes
- ( ) No

reset

For each of the symptoms listed below, please select a time frame for how long each lasted. If one does not apply, leave it blank.

	< 1 week	1-2 weeks	2-4 weeks	4-6 weeks	2 - 3 months	3 - 6 months	6 - 12 months	1 - 2 years	> 2 years
Loss of vision in one eye	○	○	○	○	○	○	○	○	○
Loss of vision in both eyes	○	○	○	○	○	○	○	○	○
Loss of vision on your left side	○	○	○	○	○	○	○	○	○
Loss of vision on your right side	○	○	○	○	○	○	○	○	○
Loss of PART of your vision	○	○	○	○	○	○	○	○	○
Double vision or tilted image(s)	○	○	○	○	○	○	○	○	○
Unsteady/ shaking image	○	○	○	○	○	○	○	○	○
Blurred vision	○	○	○	○	○	○	○	○	○
Trouble looking in certain directions	○	○	○	○	○	○	○	○	○
Unaware or missing things on one side	○	○	○	○	○	○	○	○	○
Other	○	○	○	○	○	○	○	○	○

reset

Have you been given a diagnosis for any vision disorder/ impairment related to your stroke ?

* must provide value

- (•) Yes
- ( ) No

reset

What was your visual diagnosis?

Do YOU believe that your vision/ eyes were affected by the stroke?

* must provide value

- (•) Yes
- ( ) No

reset

Did you have a vision test or eye check within 6 months after your stroke?

* must provide value

- (•) Yes
- ( ) No

reset

How long after your stroke did you have this vision test or eye check?

* must provide value

- ( ) < 1 week
- ( ) 1-3 weeks
- ( ) 3-6 weeks
- ( ) 6-8 weeks
- ( ) 2-3 months
- ( ) 3-6 months

reset

Where was the vision test or eye check performed?

* must provide value

- ( ) On the stroke ward/ bedside
- ( ) Hospital eye clinic as an in-patient
- ( ) Hospital eye clinic as an out-patient
- ( ) External eye clinic (not in hospital)

reset

Who performed the vision test or eye check?

* must provide value

- ( ) Orthoptist
- ( ) Nurse
- ( ) Doctor
- ( ) Occupational Therapist
- ( ) I don't know

reset

Were you provided with any information relating to visual problems that may occur following stroke?

* must provide value

- (•) Yes
- ( ) No

reset

Was this information written or verbal?

* must provide value

- ( ) Written
- ( ) Verbal
- ( ) Both

reset

Who provided you with this information?

- ( ) Orthoptist
- ( ) Nurse
- ( ) Doctor
- ( ) Occupational Therapist
- ( ) I don't know

reset

Were you provided with any information relating to YOUR SPECIFIC visual diagnosis/ symptoms?

* must provide value

- (•) Yes
- ( ) No

reset

Was this information written or verbal?

* must provide value

- ( ) Written
- ( ) Verbal
- ( ) Both

reset

Who provided you with this information?

* must provide value

- ( ) Orthoptist
- ( ) Nurse
- ( ) Doctor
- ( ) Occupational Therapist
- ( ) I don't know

reset

Were you provided with a care plan prior to discharge from the hospital?

* must provide value

- (•) Yes
- ( ) No

reset

Did this care plan include any management options for your visual symptoms?

* must provide value

- ( ) Yes
- ( ) No

reset

Were you referred to an eye health professional for ongoing management of your visual problems?

* must provide value

- ( ) Ophthalmologist
- ( ) Orthoptist
- ( ) Optometrist
- ( ) Low vision organisation (e.g. Vision Australia, Guide Dogs NSW)
- ( ) I was not referred to any eye health professional

reset

As an inpatient at the hospital, were you provided with any treatment or assistance relating to your vision problems?

* must provide value

- (•) Yes
- ( ) No

reset

For each of the treatment options listed below, please indicate how often each was provided to you while in hospital. If one does not apply, leave it blank.

	Daily	Weekly	Monthly	Once off	
Glasses	○	○	○	○	reset
Glasses with prisms	○	○	○	○	reset
Eye exercises	○	○	○	○	reset
Wearing an eye patch to hide double vision	○	○	○	○	reset
Vision aid(s)/ Magnifier	○	○	○	○	reset
Training to visually scan your environment	○	○	○	○	reset
Eye surgery	○	○	○	○	reset
Other	○	○	○	○	reset

Who provided this eye/vision treatment while you were in hospital?

* must provide value

- ○ Nurse
- ○ Occupational Therapist
- ○ Ophthalmologist
- ○ Orthoptist
- ○ Stroke Physician
- ○ I don't know

reset

Do you feel that your eye/vision care needs were successfully met prior to discharge from hospital?

* must provide value

- ( ) Yes
- (•) No

reset

Briefly describe why you feel that your eye/vision care needs were not met prior to discharge from hospital.

* must provide value

Expand

Do you feel that your eye/vision care needs were successfully met by the care plan and/or the referrals provided by the hospital?

* must provide value

- ( ) Yes
- (•) No

reset

Briefly describe why you feel that your eye/vision care needs were not met by the care plan or referrals?

Expand

Did you ever attend a rehabilitation hospital as part of your stroke treatment?

* must provide value

- (•) Yes
- ( ) No

reset

Was any vision care/ treatment for your vision problems provided at this rehabilitation hospital?

* must provide value

- (•) Yes
- ( ) No

reset

For each of the treatment options below, indicate how often each was provided to you while in rehabilitation hospital. If one does not apply to you, leave it blank.

	Daily	Weekly	Monthly	Once off	
Glasses	○	○	○	○	reset
Glasses with prisms	○	○	○	○	reset
Eye exercises	○	○	○	○	reset
Wearing an eye patch to hide double vision	○	○	○	○	reset
Vision aid(s)/ Magnifier	○	○	○	○	reset
Training to visually scan your environment	○	○	○	○	reset
Eye surgery	○	○	○	○	reset
Other	○	○	○	○	reset

Who provided this eye/vision care at the rehabilitation hospital?

* must provide value

- ○ Nurse
- ○ Ophthalmologist
- ○ Occupational therapist
- ○ Orthoptist
- ○ Stroke Physician
- ○ I don't know

reset

Were you referred to any external eye health professionals for your vision/eye problems while at the rehabilitation hospital?

* must provide value

- ( ) Ophthalmologist
- ( ) Orthoptist
- ( ) Optometrist
- ( ) Low vision organisation (e.g. Vision Australia, Guide Dogs NSW)
- ( ) I was not referred to any eye health professional

reset

Do you believe there were barriers to you receiving appropriate vision/eye care at any point during your treatment?

* must provide value

- (•) Yes
- ( ) No

reset

Please describe what these barriers were:

* must provide value

Do you feel that your vision disorder/ impairment has had an impact on your daily living? (please give a score out of 100, 0= not at all, 100= greatly)

* must provide value

Not at all — Moderately — Greatly

50

reset

Which aspects of daily living do you feel have been impacted by your vision disorder/ impairment? Please select all that apply.

- [ ] Shopping
- [ ] Cooking
- [ ] Mobility
- [ ] Physical activity
- [ ] Relationships
- [ ] Social interaction
- [ ] Employment
- [ ] Finances
- [ ] Hygiene
- [ ] Hobbies
- [ ] Caring for dependents
- [ ] Driving
- [ ] Going to crowded places
- [ ] Going out at night
- [ ] Reading

Do you feel that your vision disorder/ impairment has impacted your general rehabilitation following stroke? (please give a score out of 100, 0= not at all, 100= greatly)

* must provide value

Not at all — Moderately — Greatly

55

reset

Have you been diagnosed with a vision disorder/ impairment since your stroke but NOT CAUSED by the stroke?

* must provide value

- (●) Yes
- ( ) No

reset

Which of the following best describes your visual diagnosis? (please select all that apply)

* must provide value

- [ ] Refractive error (long or short sighted)
- [ ] Astigmatism
- [ ] Glaucoma
- [ ] Cataract
- [ ] Macular degeneration
- [ ] Retinal tear/ hole/ detachment
- [ ] Retinal bleed/ hemorrhage
- [ ] Dry eye
- [ ] Eyelid droop or dysfunction
- [ ] Corneal issue
- [ ] Other

Are you currently under the care of an eye care professional for any vision problems?

* must provide value

- ( ) Yes
- ( ) No

reset

Do you have any other comments you would like to make regarding your post-stroke vision care?

Expand

Submit

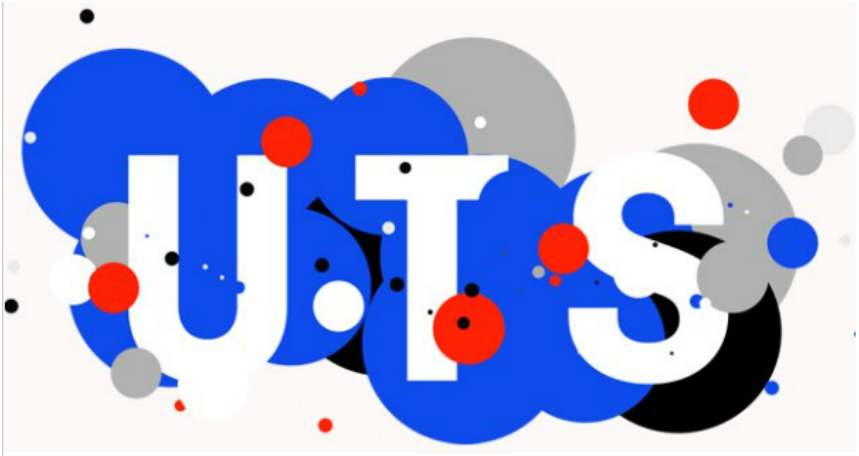
Save & Return Later

11.2 HEALTH PROFESSIONAL SURVEY – FINAL VERSION USED IN PRECIS: STAGE ONE

11.2.1 HPS Pre-text/ Participant information

Returning?

A A A



Health Professional Survey

NSW Stroke Survivor Visual Rehabilitation Study

Please ensure that you read and understand the following information.

This research is being conducted by a team of researchers from the University of Technology Sydney. The goal of the study is to determine the nature of care pathways for stroke survivors with visual impairment in NSW. It aims to find out the timing and tools used for vision screening, the type of management and referrals given, as well as the long term visual rehabilitation. From the information you give us, coupled with the perspectives of stroke survivors, we aim to identify gaps in the eye care pathway and potential barriers to successful management and rehabilitation for visual conditions.

You have been invited to participate in this study because you are a healthcare professional whom provides care for stroke survivors in NSW. You have responded to an invitation to participate in this survey OR you have sought out this survey via an advertisement. Please note that there is no financial remuneration provided to participants in this study.

If you decide to participate, you will be asked to complete a series of questions about your experience and perspective on the nature of vision disorders post-stroke and the resulting vision care provided in your workplace. The questions in this survey will collect information on the following:

- The type of stroke setting your workplace is and how stroke patients are referred to you
- The vision screening process in your workplace
- The types and frequency of visual problems found in stroke patients in your workplace
- How these visual problems are managed in your workplace
- Your experience of barriers to providing assessment and/or management of these visual problems

The survey takes approximately 30 minutes to complete. If completing the survey online, you may save your responses at any point and resume the survey at a later time.

ARE THERE ANY INCONVENIENCE OR RISKS?

Yes, the time given (30 minutes) to complete the survey may be an inconvenience. You might also feel some uncomfortable emotions when recalling information about the experiences of stroke patients and barriers to providing care within the workplace. If so, you can stop the survey at any time without giving a reason.

You don't have to say yes. Participation in this study is voluntary. It is completely up to you whether or not you decide to take part. Your decision to participate, or not, will not affect your relationship with the researchers or UTS.

WHAT WILL HAPPEN IF I SAY NO?

Nothing, I will thank you for your time and won't contact you about this research again. If you decide not to participate in the survey, we will not collect additional information from you and destroy existing information and contact details. If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason, by contacting Dr Amanda French - E: Amanda.French@uts.edu.au PH: (02) 9514 7238 or Shanelle Sorbello - E: Shanelle.Sorbello@student.uts.edu.au PH: (02) 9514 4106.

CONFIDENTIALITY

By submitting this survey you consent to the research team collecting and using the information provided in this survey for the research study. All this information will be treated confidentially. The data will be de-idetified and securely stored on a UTS internal server, which is accessible only via an authenticated UTS system login and only available to the researchers involved in this study. Your information will only be used for the purpose of this research project. It can only be disclosed with your permission, except as required by law.

We plan to publish the results of the study in scientific journals and present results at relevant scientific conferences. In any publication, information will be provided in such a way that **you or your workplace cannot be identified.**

WHAT IF I HAVE CONCERNS OR A COMPLAINT?

If you have concerns about the research, please feel free to contact Dr Amanda French - E: Amanda.French@uts.edu.au PH: (02) 9514 7238 or Shanelle Sorbello - E: Shanelle.Sorbello@student.uts.edu.au PH: (02) 9514 4106.

NOTE:

This study has been approved by the University of Technology Sydney Human Research Ethics Committee. If you have any concerns or complaints about any aspect of the conduct of this research, please contact the Ethics Secretariat on ph.: +61 2 9514 2478 or email: [Research.Ethics@uts.edu.au], and quote the UTS HREC reference number [ETH18-2675]. Any matter raised will be treated confidentially, investigated and you will be informed of the outcome.

By completing and submitting this survey you are indicating your consent to participate.

Please complete the survey below.

11.2.2 HPS used in PRECiS: Stage One

Branching logic was used in this survey to change the questions displayed depending on the answer provided to the questions 3 and 5. Branching questions for Q3 answer ‘Inpatient service’ is shown on the left hand side, and for answers ‘outpatient service’ or ‘mixed’ shown on the right hand side. Branching questions for Q5 answer ‘yes’ are shown on the left hand side and for answer ‘no’ on the right hand side. Where there is no change in questions between branches, only one image is shown per page.

Please complete the survey below.

Reference to withdraw
* must provide value

1001

As all surveys are completely anonymous, we cannot identify which response belongs to you. If you wish to withdraw your responses, please quote this reference number when contacting the researchers. Please take note of this reference as you will not have access to it again after submitting the survey.

Which type of care setting best describes your place of employment?
* must provide value

- ○ Primary care
- ○ Community care

reset

Which type of care setting best describes your place of employment?
* must provide value

- ○ Acute
- ○ Sub-acute
- ○ Rehabilitation
- ○ Mixed (a combination of the above)

reset

Which type of care setting best describes your place of employment?
* must provide value

- ○ Outpatient service
- ◉ Inpatient service
- ○ Mixed (a combination of the above)

reset

What type of care setting best describes your place of employment?
* must provide value

- ○ Public
- ○ Private
- ○ Non-government organisation

reset

Do you specifically assess and/or manage eye conditions?
* must provide value

- ◉ Yes
- ○ No

reset

Which of the following best describes the setting where you assess and/or manage eye conditions?
* must provide value

- ○ Inpatient vision service
- ○ Outpatient eye clinic in a hospital
- ○ Private eye clinic
- ○ Low vision organisation

reset

Please enter the postcode of your place of employment:
* must provide value

(NB: this will be used to categorise responses according to the Australian Accessibility and Remoteness Index. Postcodes and/or suburbs will not be published.)

Which type of care setting best describes your place of employment?
* must provide value

- ◉ Outpatient service
- ○ Inpatient service
- ○ Mixed (a combination of the above)

reset

What type of care setting best describes your place of employment?
* must provide value

- ○ Public
- ○ Private
- ○ Non-government organisation

reset

Do you specifically assess and/or manage eye conditions?
* must provide value

- ◉ Yes
- ○ No

reset

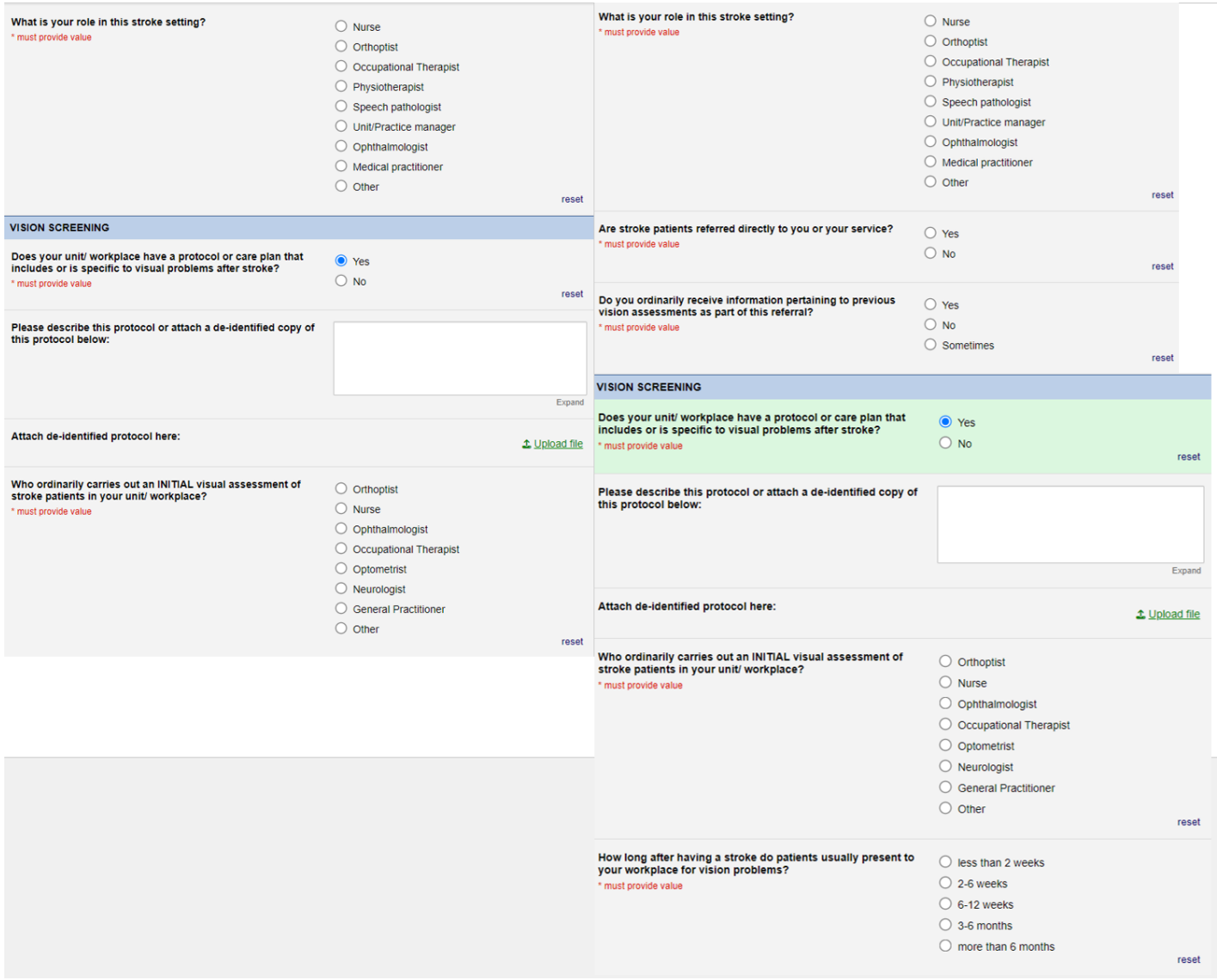
Which of the following best describes the setting where you assess and/or manage eye conditions?
* must provide value

- ○ Inpatient vision service
- ○ Outpatient eye clinic in a hospital
- ○ Private eye clinic
- ○ Low vision organisation

reset

Please enter the postcode of your place of employment:
* must provide value

(NB: this will be used to categorise responses according to the Australian Accessibility and Remoteness Index. Postcodes and/or suburbs will not be published.)



What is your role in this stroke setting?
* must provide value

- Nurse
- Orthoptist
- Occupational Therapist
- Physiotherapist
- Speech pathologist
- Unit/Practice manager
- Ophthalmologist
- Medical practitioner
- Other

reset

VISION SCREENING

Does your unit/ workplace have a protocol or care plan that includes or is specific to visual problems after stroke?
* must provide value

- Yes
- No

reset

Please describe this protocol or attach a de-identified copy of this protocol below:

Expand

Attach de-identified protocol here:

Upload file

Who ordinarily carries out an INITIAL visual assessment of stroke patients in your unit/ workplace?
* must provide value

- Orthoptist
- Nurse
- Ophthalmologist
- Occupational Therapist
- Optometrist
- Neurologist
- General Practitioner
- Other

reset

What is your role in this stroke setting?
* must provide value

- Nurse
- Orthoptist
- Occupational Therapist
- Physiotherapist
- Speech pathologist
- Unit/Practice manager
- Ophthalmologist
- Medical practitioner
- Other

reset

Are stroke patients referred directly to you or your service?
* must provide value

- Yes
- No

reset

Do you ordinarily receive information pertaining to previous vision assessments as part of this referral?
* must provide value

- Yes
- No
- Sometimes

reset

VISION SCREENING

Does your unit/ workplace have a protocol or care plan that includes or is specific to visual problems after stroke?
* must provide value

- Yes
- No

reset

Please describe this protocol or attach a de-identified copy of this protocol below:

Expand

Attach de-identified protocol here:

Upload file

Who ordinarily carries out an INITIAL visual assessment of stroke patients in your unit/ workplace?
* must provide value

- Orthoptist
- Nurse
- Ophthalmologist
- Occupational Therapist
- Optometrist
- Neurologist
- General Practitioner
- Other

reset

How long after having a stroke do patients usually present to your workplace for vision problems?
* must provide value

- less than 2 weeks
- 2-6 weeks
- 6-12 weeks
- 3-6 months
- more than 6 months

reset

How often do you utilise the following tests in the vision assessment of stroke patients?

	With every patient	Regularly	Rarely	Never	
Visual acuity * must provide value	○	○	○	○	reset
Visual fields * must provide value	○	○	○	○	reset
Contrast sensitivity * must provide value	○	○	○	○	reset
Ocular movements * must provide value	○	○	○	○	reset
Eye alignment test (Cover test) * must provide value	○	○	○	○	reset
Colour vision * must provide value	○	○	○	○	reset
Pupil function * must provide value	○	○	○	○	reset
Visual attention * must provide value	○	○	○	○	reset
Visual scanning * must provide value	○	○	○	○	reset
Fundus examination * must provide value	○	○	○	○	reset

How often do you utilise the following test batteries in the vision assessment of stroke patients?

Adapted from: *Alex Pollock, Christine Hazelton & Marian Brady (2011) Visual Problems After Stroke: A Survey of Current Practice by Occupational Therapists Working in UK Stroke Inpatient Settings, Topics in Stroke Rehabilitation, 18:sup1, 643-651*

	With every patient	Regularly	Rarely	Never	
Behavioral inattention test * must provide value	○	○	○	○	reset
Brain injury visual assessment battery for adults * must provide value	○	○	○	○	reset
Biometrics E link evaluation * must provide value	○	○	○	○	reset
Motor free visual perception test * must provide value	○	○	○	○	reset
Stroke-Vision Impairment Screening Tool (SVIST) * must provide value	○	○	○	○	reset

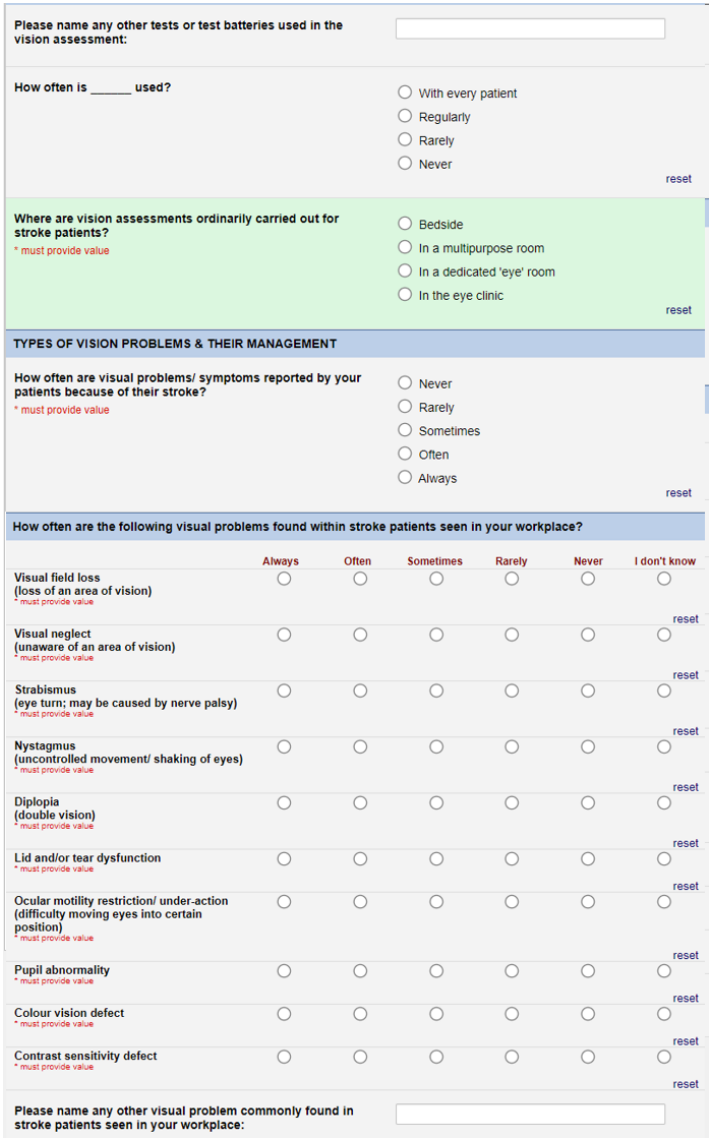
How often do you observe the use of the following tests in the vision assessment of stroke patients?

	With every patient	Regularly	Rarely	Never	I don't know	
Visual Acuity * must provide value	○	○	○	○	○	reset
Visual fields * must provide value	○	○	○	○	○	reset
Contrast sensitivity * must provide value	○	○	○	○	○	reset
Ocular movements * must provide value	○	○	○	○	○	reset
Eye alignment test (Cover test) * must provide value	○	○	○	○	○	reset
Colour vision * must provide value	○	○	○	○	○	reset
Pupil function * must provide value	○	○	○	○	○	reset
Visual attention * must provide value	○	○	○	○	○	reset
Visual scanning * must provide value	○	○	○	○	○	reset
Fundus examination * must provide value	○	○	○	○	○	reset

How often do you observe the use of the following test batteries in the vision assessment of stroke patients?

Adapted from: *Alex Pollock, Christine Hazelton & Marian Brady (2011) Visual Problems After Stroke: A Survey of Current Practice by Occupational Therapists Working in UK Stroke Inpatient Settings, Topics in Stroke Rehabilitation, 18:sup1, 643-651*

	With every patient	Regularly	Rarely	Never	I don't know	
Behavioral inattention test * must provide value	○	○	○	○	○	reset
Brain injury visual assessment battery for adults * must provide value	○	○	○	○	○	reset
Biometrics E link evaluation * must provide value	○	○	○	○	○	reset
Motor free visual perception test * must provide value	○	○	○	○	○	reset
Stroke-Vision Impairment Screening Tool * must provide value	○	○	○	○	○	reset



Please name any other tests or test batteries used in the vision assessment:

How often is _____ used?

- With every patient
- Regularly
- Rarely
- Never

reset

Where are vision assessments ordinarily carried out for stroke patients?
* must provide value

- Bedside
- In a multipurpose room
- In a dedicated 'eye' room
- In the eye clinic

reset

TYPES OF VISION PROBLEMS & THEIR MANAGEMENT

How often are visual problems/ symptoms reported by your patients because of their stroke?
* must provide value

- Never
- Rarely
- Sometimes
- Often
- Always

reset

How often are the following visual problems found within stroke patients seen in your workplace?

	Always	Often	Sometimes	Rarely	Never	I don't know
Visual field loss (loss of an area of vision) * must provide value	○	○	○	○	○	○
Visual neglect (unaware of an area of vision) * must provide value	○	○	○	○	○	○
Strabismus (eye turn; may be caused by nerve palsy) * must provide value	○	○	○	○	○	○
Nystagmus (uncontrolled movement/ shaking of eyes) * must provide value	○	○	○	○	○	○
Diplopia (double vision) * must provide value	○	○	○	○	○	○
Lid and/or tear dysfunction * must provide value	○	○	○	○	○	○
Ocular motility restriction/ under-action (difficulty moving eyes into certain position) * must provide value	○	○	○	○	○	○
Pupil abnormality * must provide value	○	○	○	○	○	○
Colour vision defect * must provide value	○	○	○	○	○	○
Contrast sensitivity defect * must provide value	○	○	○	○	○	○

reset

Please name any other visual problem commonly found in stroke patients seen in your workplace:

Please name any other tests or test batteries used in the vision assessment:

How often is _____ used?

- With every patient
- Regularly
- Rarely
- Never

reset

TYPES OF VISION PROBLEMS & THEIR MANAGEMENT

How often are visual problems/ symptoms reported by your patients because of their stroke?
* must provide value

- Never
- Rarely
- Sometimes
- Often
- Always

reset

How often are the following visual problems found within stroke patients seen in your workplace?

	Always	Often	Sometimes	Rarely	Never	I don't know
Visual field loss (loss of an area of vision) * must provide value	○	○	○	○	○	○
Visual neglect (unaware of an area of vision) * must provide value	○	○	○	○	○	○
Strabismus (eye turn; may be caused by nerve palsy) * must provide value	○	○	○	○	○	○
Nystagmus (uncontrolled movement/ shaking of eyes) * must provide value	○	○	○	○	○	○
Diplopia (double vision) * must provide value	○	○	○	○	○	○
Lid and/or tear dysfunction * must provide value	○	○	○	○	○	○
Ocular motility restriction/ under-action (difficulty moving eyes into certain position) * must provide value	○	○	○	○	○	○
Pupil abnormality * must provide value	○	○	○	○	○	○
Colour vision defect * must provide value	○	○	○	○	○	○
Contrast sensitivity defect * must provide value	○	○	○	○	○	○

reset

Please name any other visual problem commonly found in stroke patients seen in your workplace:

How often is _____ found within these patients?

- ○ Always
- ○ Often
- ○ Sometimes
- ○ Rarely
- ○ Never

reset

Are stroke patients routinely provided with information about post-stroke vision problems?

* must provide value

- ◉ Yes
- ○ No
- ○ I don't know

reset

What sort of information is provided regarding post-stroke vision problems?

- ☐ General post-stroke vision loss information
- ☐ Information specific to their vision problem
- ☐ Information on the services available to assist
- ☐ Information on management options
- ☐ Information on driving regulations
- ☐ Information on expected recovery
- ☐ Information on support groups and services

Are stroke patients routinely provided with the Stroke Foundation 'My Stroke Journey Information Pack'?

* must provide value

- ○ Yes
- ○ No
- ○ I don't know

reset

Within your workplace, what health professionals does the stroke multi-disciplinary team consist of? (please select all that apply)

* must provide value

- ☐ Nurse
- ☐ Occupational therapist
- ☐ Physiotherapist
- ☐ Speech Pathologist
- ☐ Psychologist
- ☐ Stroke Physician
- ☐ Neurologist
- ☐ Ophthalmologist
- ☐ Orthoptist
- ☐ Optometrist
- ☐ Radiologist
- ☐ Other

Within this multi-disciplinary team, who primarily leads or carries out vision care for stroke patients?

* must provide value

- [ ] Nurse
- [ ] Occupational therapist
- [ ] Physiotherapist
- [ ] Speech pathologist
- [ ] Psychologist
- [ ] Stroke physician
- [ ] Neurologist
- [ ] Ophthalmologist
- [ ] Orthoptist
- [ ] Optometrist
- [ ] Radiologist
- [ ] Other

If a patient is found to have the below visual problem, what is the likely outcome in your workplace?
(You may select more than one option for each condition)

*** MDT = multi-disciplinary team**

	Refer to ophthalmologist	Refer to optometrist	Refer to orthoptist	Refer to low vision service	Refer to psychologist	Treatment delivered in house	MDT* management plan	Suggest to patient to follow up	No action taken	I don't know	Other
Reduced vision * must provide value	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Double vision * must provide value	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Visual field loss (loss of an area of vision) * must provide value	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Visual neglect (unaware of an area of vision) * must provide value	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Eye movement problem * must provide value	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Lid and/or tear dysfunction * must provide value	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Functional vision defect * must provide value	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Pupil defect * must provide value	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Which of the following treatments are provided in your workplace for the visual problems listed below?
(You may select more than one option for each condition)

	Visual scanning training	Patching	Prisms	Eccentric fixation training	Vision aids/ Magnifiers	Orthoptic exercises	Education on condition	Environmental modification	Glasses	Surgery	No treatment offered	I don't know	Other
Reduced vision * must provide value	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Double vision * must provide value	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Visual field loss (loss of an area of vision) * must provide value	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Visual neglect (unaware of an area of vision) * must provide value	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Eye movement problem * must provide value	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Lid or tear dysfunction * must provide value	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Colour vision defect * must provide value	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Pupil defect * must provide value	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

How long after stroke do you usually begin treatment for visual problems?
* must provide value

- ○ < 2 weeks
- ○ 2-6 weeks
- ○ 6 weeks-3 months
- ○ 3-6 months
- ○ >6 months

reset

How long do you generally continue to treat patients in your workplace for visual problems caused by stroke?
* must provide value

- ○ One-off treatment
- ○ Up to 1 month
- ○ Up to 3 months
- ○ Up to 6 months
- ○ Up to 1 year
- ○ Indefinitely

reset

Do stroke patients seen in your workplace routinely receive treatment when an eye or vision condition is present?
* must provide value

- ○ Yes
- ○ No
- ○ I don't know

reset

Which of the following treatments are provided in your workplace for the visual problems listed below?
(You may select more than one option for each condition)

	Visual scanning training	Patching	Prisms	Eccentric fixation training	Vision aids/ Magnifiers	Orthoptic exercises	Education on condition	Environmental modification	Glasses	Surgery	No treatment offered	I don't know	Other
Reduced vision * must provide value	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Double vision * must provide value	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Visual field loss (loss of an area of vision) * must provide value	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Visual neglect (unaware of an area of vision) * must provide value	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Eye movement problem * must provide value	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Lid or tear dysfunction * must provide value	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Colour vision defect * must provide value	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Pupil defect * must provide value	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

How long do you generally continue to treat patients in your workplace for visual problems caused by stroke?
* must provide value

- ○ One-off treatment
- ○ Up to 1 month
- ○ Up to 3 months
- ○ Up to 6 months
- ○ Up to 1 year
- ○ Indefinitely

reset

Do stroke patients seen in your workplace routinely receive treatment when an eye or vision condition is present?
* must provide value

- ○ Yes
- ○ No
- ○ I don't know

reset

How long is your typical follow up period for patients with any of these problems after stroke?

	2 weeks	4 weeks	6 weeks	8 weeks	3 months	6 months	12 months
Reduced vision * must provide value	○	○	○	○	○	○	○ reset
Double vision * must provide value	○	○	○	○	○	○	○ reset
Visual field loss (loss of an area of vision) * must provide value	○	○	○	○	○	○	○ reset
Visual neglect (unaware of an area of vision) * must provide value	○	○	○	○	○	○	○ reset
Eye movement problem * must provide value	○	○	○	○	○	○	○ reset
Lid and/or tear dysfunction * must provide value	○	○	○	○	○	○	○ reset
Functional vision defect * must provide value	○	○	○	○	○	○	○ reset
Pupil defect * must provide value	○	○	○	○	○	○	○ reset

BARRIERS TO PROVIDING CARE

What barriers do you experience as a health care professional in the identification and/or management of visual problems after stroke?

(You may select more than one option)

* must provide value

- ☐ No vision care protocol/ management plan
- ☐ Don't have access to specialist staff
- ☐ Don't have the skills/ experience needed to confidently perform assessment/ management
- ☐ Don't have the time to adequately perform assessment/ treatment
- ☐ Lack of support from a multi-disciplinary team
- ☐ Not enough research/ evidence in the area
- ☐ Not enough specialist training available
- ☐ Lack of referral or lack of timely referral to your workplace
- ☐ Other

What do you perceive to be the barriers for stroke patients to receive successful vision care?

(You may select more than one option)

* must provide value

- [ ] Absent or late referral
- [ ] Inappropriate referral
- [ ] Problems not identified
- [ ] Financial
- [ ] Access to appropriate specialist and/or rehabilitation services
- [ ] Other

Is there any way you think the IDENTIFICATION of visual problems after stroke might be improved?

* must provide value

Expand

Is there any way you think the MANAGEMENT of vision problems after stroke might be improved?

* must provide value

Expand

Please comment on anything else you would like to highlight about your service regarding the care pathway for vision problems following stroke:

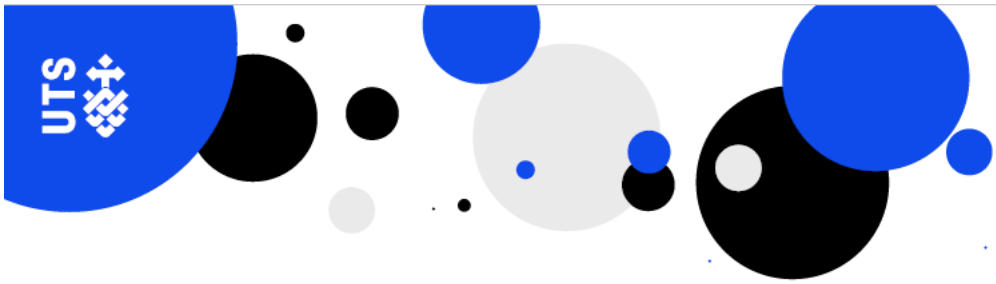
* must provide value

Expand

Submit

Save & Return Later

11.3 STROKE SURVIVOR INTERVIEW SCHEDULE



Stroke survivor interview questions

Questions

I would like you to think back to when you first had your stroke and tell me what happened from that point.

About the stroke

1. When did you have the stroke?

2. How did you get to the hospital following the stroke?

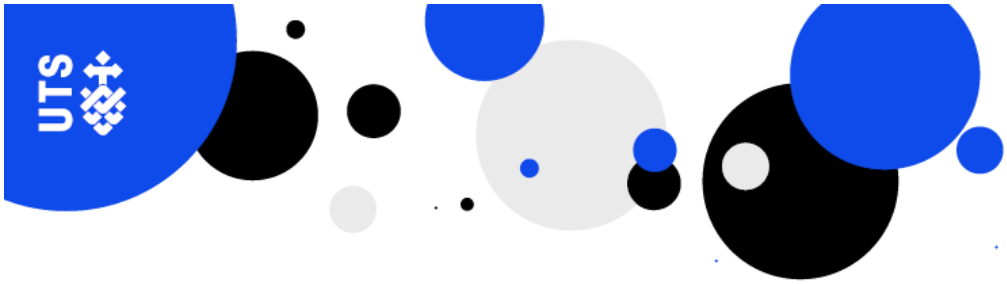
    a. How long after the stroke did you get to the hospital?

3. Were you aware that you had had a stroke?

    a. What alerted you to this?

4. Where in the brain or brainstem did the stroke occur?

5. What symptoms or changes did you notice after the stroke?



Impact of the stroke on your eyes

6. Did you have any visual symptoms immediately after the stroke?

    a. What were they?

7. Did you have any visual symptoms at a later stage which were related to the stroke?

    a. What were they?

    b. How long after the stroke did you notice them?

If visual symptoms were present:.

8. Did you tell anyone about the visual symptoms you were having?

    a. If yes, did this prompt a vision assessment?

9. Were you diagnosed with a vision disorder/impairment related to the stroke? If so, what was your diagnosis?

    a. For how long did this condition persist?

10. Had you had any eye conditions prior to having the stroke?

11. Did you wear glasses or use any drops on a regular basis prior to having the stroke?

    a. If yes, did you have these with you while in hospital?

Vision Assessment & Care

12. Did you have a vision assessment while you were an inpatient?

13. Did you feel as though you needed to have a vision assessment?

[if no vision assessment was performed skip to question 16]

14. How long after your stroke did you have a vision assessment?

    a. Who performed the vision assessment and where was this performed?

15. What was done during this vision assessment/ what tests do you recall being done?

16. Were you provided with any information on vision problems/ disorders following stroke?

    a. Was it verbally communicated to you or given in the form of printouts?

    b. Who provided this information to you?

17. Did you receive any type of treatment related to your eyes/vision while in hospital?

    a. Please describe this treatment

18. How long after your stroke was this treatment provided?

Discharge & Long term follow up

19. Upon discharge, were you given a general care plan relating to your rehabilitation/recovery following the stroke?

    a. Did this care plan include any **proposed management** or **referral** for your visual symptoms/conditions (if you still had any by this stage)?

20. Were you given any additional information related to your specific visual condition and/or symptoms upon discharge?

21. If you were referred for ongoing eye care of your visual symptoms/conditions, what type of eye care professional were you referred to?

22. Did you go to see this eye care professional for follow up?

    a. If yes, were you satisfied with your care?

    b. If no, why not?

    i. Did you go to see another type of eye care professional?

23. Are you still under the care of an eye care professional?

    a. What type and why?

Impact of visual disorder

24. Do you feel that the vision disorder/condition caused by your stroke had an impact on you while you were an inpatient?

    a. In what ways specifically? b. why/ why not?

25. Do you feel that the vision disorder/condition caused by your stroke had an impact on you once you were discharged and back home?

    a. In what ways specifically? b. why/ why not?

26. Do you feel that the vision disorder/condition has had a continued impact on your daily life and activities?

    a. In what ways specifically?

Unmet care needs

27. Do you feel your vision care needs were met adequately as an inpatient? Why/ why not?

28. Do you feel your vision care needs were met adequately through the long-term care plan provided? Why/ why not?

Barriers to appropriate care

29. What do you think would have helped minimise the impact of this vision disorder/condition on your rehabilitation?

30. Do you feel that there were barriers within the health care system to you receiving appropriate care?

    a. What were these barriers?

31. Is there anything else you would like to comment on that hasn't already been discussed?

11.4 FEASIBILITY STUDY FEEDBACK QUESTIONS

NSW Stroke Survivor Visual Rehabilitation Study

Feasibility Study – Interview Questions

Date: **Participant ID:**

How long did the survey take you to complete?
Do you feel that this is a reasonable amount of time?
Did you feel that the survey questions were clear and easy to understand? **If not, which questions were difficult to understand and why?**
Did you feel that the survey questions were relevant to your experience/provision of post stroke vision care in NSW? **If not, which questions were not relevant?**
Do you think that the survey covered ALL aspects relevant to your experience/provision of post stroke vision care? **If not, what is missing?**
Is there anything else you would like to comment on about the survey and its content?

11.5 SSS AND HPS USED IN FEASIBILITY STUDY (CHAPTER 5)

11.5.1 Stroke Survivor Survey Questions



Stroke Survivor Survey

This portion of the survey is to demonstrate that you are cognitively able to provide consent.

1. What is the purpose of this study as described to you in the participant information form?
   a. To determine the vision of stroke survivors
   b. Investigate vision care after stroke
   c. Investigate the impact of diabetes on the eyes

2. Do you have to be in this study if you do not want to participate?
   a. Yes
   b. No
   c. I don't know

3. If you withdraw from this study, will it affect your relationship with the researcher or UTS?
   a. Yes
   b. No
   c. I don't know

4. Please describe some **possible** risks or discomforts that people may experience if they participate in this study:
   a. Uncomfortable emotions from reminiscing on the time after the stroke event
   b. Liver problems
   c. Psychological trauma

5. Will you receive any financial remuneration for participating in this study?
   a. Yes
   b. No
   c. I don't know

1

Survey Questions

1. Please indicate whether the person filling out this questionnaire is:
    a. A stroke survivor
    b. The primary carer of a stroke survivor
    (all questions are relating to details and experiences of the stroke survivor)

2. Age of stroke survivor (in years) : _____
3. Sex:
    a. Male
    b. Female
    c. Other
4. Which of the below best describes where you live:
    a. Metropolitan
    b. Regional
    c. Rural
5. What type of stroke did you have?
    a. Haemorrhagic (bleed)
    b. Ischemic (clot)
    c. I don't know

6. What was the location of the stroke in the brain?
    a. Frontal
    b. Temporal
    c. Parietal
    d. Occipital
    e. Brain stem
    f. Thalamus
    g. I don't know

7. How long ago did stroke occur?
    a. < 1 month
    b. 1-3 months
    c. 3-6 months
    d. 6-12 months
    e. >1 year ago
    f. 1-5 years ago
    g. 5-10 years ago
    h. >10 years ago

8. Did you have any visual diagnoses/ visual symptoms prior to having stroke?
    a. Yes (please select all that apply)

□ Refractive error (long or short sighted)
□ Astigmatism
□ Glaucoma
□ Macular degeneration
□ Cataracts
□ Retinal tear/ hole/ detachment
□ Retinal bleed/ haemorrhage
□ Dry eye
□ Eye lid droop or dysfunction
□ Corneal issue
□ Unexplained blurred vision
□ loss of side vision
□ double vision
□ Flashes and/or floaters
□ Other _____

b. No

9. Did you experience any visual symptoms immediately following stroke?

a. Yes

b. No (go to question 11)

10. For each of the symptoms listed below please state how long each lasted. If one does not apply, leave blank.

Symptom	Duration
Loss of vision in one eye	____ days ____ months _____ years □ permanent
Loss of vision in both eyes	____ days ____ months _____ years □ permanent

Loss of vision on one side *Please circle* (Left / Right)	____ days ____ months _____ years □ permanent
Loss of part of vision *Please describe area of vision loss*	____ days ____ months _____ years □ permanent
Double vision or tilted image(s)	____ days ____ months _____ years □ permanent
Unsteady/shaking image	____ days ____ months _____ years □ permanent
Blurred vision	____ days ____ months _____ years □ permanent
Trouble looking in certain directions	____ days ____ months _____ years □ permanent
Ignoring or missing things on one side	____ days ____ months _____ years □ permanent
Other (please specify)	____ days ____ months _____ years □ permanent

11. Have you been diagnosed with a vision disorder/ impairment related to the stroke event?

    a. Yes. My diagnosis was _____

    b. No

12. Do you believe your vision/eyes were affected by the stroke?
    a. Yes
    b. No

13. Did you have a visual assessment within 6 months following the stroke event?
    a. Yes
    b. No (go to question 18)

14. How long after the stroke did you have this vision assessment?
    a. < 1 week
    b. 1-3 weeks
    c. 3- 6 weeks
    d. 6-8 weeks
    e. 2 -3 months
    f. 3 – 6 months

15. Was the assessment performed while you were an inpatient or post-discharge?
    a. Inpatient
    b. Outpatient

16. Where was the assessment performed?
    a. On the stroke ward/ bedside
    b. Eye clinic in hospital
    c. External eye clinic

17. Who performed this assessment?
    a. Orthoptist
    b. Nurse
    c. Doctor
    d. Occupational Therapist
    e. I don't know

18. Were you provided with any written or verbal information relating to visual problems that may occur following stroke?
    a. Written
    b. Verbal
    c. Both written & verbal
    d. No (go to question 20)

19. Who provided you with this information?
    a. Orthoptist

b. Nurse

c. Doctor

d. Occupational Therapist

e. I don't know

20. Were you provided with any written or verbal information relating to **your specific visual symptoms/ diagnoses**?

    a. Written

    b. Verbal

    c. Both written & verbal

    d. No (go to question 22)

21. Who provided you with this information?

    a. Orthoptist

    b. Nurse

    c. Doctor

    d. Occupational therapist

    e. I don't know

22. Were you provided with a care plan prior to discharge from the hospital?

    a. Yes

    b. No (go to question 24)

23. Did this care plan include any management options for your visual symptoms?

    a. Yes

    b. No

24. Were you referred to an eye health professional for ongoing management of your visual problems?

    a. Ophthalmologist

    b. Orthoptist

    c. Optometrist

    d. Low vision organisation

    e. I was not referred to any eye health professional

25. As an inpatient at the hospital, were you provided with any treatment or assistance relating to your vision problems?

    a. Yes

    b. No (go to question 28)

26. Please briefly describe what sort of vision care you were provided including how often.

27. Who provided this care?

    a. Nurse

    b. Occupational therapist

    c. Ophthalmologist

    d. Orthoptist

    e. Neurologist

    f. I don't know

28. Do you feel your vision needs were adequately met prior to discharge from hospital?

    a. Yes (go to question 34)

    b. No

29. If no, please briefly describe why you feel these needs were not met.

30. Do you feel your vision needs were adequately met by the care plan and/or referral provided?

    a. Yes

    b. No

31. Did you ever attend a rehabilitation hospital as part of your stroke treatment?

    a. Yes

    b. No (go to question 36)

32. Was any vision care or referral for vision problems provided at this rehabilitation hospital?

    a. Vision care (go to question 33)

    b. Referral (go to question (35)

    c. No (go to question 36)

33. Please briefly describe what sort of vision care you were provided including how often.

34. Who provided this care?
    a. Nurse
    b. Occupational therapist
    c. Ophthalmologist
    d. Orthoptist
    e. Neurologist
    f. I don't know

35. Which of the below eye health professionals were you referred to?
    a. Ophthalmologist
    b. Orthoptist
    c. Optometrist
    d. Low vision organisation

36. Do you believe there were barriers to you receiving appropriate vision care?
    a. Yes
    b. No (go to question 38)

37. Please list what you believe to be the barriers preventing you from receiving appropriate care:

38. Do you feel that this vision disorder/impairment has had an impact on your daily living?

    a. Greatly

    b. Moderately

    c. Minimally

    d. Not at all (go to question 40)

39. Which aspects of daily living do you feel have been impacted by this vision disorder/impairment? Please tick all that apply:

	Shopping		Relationships		Hygiene
	Cooking		Social interaction		Hobbies
	Mobility		Employment		Caring for dependents
	Physical activity		Finances		Driving

	Going to crowded places		Going out at night		Reading

40. Do you believe this vision disorder/impairment impacted your general rehabilitation following the stroke?

    a. Greatly

    b. Moderately

    c. Minimally

    d. Not at all

41. Have you been diagnosed with a vision disorder/impairment since the stroke event but NOT CAUSED by the stroke?

    a. Yes, my diagnosis was (please select all that apply)

□ Refractive error (long or short sighted)
□ Astigmatism
□ Glaucoma
□ Macular degeneration
□ Cataracts
□ Retinal tear/ hole/ detachment
□ Retinal bleed/ haemorrhage
□ Dry eye
□ Eye lid droop or dysfunction
□ Corneal issue
□ Other _____

    b. No

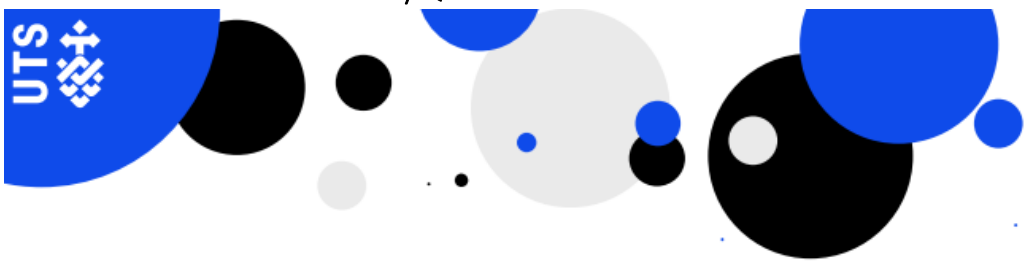
42. Are you currently under the care of an eye care professional for these vision problems?

    a. Yes

    b. No

43. Do you have any other comments you would like to make?

11.5.2 Health Professional Survey Questions



Health Professional Survey

Questions

1. Which TYPE of stroke care setting best describes your place of employment? (please tick one per column)

Acute		Hospital ward	
Rehabilitation		Eye clinic in hospital	
Combined		Private eye clinic	
		Visual rehabilitation service	

2. Please indicate the **postcode** of your place of employment:
(NB – this will be used to categorise responses according to the Australian Accessibility and Remoteness Index. Postcodes or suburbs will not be published)

_____

3. What is your role in this stroke setting?
   a. Nurse
   b. Orthoptist
   c. OT
   d. Physiotherapist
   e. Speech Pathologist
   f. Unit/Practice manager
   g. Medical Practitioner
   h. Other, please specify _____

4. Are stroke patients referred directly to you or your service?
   a. Yes
   b. No (go to question 5)

5. Where are these stroke patients referred from? (select all that apply)
   a. Acute stroke wards
   b. Rehabilitation hospital
   c. Hospital outpatients eye clinic
   d. Private ophthalmologist
   e. Optometrist
   f. Neurologist
   g. General practitioner
   h. Other _____

6. Is it routine practice to ensure that patients have their prescribed glasses/ drops/ medications for pre-existing ophthalmic conditions with them on the ward?
   a. Yes
   b. No
   c. Not applicable

VISION SCREENING

7. Does your unit/workplace have a protocol or management plan that includes or is specific to visual problems after stroke?
    a. Yes (please describe below)
    b. No
8. Who ordinarily carries out an INITIAL visual assessment of stroke patients in your unit/workplace?
    a. Orthoptist
    b. Nurse
    c. Ophthalmologist
    d. OT
    e. Optometrist
    f. Neurologist
    g. Visual assessment is not performed (go to 12)
    h. Other _____
9. When is a visual assessment of a patient who has had stroke usually performed?
    a. On admission
    b. If the patient or their family/friend reports visual problems
    c. If yourself or another healthcare professional suspects a visual problem
    d. Just prior to discharge/release
    e. Other _____
10. How long after stroke, on average, is a visual assessment usually carried out?
    a. Less than 2 weeks
    b. 2-6 weeks
    c. 6 weeks- 3 months
    d. 3-6 months
    e. >6 months
11. How often are the following assessments utilised in the visual assessment carried out?

Test	With every patient	Regularly	Rarely	Never	Brand/ Type of test
Visual Acuity					
Visual Fields					
Contrast sensitivity					
Ocular movements					
Cover Test					
Colour vision					
Pupil function					
Visual attention					
Visual Scanning					
Fundus examination					
Other (please state)					
Test Batteries					
Behavioral inattention test					
Brain Injury Visual Assessment Battery for adults					
Biometrics E Link Evaluation					
Motor Free Visual Perception Test					
Stroke vision screening tool					
Other (please state)					

(Adapted from: *Visual problems after stroke: a survey of current practice by occupational therapists working in UK stroke inpatient settings*)

12. Where are vision assessments ordinarily carried out for stroke patients?
    a. Bedside
    b. In a multipurpose room
    c. In a dedicated room
    d. In the eye clinic

TYPES OF VISUAL PROBLEMS & THEIR MANAGEMENT

13. How often are visual problems/symptoms reported by your patients because of their stroke?
    a. never
    b. Rarely
    c. Sometimes
    d. Often
    e. Always

14. How often are the following visual problems seen within stroke patients in your ward/workplace?

Condition/Disorder	Always	Often	Sometimes	Rarely	Never
Visual field loss					
Visual neglect					
Strabismus					
Nystagmus					
Diplopia					
Lid and/or tear dysfunction					
Ocular motility restriction/ under-action					
Pupil abnormality					
Colour vision defect					
Contrast sensitivity defect					
Other *(please state)*					

15. Are stroke patients routinely provided with information about post-stroke vision problems?
    a. Yes
    b. No

16. What sort of information is provided regarding post-stroke vision problems? *(circle all that apply)*
    a. General post-stroke vision loss information
    b. Information specific to their vision problems
    c. Information on the services available to assist
    d. Information on management options
    e. Information on driving regulations
    f. Information on expected recovery
    g. Information on support groups and services

17. Are stroke patients routinely provided with the Stroke Foundation 'My Stroke Journey Information Pack'?
    a. Yes
    b. No

18. If a patient is found or suspected to have a visual problem, what is the likely outcome?

Please tick all treatment options that apply	Refer to Ophthalmologist	Refer to optometrist	Refer to orthoptist	Refer to low vision service	Refer to psychologist	Treatment delivered by _____ in clinic/ward	Multidisciplinary team management plan	Suggest to patient/ family to follow-up	No action is taken	Other (please state)
Reduced vision										
Double vision										
Visual field loss										
Visual neglect										
Eye movement problem										
Lid and/or tear dysfunction										
Functional vision defect										
Pupil defect										
Other (please state)										

(Adapted from: *Visual problems after stroke: a survey of current practice by occupational therapists working in UK stroke inpatient settings*)

19. Which of the following treatments are provided in your workplace for the problems listed below?

Please tick all treatment options that apply	Computer based visual scanning training	Non- computer based visual scanning training	Patching	Prisms	Eccentric fixation training	Vision aids/ magnifiers	Orthoptic exercises	Education on condition	Environmental modification	Glasses	Surgical management	No treatment offered	Other (please state)
Reduced vision													
Double vision													
Visual field loss													
Visual neglect													
Eye movement problem													
Lid and/or tear dysfunction													

Colour vision defect													
Pupil defect													
Other (please state)													

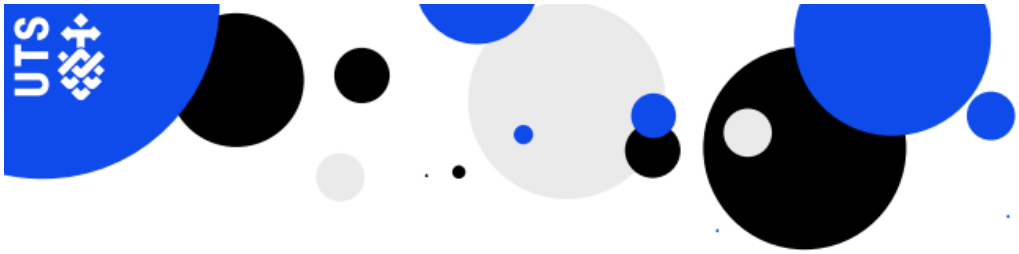
20. How long after stroke do you most often treat patients for visual problems?
    a. Less than 2 weeks
    b. 2-6 weeks
    c. 6 weeks – 3 months
    d. 3-6 months
    e. > 6 months

21. How long do you generally continue to treat patients in your workplace for visual problems caused by stroke?
    a. One-off treatment
    b. Up to 1 month
    c. Up to 3 months
    d. Up to 6 months
    e. Up to 1 year
    f. Indefinitely

22. If stroke patients are visually asymptomatic but have an underlying visual condition that you have identified, do you still treat this condition?
    a. Yes
    b. No

23. How long is your typical follow up period for patients with the following problems after their stroke? *(mark relevant box with an 'X' for each visual condition)*

	2 weeks	**4 weeks**	**6 weeks**	**8 weeks**	**3 months**	**6 months**	**12 months**
Reduced vision							
Double vision							
Visual field loss							
Visual neglect							
Eye movement problem							
Lid and/or tear dysfunction							
Functional vision defect							
Pupil defect							
Other (please state)							



BARRIERS TO PROVIDING CARE

24. What barriers do you experience as a health care professional to identification and/or management of visual problems after stroke? *(circle all that apply)*
    a. No vision care protocol/management plan
    b. Don't have necessary access to specialist staff
    c. Don't have the skills/experience needed to confidently perform assessment/management
    d. Don't have the time to adequately perform assessment/management
    e. Not aware of best assessments
    f. Not aware of best treatments
    g. Do not have the resources to perform adequate assessment/treatment
    h. Lack of support from MDT
    i. Not enough research evidence
    j. Not enough specialist training available
    k. Lack of referral or lack of timely referral to your workplace
    l. Other (please state) _____

25. What do you perceive as barriers for receiving appropriate vision care for stroke patients? *(circle all that apply)*
    a. Absent or late referral
    b. Inappropriate referral
    c. Problems not identified
    d. Financial
    e. Access to appropriate specialists and/or rehabilitation services

26. Is there any way you think the **identification** of visual problems after stroke might be improved?

27. Is there any way you think the **management** of vision problems after stroke might be improved?

28. Please comment on anything else you would like to highlight about your service regarding the care pathway for vision problems following stroke:

11.6 SSS: CONSENT FORM

PARTICIPANT CONSENT PAGE

I _____ agree to participate in the research project Pathway Research for Eye Care in Stroke (PRECiS) Study being conducted by University of Technology, Sydney. I understand that this study is being conducted independently by UTS researchers.

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research as described in the Participant Information Sheet.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time without affecting my relationship with the researchers or the University of Technology Sydney.

I understand that I will be given a signed copy of this document to keep.

I agree that the research data gathered from this project may be published in a form that does not identify me in any way

If I have any concerns about this research I am aware that I can contact
Dr Amanda French - E: Amanda.French@uts.edu.au PH: (02) 9514 7238 or
Shanelle Sorbello – E: Shanelle.Sorbello@student.uts.edu.au PH: (02) 9514 4106 of the University of Technology Sydney or the UTS Ethics Secretariat (02 9514 2478) and quote the approval number [ETH18-2675].

_____ ____/____/____
Name and Signature [participant] Date

_____ ____/____/____
Name and Signature [researcher or delegate] Date

Please return this signed consent page to Shanelle Sorbello from the University of Technology Sydney [Shanelle.sorbello@student.uts.edu.au]

NOTE:
This study has been approved by the University of Technology Sydney Human Research Ethics Committee [UTS HREC]. If you have any concerns or complaints about any aspect of the conduct of this research, please contact the Ethics Secretariat on ph.: +61 2 9514 2478 or email: Research.Ethics@uts.edu.au, and quote the UTS HREC reference number. Any matter raised will be treated confidentially, investigated and you will be informed of the outcome.

3

11.7 HPS: CONSENT FORM

PARTICIPANT CONSENT PAGE

I _____ agree to participate in the research project Pathway Research for Eye Care in Stroke (PRECiS) Study being conducted by University of Technology, Sydney. I understand that this study is being conducted independently by UTS researchers.

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research as described in the Participant Information Sheet.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time without affecting my relationship with the researchers or the University of Technology Sydney.

I understand that I will be given a signed copy of this document to keep.

I agree to keep confidential all information including all conversations and discussions, materials and methods provided to me by the UTS research team.

If I have any concerns about this research I am aware that I can contact:
Dr Amanda French - E: Amanda.French@uts.edu.au PH: (02) 9514 7238 or
Shanelle Sorbello – E: Shanelle.Sorbello@student.uts.edu.au PH: (02) 9514 4106 of the University of Technology Sydney or the UTS Ethics Secretariat (02 9514 2478) and quote the approval number [ETH18-2675].

_____ ____/____/____
Name and Signature [participant] Date

_____ ____/____/____
Name and Signature [researcher or delegate] Date

Please return this signed consent page to Shanelle Sorbello from the University of Technology Sydney [shanelle.sorbello@student.uts.edu.au]

NOTE:
This study has been approved by the University of Technology Sydney Human Research Ethics Committee [UTS HREC]. If you have any concerns or complaints about any aspect of the conduct of this research, please contact the Ethics Secretariat on ph.: +61 2 9514 2478 or email: Research.Ethics@uts.edu.au, and quote the UTS HREC reference number. Any matter raised will be treated confidentially, investigated and you will be informed of the outcome.

11.8 Stroke Survivor Interview: Consent Form

Pathway Research for Eye Care in Stroke (PRECiS) Study

Stroke survivors and carers - Interview

Participant information

WHO IS DOING THE RESEARCH?

This research is being conducted by a team of researchers from the University of Technology, Sydney.

WHAT IS THIS RESEARCH ABOUT?

The goal of the project is to determine what the care pathway is for stroke survivors with visual impairment in NSW. This will include information including the timing and tools used for vision screening, the type of management and referrals given, as well as the long term visual rehabilitation. From this information and the perspectives of both stroke survivors and stroke health care professionals, we aim to identify gaps in this pathway and potential barriers to appropriate care.

FUNDING

This project is being run independently by the participating researchers.

WHY HAVE I BEEN ASKED?

You have been invited to participate in this study because you are a stroke survivor or carer of a stroke survivor that was under the care of NSW healthcare professionals following the stroke event. Your contact details were obtained from the information provided by yourself upon completion of the NSW Stroke Survivor Visual Rehabilitation Study – Patient Survey. You indicated that you were willing to be followed up by UTS researchers for a short interview.

IF I SAY YES, WHAT WILL IT INVOLVE?

If you decide to participate, I will invite you to participate in an interview that will take 60 minutes. The purpose is to ask for your experiences and perspectives on the vision care you received following the stroke event:

- The timing and nature of the stroke
- The impact of the stroke on your eyes and vision
- Your experience of vision assessment and treatment as an inpatient following the stroke
- The long term vision care plan provided to you and your perspective on how this affected your rehabilitation
- Your experience of any unmet care needs and what you perceive the barriers are to the delivery of adequate vision care.

The interview can be conducted either via telephone, on UTS premises, or at a location convenient to you.

ARE THERE ANY INCONVENIENCE OR RISKS?

Yes, the time given (60 minutes) to participate in this interview. You might also feel some uncomfortable emotions when discussing experiences of the stroke event and the recovery process. If so, you can stop the interview at any time without giving a reason. As the interview can be conducted over the phone, no travel is required.

DO I HAVE TO SAY YES?

You don't have to say yes. Participation in this study is voluntary. It is completely up to you whether or not you decide to take part. Your decision to participate, or not participate, will not affect your relationship with the researchers or UTS

WHAT WILL HAPPEN IF I SAY NO?

Nothing, I will thank you for your time and won't contact you about this research again. If you decide not to participate in the interview, we will not collect additional personal information from you and destroy existing personal information and contact details. If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason, by contacting Dr Amanda French - E: Amanda.French@uts.edu.au PH: (02) 9514 7238 or Shanelle Sorbello – E: Shanelle.Sorbello@student.uts.edu.au PH: (02) 9514 4106.

CONFIDENTIALITY

By signing the consent form you consent to the research team collecting and using personal information about you for the research project. All this information will be treated confidentially. The data will be securely stored on a UTS internal server, which is accessible only via an authenticated UTS system login and only available to researchers involved in the research. Participant names/contact details will be stored separately to digital recordings and transcripts. Any hardcopy transcripts will be stored in a locked drawer in a locked office. Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law. We plan to publish the results of the study in a scientific journal and present the results at relevant scientific conferences. In any publication, information will be provided in such a way that you cannot be identified.

You are not required to keep your participation in this study confidential.

WHAT IF I HAVE CONCERNS OR A COMPLAINT?

If you have concerns about the research that you think I can help you with, please feel free to contact Dr Amanda French - E: Amanda.French@uts.edu.au PH: (02) 9514 7238 or Shanelle Sorbello – E: Shanelle.Sorbello@student.uts.edu.au PH: (02) 9514 4106.

NOTE:

This study has been approved by the University of Technology Sydney Human Research Ethics Committee. If you have any concerns or complaints about any aspect of the conduct of this research, please contact the Ethics Secretariat on ph.: +61 2 9514 2478 or email: [Research.Ethics@uts.edu.au], and quote the UTS HREC reference number [********]. Any matter raised will be treated confidentially, investigated and you will be informed of the outcome.

PARTICIPANT CONSENT PAGE

I _____ agree to participate in the research project NSW Stroke Survivor Visual Rehabilitation Study being conducted by University of Technology, Sydney. I understand that this study is being conducted independently by UTS researchers.

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research as described in the Participant Information Sheet.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time without affecting my relationship with the researchers or the University of Technology Sydney.

I understand that I will be given a signed copy of this document to keep.

I agree to keep confidential all information including all conversations and discussions, materials and methods provided to me by the UTS research team.

I agree that the research data gathered from this project may be published in a form that does not identify me in any way

If I have any concerns about this research I am aware that I can contact
Dr Amanda French - E: Amanda.French@uts.edu.au PH: (02) 9514 7238 or
Shanelle Sorbello – E: Shanelle.Sorbello@student.uts.edu.au PH: (02) 9514 4106 of the University of Technology Sydney or the UTS Ethics Secretariat (02 9514 2478) and quote the approval number [ETH18-2675].

_____ ____/____/____
Name and Signature [participant] Date

_____ ____/____/____
Name and Signature [researcher or delegate] Date

Please return this signed consent page to Shanelle Sorbello from the University of Technology Sydney [Shanelle.Sorbello@student.uts.edu.au]

NOTE:
This study has been approved by the University of Technology Sydney Human Research Ethics Committee [UTS HREC]. If you have any concerns or complaints about any aspect of the conduct of this research, please contact the Ethics Secretariat on ph.: +61 2 9514 2478 or email: Research.Ethics@uts.edu.au, and quote the UTS HREC reference number. Any matter raised will be treated confidentially, investigated and you will be informed of the outcome.

11.9 PRECiS: Stage 2 Consent Form



A A A

PRECiS Study - Information and Consent

About this research:

Evidence indicates that up to 60% of stroke survivors have some form of visual impairment. Despite this, this area of stroke care has received little attention in Australian research and is reflected by the limited mention of vision care in the current Australian Clinical Guidelines for Stroke Management (see *Appendix III*). The PRECiS Study is comprised of two stages, of which stage one is now complete. Stage one utilised a mixed methods exploratory approach in order to determine the current post-stroke vision care pathways and practices in NSW, Australia. This involved survey of stroke health professionals (both eye care specific and non-eye care) and stroke survivors, as well as a series of interviews with stroke survivors residing in NSW. Information was also collected from both participant groups regarding their perceived barriers to accessing/providing post-stroke vision care and potential gaps in these pathways. The data from this stage is summarised in *Appendix II*.

The results of stage one highlighted a number of unmet care needs and barriers to successful provision of post-stroke vision care. With this information, together with existing literature (see *Appendix I*), a number of best practice statements (BPS) were created that will form the basis of a post-stroke vision care pathway suitable for implementation in Australia that best addresses these issues.
Stage two of the PRECiS Study is a consensus study where we are asking stroke health professionals in NSW to rate the appropriateness of each BPS and provide an opportunity for them to provide feedback on the composition and structure of this pathway over two rounds of survey. In order to build adequate consensus on this pathway we require responses from a range of health professionals working in all stages of stroke care including but not limited to: Occupational Therapists, Stroke/Neuro nurses, Orthoptists, Physiotherapists, Speech pathologists, Stroke physicians, Social workers, Neuro-ophthalmologists, General practitioners, Paramedics and Optometrists.

Participant information:

WHO IS DOING THE RESEARCH?
This research is being done as part of a doctoral research project by Shanelle Sorbello (E. shanelle.sorbello@uts.edu.au) at the University of Technology Sydney. Primary supervisor: Prof Kathryn Rose; Co-Supervisors: Dr Amanda French (E. amanda.french@uts.edu.au T.+612 9514 7238) and Prof. Fiona Rowe.

WHAT IS THIS RESEARCH ABOUT?
This research aims to create a post-stroke vision care pathway that is suitable for implementation in NSW. This care pathway will address the gaps and barriers in current post-stroke vision care in NSW as identified by previous research as well as provide clear, evidence based guidance to the approach and delivery of vision care to stroke survivors.

FUNDING
This project is being run independently by the participating researchers.

WHY HAVE I BEEN ASKED?
You have been invited to participate in this study because you are a stroke healthcare professional or stroke survivor in NSW and so, have a direct involvement in the area of stroke care and the desired expertise to help us in this research. Your contact details were
obtained from previous expression of interest provided by yourself, OR recommendation from a colleague/peer, OR through your professional association/ support group.

IF I SAY YES, WHAT WILL IT INVOLVE?
If you decide to participate, I will invite you to participate in developing and evaluating a post-stroke vision care pathway as part of a group of experts in the area of post-stroke vision care. This will involve responding to TWO online questionnaires with the option to participate in an online panel meeting/focus group discussion.

- The questionnaires will ask for you to rate a series of best practice statements about post stroke vision care from 1 (highly inappropriate) to 9 (highly appropriate). You will also be asked to contribute any additional statements as you see necessary. Each questionnaire will take approximately 60 minutes to complete, with the second survey to be completed 4-6 weeks after the first. The aim of each questionnaire is to build agreement within the group about which statements are appropriate for inclusion in the pathway.
- **The panel meeting will involve a facilitated discussion via video call with approximately 7 other people and will take approximately 90 minutes.** The video call will be recorded for the purpose of analysis. The aim of the meeting is to reach consensus on the items for inclusion in the pathway and the structure of the pathway overall.

ARE THERE ANY RISKS/INCONVENIENCE?
Yes, the time given to participate (approximately 4 hours, over the course of 6-8 weeks). If participating in the panel meeting, you may also feel uncomfortable sharing your opinion among others, feel fear of judgement or frustration relating to opposing opinions. The facilitator will mediate these risks by ensuring the rules of engagement are followed during the meeting whereby all participants speak to each other respectfully, and all are given opportunity to speak freely, without judgement. You may also withdraw at any time.

DO I HAVE TO SAY YES?
Participation in this study is voluntary. It is completely up to you whether or not you decide to take part.

WHAT WILL HAPPEN IF I SAY NO?
If you decide not to participate, it will not affect your relationship with the researchers or the University of Technology Sydney. If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason, by contacting Dr Amanda French (E. Amanda.french@uts.edu.au T.+61 2 9514 7238 or Shanelle Sorbello (E. shanelle.sorbello@uts.edu.au).
If you withdraw from the study, your questionnaire responses will be deleted/ destroyed, and your comments from the focus group will be removed from the transcript/ discounted from analysis.
If you decide to leave the research project, we will not collect additional personal information from you, although personal information already collected will be retained to ensure that the results of the research project can be measured properly and to comply with law. You should be aware that data collected up to the time you withdraw will form part of the research project results. If you do not want them to do this, you must tell them before you join the research project.

CONFIDENTIALITY
By signing the consent form you consent to the research team collecting and using personal information about you for the research project. All this information will be treated confidentially. The data will be securely stored on a UTS internal server, which is accessible only via an authenticated UTS system login and only available to researchers involved in the research. Participant names/contact details will be stored separately to questionnaire responses and focus group recordings/ transcripts. Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law.
We plan to publish the results of the study in a scientific journal and present the results at relevant scientific conferences. In any publication, information will be provided in such a way that you cannot be identified. You are not required to keep your participation in this study confidential.

WHAT IF I HAVE CONCERNS OR A COMPLAINT?
If you have concerns about the research that you think myself or my supervisor can help you with, please feel free to contact us on Dr Amanda French (E. Amanda.french@uts.edu.au T.+61 2 9514 7238 or Shanelle Sorbello (E. shanelle.sorbello@uts.edu.au).

NOTE:
This study has been approved in line with the University of Technology Sydney Human Research Ethics Committee [UTS HREC] guidelines. If you have any concerns or complaints about any aspect of the conduct of this research, please contact the Ethics Secretariat on ph.: +61 2 9514 2478 or email: Research.Ethics@uts.edu.au], and quote the UTS HREC reference number. Any matter raised will be treated confidentially, investigated and you will be informed of the outcome.

Participating in the Round one consensus survey does not obligate you to participate in Round two or in the panel meeting held thereafter should you wish to end your involvement in the research.

Please provide your contact details below:

This will be used to send consensus results from this round of survey back to you and invite you to participate in round 2.

First Name:
* must provide value

Discipline/ Role in stroke care:
* must provide value

E-mail:
* must provide value

Telephone: *(optional)*

CONSENT FORM

The Pathway Research for Eye Care in Stroke (PRECiS) Study [ETH20-5446]

I agree to participate in the research project The Pathway Research for Eye Care in Stroke (PRECiS) Study [ETH20-5446] being conducted by Shanelle Sorbello, University of Technology Sydney, +612 9514 7238. I understand that this research is being conducted independently by UTS researchers.

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research as described in the Participant Information Sheet.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time without affecting my relationship with the researchers or the University of Technology Sydney.

I understand that I will be given a signed copy of this document to keep.

* must provide value

- ○ Yes
- ○ No

reset

I agree to be:

- ☐ Audio recorded
- ☐ Video recorded

I agree that the research data gathered from this project may be published in a form that:

- ☐ Does not identify me in any way
- ☐ May be used for future research purposes

I am aware that I can contact Shanelle Sorbello or Dr Amanda French if I have any concerns about the research.

Signature (participant):
* must provide value

Add signature

Submit

11.10 Round 1 Best Practice Statements Survey

UTS UNIVERSITY OF TECHNOLOGY SYDNEY

PATHWAY RESEARCH FOR EYE CARE IN STROKE (PRECIS) STUDY

Research Team:

Shanelle Sorbello[1]

Prof. Kathryn Rose[1]

Dr. Amanda French[1]

Prof. Fiona Rowe[2]

[1]University of Technology Sydney, Sydney, Australia

[2]University of Liverpool, Liverpool, UK

UTS HREC approval: ETH20-5446

APRIL 19, 2021

UNIVERSITY OF TECHNOLOGY SYDNEY

Discipline of Orthoptics, GSH

About this research:

Evidence indicates that up to 60% of stroke survivors have some form of visual impairment. Despite this, this area of stroke care has received little attention in Australian research and is reflected by the limited mention of vision care in the current Australian Clinical Guidelines for Stroke Management (see Appendix III). The PRECiS Study is comprised of two stages, of which stage one is now complete. Stage one utilised a mixed methods exploratory approach in order to determine the current post-stroke vision care pathways and practices in NSW, Australia. This involved survey of stroke health professionals (both eye care specific and non-eye care) and stroke survivors, as well as a series of interviews with stroke survivors residing in NSW. Information was also collected from both participant groups regarding their perceived barriers to accessing/providing post-stroke vision care and potential gaps in these pathways. The data from this stage is summarised in Section 3 and further detail provided in Appendix II.

The results of stage one highlighted a number of unmet care needs and barriers to successful provision of post-stroke vision care. With this information, together with existing literature (see Appendix I), a number of best practice statements (BPS) were created that will form the basis of a post-stroke vision care pathway suitable for implementation in Australia that best addresses these issues.

Stage two of the PRECiS Study is a consensus study where we are asking **stroke health professionals in NSW** to rate the appropriateness of each BPS and provide an opportunity for them to provide feedback on the composition and structure of this pathway over two rounds of survey (see Section 2). In order to build adequate consensus on this pathway we require responses from a range of health professionals working in all stages of stroke care including but not limited to: Occupational Therapists, Stroke/Neuro nurses, Orthoptists, Physiotherapists, Speech pathologists, Stroke physicians, Social workers, Neuro-ophthalmologists, General practitioners, Paramedics and Optometrists.

Participant information:

WHO IS DOING THE RESEARCH?

This research is being done as part of a doctoral research project by Shanelle Sorbello (E. shanelle.sorbello@uts.edu.au) at the University of Technology Sydney. Primary supervisor: Prof Kathryn Rose; Co-Supervisors: Dr Amanda French (E. amanda.french@uts.edu.au T. +612 9514 7238) and Prof. Fiona Rowe.

WHAT IS THIS RESEARCH ABOUT?

This research aims to create a post-stroke vision care pathway that is suitable for implementation in NSW. This care pathway will address the gaps and barriers in current post-stroke vision care in NSW as identified by previous research as well as provide clear, evidence based guidance to the approach and delivery of vision care to stroke survivors.

FUNDING

This project is being run independently by the participating researchers.

WHY HAVE I BEEN ASKED?

You have been invited to participate in this study because you are a stroke healthcare professional or stroke survivor in NSW and so, have a direct involvement in the area of stroke care and the desired expertise to help us in this research. Your contact details were

obtained from previous expression of interest provided by yourself, OR recommendation from a colleague/peer, OR through your professional association/ support group.

IF I SAY YES, WHAT WILL IT INVOLVE?

If you decide to participate, I will invite you to participate in developing and evaluating a post-stroke vision care pathway as part of a group of experts in the area of post-stroke vision care. This will involve responding to **TWO online questionnaires with the option to participate in an online focus group discussion.**

- The questionnaires will ask for you to rate a series of best practice statements about post stroke vision care from 1 (highly inappropriate) to 9 (highly appropriate). You will also be asked to contribute any additional statements as you see necessary. **Each questionnaire will take approximately 60 minutes to complete, with the second survey to be completed 4-6 weeks after the first.** The aim of each questionnaire is to build agreement within the group about which statements are appropriate for inclusion in the pathway.
- The focus group will involve a facilitated discussion via video call with approximately 10 other people and will take approximately 2 hours. The video call will be recorded for the purpose of analysis. The aim of the focus group is to reach consensus on the items for inclusion in the pathway and the structure of the pathway overall.

ARE THERE ANY RISKS/INCONVENIENCE?

Yes, the time given to participate (approximately 4 hours, over the course of 6-8 weeks). If participating in the focus group, you may also feel uncomfortable sharing your opinion among others, feel fear of judgement or frustration relating to opposing opinions. The facilitator will mediate these risks by ensuring the rules of engagement are followed during the focus group whereby all participants speak to each other respectfully, and all are given opportunity to speak freely, without judgement. You may also withdraw at any time.

DO I HAVE TO SAY YES?

Participation in this study is voluntary. It is completely up to you whether or not you decide to take part.

WHAT WILL HAPPEN IF I SAY NO?

If you decide not to participate, it will not affect your relationship with the researchers or the University of Technology Sydney. If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason, by contacting Dr Amanda French (E. Amanda.french@uts.edu.au T.+61 2 9514 7238 or Shanelle Sorbello (E. shanelle.sorbello@uts.edu.au).

If you withdraw from the study, your questionnaire responses will be deleted/ destroyed, and your comments from the focus group will be removed from the transcript/ discounted from analysis.

If you decide to leave the research project, we will not collect additional personal information from you, although personal information already collected will be retained to ensure that the results of the research project can be measured properly and to comply with law. You should be aware that data collected up to the time you withdraw will form part of the research project results. If you do not want them to do this, you must tell them before you join the research project.

UTS UNIVERSITY OF TECHNOLOGY SYDNEY

CONFIDENTIALITY

By signing the consent form you consent to the research team collecting and using personal information about you for the research project. All this information will be treated confidentially. The data will be securely stored on a UTS internal server, which is accessible only via an authenticated UTS system login and only available to researchers involved in the research. Participant names/contact details will be stored separately to questionnaire responses and focus group recordings/ transcripts. Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law.

We plan to publish the results of the study in a scientific journal and present the results at relevant scientific conferences. In any publication, information will be provided in such a way that you cannot be identified. You are not required to keep your participation in this study confidential.

WHAT IF I HAVE CONCERNS OR A COMPLAINT?

If you have concerns about the research that you think myself or my supervisor can help you with, please feel free to contact us on Dr Amanda French (E. Amanda.french@uts.edu.au T.+61 2 9514 7238 or Shanelle Sorbello (E. shanelle.sorbello@uts.edu.au).

NOTE:

This study has been approved in line with the University of Technology Sydney Human Research Ethics Committee [UTS HREC] guidelines. If you have any concerns or complaints about any aspect of the conduct of this research, please contact the Ethics Secretariat on ph.: +61 2 9514 2478 or email: Research.Ethics@uts.edu.au], and quote the UTS HREC reference number. Any matter raised will be treated confidentially, investigated and you will be informed of the outcome.

NOTE: Participating in the Round one consensus survey does not obligate you to participate in Round two or in the focus group held thereafter should you wish to end your involvement in the research.

Please provide your contact details below:

This will be used to send consensus results from this round of survey back to you and invite you to participate in round 2.

First name:	
Discipline/ Role in stroke care:	
E-mail:	
Telephone: *(optional)*	

UTS UNIVERSITY OF TECHNOLOGY SYDNEY

CONSENT FORM

The Pathway Research for Eye Care in Stroke (PRECiS) Study

[ETH20-5446]

I _____ *(participant name)* agree to participate in the research project *The Pathway Research for Eye Care in Stroke (PRECiS) Study [ETH20-5446]* being conducted by *Shanelle Sorbello, University of Technology Sydney, +612 9514 7238*. I understand that this research is being conducted independently by UTS researchers.

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research as described in the Participant Information Sheet.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time without affecting my relationship with the researchers or the University of Technology Sydney.

I understand that I will be given a signed copy of this document to keep.

I agree to be:

☐ Audio recorded

☐ Video recorded

I agree that the research data gathered from this project may be published in a form that:

☐ Does not identify me in any way

☐ May be used for future research purposes

I am aware that I can contact *Shanelle Sorbello or Dr Amanda French* if I have any concerns about the research.

_____ ____/____/____

Name and Signature [participant] Date

_____ ____/____/____

Name and Signature [researcher or delegate] Date

UTS UNIVERSITY OF TECHNOLOGY SYDNEY

SECTION 2: POST-STROKE VISION CARE PATHWAY

Consensus survey
Round 1
The PRECiS Study

APRIL 20, 2021

UTS
Discipline of Orthoptics, GSH

About this survey:
This survey aims to build consensus on a number of best practice statements (BPS) regarding the vision care of stroke survivors in NSW, Australia. These statements will form the basis of a 'post-stroke vision care pathway' created for implementation in Australian stroke care facilities as a means of improving and standardising post-stroke vision care. The statements were gathered from existing literature as well as from data gathered in Stage One of the PRECiS Study (see Appendix I and II).

Survey information and instructions:
You have been provided with the following resources to assist you in completing the survey below:

- A summary review of the literature relevant to post-stroke vision care *(Appendix I)*
- A summary of results from Stage One of the PRECiS Study *(Section 3, Appendix II)*
- A DropBox link to all full text articles referenced in this survey *(below)*

The first column of the document below contains the number of each BPS listed. A list of BPS can be found in the second column of the document below, with the respective rationale written below each statement. The reference from which this statement was taken, or the reference(s) supporting the rationale for this statement can be found in the third column, with a full reference list provided at the end of the document. A DropBox link containing all full text references has also been provided to you below. The fourth column across contains the NHMRC evidence level (Merlin et al. 2009) for each reference used. This provides you with a quick and reliable indication of the strength of evidence supporting each statement.

Appendices & Full text articles available from:
https://www.dropbox.com/sh/sdw1o71cu1y16ut/AAD7lEWaUvm0AJgnkpKwxQ2wa?dl=0

Pages 9 and 10 of this document contain a scoring sheet. The scoring sheet lists the numbers corresponding to each BPS in the first column, with a place to score and comment on each statement in the second and third columns respectively. When scoring each BPS, a single value from 1 to 9 should be indicated. ***A score of 1 indicates that the BPS is highly inappropriate and a score of 9 indicates that the BPS is highly appropriate.*** You are asked to rate each statement according to your own clinical judgement, considering the implications of the BPS on an average patient within an average stroke care setting. You should NOT consider cost implications when making your judgement on each BPS. A BPS is considered 'appropriate' if:

> *"the expected health benefit (e.g. increased life expectancy, relief of pain, reduction in anxiety, improved functional capacity) exceeds the expected negative consequences (e.g. mortality, morbidity, anxiety, pain, time lost from work) by a sufficiently wide margin that the procedure is worth doing, exclusive of cost."*
> (Brook et al, 1986)

Comments can be provided if you think the statement needs revision, restructuring, if the statement should be split or combined with another, or if you think an additional statement should be included. If you have any questions about how to complete the survey or the contents of the survey and it's supporting documents, please contact Shanelle Sorbello (UTS) using the details below:

E: shanelle.sorbello@uts.edu.au T: +61

Please return your response via email to shanelle.sorbello@uts.edu.au by May 24, 2021.

Pathway Research for Eye Care in Stroke (PRECiS) Study

POST-STROKE VISION CARE PATHWAY

Consensus survey 1.0

	Statement and rationale	Reference	NHMRC evidence level
1	**PRE-HOSPITAL PATHWAYS**		
	Community awareness		
1.1	Orthoptists, optometrists and ophthalmologists should endeavour to raise community awareness of visual stroke symptoms. *Rationale:* Visual symptoms of stroke are not well recognised within the community and so may result in delayed contact of health services.	The PRECiS Study (Aroor, Singh, and Goldstein 2017)	N/A III-2
1.2	Orthoptists and ophthalmologists should provide training to general practitioners, accident and emergency personnel and other 'first point of care' professionals regarding differentiating diagnosis of migraine with visual aura, drug overdose and stroke, particularly in younger people. *Rationale:* Stroke with primarily visual symptoms are often misdiagnosed initially as migraine with aura. In younger people specifically, misdiagnosis of drug overdose also occurs. This happens due to a lack of awareness and training on visual stroke symptoms.	(Räty, Silvennoinen, and Tatlisumak 2018) The PRECiS Study (Rowe 2017b) (Aroor, Singh, and Goldstein 2017) (Rowe, Dent, et al. 2020)	III-3 N/A N/A III-2 II
	Referral process		
1.3	Patients that present to their general practitioner, community vision service, or hospital outpatient clinic with sudden onset of visual symptoms (onset <4 hours) indicative of stroke (e.g. double vision, field loss, loss of vision) and unexplained by identifiable pathology should be referred to nearest emergency department. *Rationale:* Stroke with visual deficits as the primary symptom are a risk for delayed diagnosis due to lack of awareness regarding visual consequences of stroke/ TIA.	(Rowe, Hepworth, Howard, Hanna, and Helliwell 2020) (Räty, Silvennoinen, and Tatlisumak 2018)	N/A III-3
1.4	Patients presenting to emergency services (emergency department, ambulance) with sudden onset of visual symptoms (onset <4 hours) indicative of stroke (e.g. double vision, field loss, loss of vision) should be investigated for stroke/ TIA. *Rationale:* Eligibility for intravenous thrombolysis is time sensitive. Hence, if visual symptoms of stroke are misdiagnosed initially, the opportunity to prevent permanent loss of function may be lost.	(Räty, Silvennoinen, and Tatlisumak 2018)	III-3
2	**SCREENING & ASSESSMENT**		
	Timing of assessment		
2.1	Vision screening, including objective measures, should be provided to all stroke patients within 4 weeks of regained consciousness, OR before rehabilitation activities begin. *Rationale:* Visual deficits can complicate rehabilitation (e.g. physical rehabilitation, occupational therapy training, communication training). Strategies to minimise the impact of vision loss on these rehabilitation activities can be utilised if both the patient and other health professionals are aware of the deficits and informed on how to manage them. Objective measures of visual function should be used in screening as many stroke survivors do not or cannot report visual symptoms.	The PRECiS Study (Rowe 2017b) (Sand et al. 2013) (Hepworth et al. 2021)	N/A N/A N/A II

2.2	Where vision screening indicates the need for further vision assessment, this should take place before rehabilitation activities begin or in the early stages of rehabilitation. *Rationale:* Visual deficits can complicate rehabilitation (e.g. physical rehabilitation, occupational therapy training, communication training). Strategies to minimise the impact of vision loss on these rehabilitation activities can be utilised if both the patient and other health professionals are aware of the deficits and informed on how to manage them.	(Rowe 2017b) (Sand et al. 2013)	N/A N/A
2.3	All stroke survivors should be encouraged to have an optometry assessment within 3 months of discharge. *Rationale:* Most stroke survivors are within the age group prone to presbyopia and other age related visual conditions. Hence vision may be compromised even if there is no obvious visual deficit. Having an optometry assessment will ensure refractive error is corrected and age related pathologies identified/ managed.	(Lotery et al. 2000) (Herron 2016)	III-3 III-2
	Health professional(s) performing assessment		
2.4	Where an orthoptist is not available, the use of a suitable, validated vision screening tool(s) for stroke survivors (e.g. VISA, Vision defect in stroke screening tool) by non-eye care specialists should be supplemented with appropriate training and education around how to administer and interpret results of the tool. *Rationale:* Non-eye care professionals have been shown to be less accurate/effective at administering vision screening tools than eye specialist health professionals. However, when appropriate training and education is provided, there is significant improvement.	(Courtney-Harris 2016) (Jolly, Macfarlane, and Heard 2013) (Rowe, Hepworth, Howard, Bruce, et al. 2020)	II III-1 III-1
2.5	Stroke survivors suspected of having visual deficits, who report visual deficits, or show potential visual deficits as a result of screening should be referred for assessment by an orthoptist or ophthalmologist. *Rationale:* Accurate assessment, diagnosis and explanation of visual deficits can only be provided by eye specialist health professionals. Ophthalmologists and orthoptists have the required training to identify and manage stroke related visual deficits.	(Rowe 2010) (Rowe 2011)	N/A II
	Execution of assessment		
2.6	All stroke survivors should have an assessment of visual acuity wearing the appropriate glasses, to check their ability to read newspaper text and see distant objects clearly. *Rationale:* The ability to read at near and distance is an important functional aspect of vision for everyday life. Reduced visual acuity in one or both eyes may be indicative of several pathologies and provides crucial information when forming a visual diagnosis.	Aus Clinical Guidelines for Stroke Management – SF (chp 5; 10.4) (Rowe, Hepworth, and Kirkham 2019)	N/A N/A
2.7	All stroke survivors should have an examination for the presence of visual field deficit (e.g. hemianopia) and eye movement disorders (e.g. strabismus and motility deficits). *Rationale:* Visual field defects and eye movement disorders are the most common visual consequences of stroke and have a severe impact on a survivor's visual function. Consensus has been previously established in a UK study regarding inclusion of visual field and eye motility assessment in the vision screening of stroke survivors.	Aus Clinical Guidelines for Stroke Management – SF (chp 5; 10.4) (Rowe, Hepworth, and Kirkham 2019)	N/A N/A

2.8	All stroke survivors should be assessed for visual neglect and visual perception disorders at the time of vision assessment or perceptual assessment. *Rationale:* Visual neglect is a common consequence of stroke and has a severe impact on a survivor's visual function. It can also occur in conjunction with other visual and perceptual deficits after stroke and so should be accurately diagnosed through a battery of tests. Visual perceptual disorders are less common but are also less likely to be reported by stroke survivors and have a significant impact of their quality of life.	(Rowe, Hepworth, Howard, Hanna, and Helliwell 2020) Aus Clinical Guidelines for Stroke Management – SF (chp 5; 14.2) (Jones and Shinton 2006)	N/A N/A N/A
2.9	Vision screening should include vision history (with carer present if necessary) to identify any pre-existing vision conditions. *Rationale:* Pre-existing vision conditions may explain visual complaints and require ongoing management throughout the patient's rehabilitation in order to reduce impact on recovery.	(Rowe, Hepworth, Howard, Hanna, and Helliwell 2020)	N/A
3	**MANAGEMENT & REFERRAL** **Timing of management/ referral**		
3.1	Orthoptists should initiate management and referrals for visual deficits based on the patient's needs, readiness for information and capacity for participation in these services based on discussion with the stroke survivor and their family. *Rationale:* Due to the varying severity of stroke and individual personalities/ circumstances, stroke survivors and their carers may be ready to participate in vision management at different times, with some visual conditions requiring more immediate treatment than others.	The PRECiS Study (Rowe 2017b)	N/A N/A
3.2	Where a visual deficit is found through screening, or by report of the patient/ carer/ other health professional, there should be immediate referral to an orthoptist. *Rationale:* Immediate referral allows the visual condition to be investigated and diagnosed in a timely manner. This enables time sensitive treatment to be provided as necessary, as well as clarity for the patient and other treating health professionals regarding their condition.	(Jones and Shinton 2006) (Jolly, Macfarlane, and Heard 2013) (Rowe 2011)	N/A III-1 II
3.3	Where short-term management (e.g. advice, patching, Fresnel prisms) is appropriate and available, this should be provided as soon as it becomes beneficial for the stroke survivor. *Rationale:* Simple interventions such as advice (on gaze or head position) or patching/ Fresnel prisms for double vision can be quickly and easily administered and may provide significant improvement to comfort and functionality.	The PRECiS Study	N/A
3.4	If a visual deficit is found that has a known treatment/ intervention available, referral to the appropriate health professional should be made immediately. *Rationale:* Immediate referral allows for intervention to be provided promptly, minimising the impact of the visual deficit on overall recovery. It also provides clear understanding of where and how to seek treatment, should the patient wish to pursue it at a later time.	(Sand et al. 2013) (Jones and Shinton 2006)	N/A N/A
3.5	If a visual deficit is found that does not have a known treatment/ intervention available, but can be managed through therapy/ training, there should be a referral provided at the time the stroke survivor is physically and cognitively able to participate in said management OR on	The PRECiS Study (Falkenberg et al. 2020)	N/A N/A

	discharge. *Rationale:* Commencement of therapy/ training is not appropriate until the stroke survivor is able to understand and participate to an extent that is beneficial to their condition. However, patients should not be discharged without receiving referral.		
3.6	If a visual deficit is found that does not have any known treatment/ intervention or therapy/ training that is appropriate, referral to a vision support service and/or social worker should be provided on discharge. *Rationale:* Referral to support services before they return home ensures the patient and their family have clear information about the long term help available to them and where to obtain it.	(Rowe 2017b) The PRECiS Study	N/A N/A
	Appropriateness of referral		
3.7	Where pharmacological or surgical intervention is available/ recommended for their visual deficit, stroke survivors should be referred to an ophthalmologist. *Rationale:* Specialist eye care that requires pharmacological and/or surgical intervention can only be administered by an ophthalmologist.	Standard practice	
3.8	Where therapeutic training and/or compensatory management options are available/ recommended for their visual deficit, stroke survivors should be referred to an orthoptist and/or trained occupational therapist. *Rationale:* Orthoptists and specifically trained occupational therapists have the specialist knowledge to provide therapeutic training, and educate on compensatory strategies relating to post-stroke visual deficits.	Standard practice	
3.9	Where optical correction (such as glasses and/ or long term prisms) is available/ recommended for their visual deficit, stroke survivors should be referred to an optometrist. *Rationale:* Optometrists have the specialist knowledge to provide optical correction for age related and stroke related vision problems.	(Lotery et al. 2000) (Herron 2016)	III-3 III-2
3.10	Visual perceptual deficits should be referred to a neuro-ophthalmologist. *Rationale:* Visual perceptual deficits are a less common visual occurrence and so are not as widely understood. Neuro-ophthalmologists work specifically with neurological vision loss, and so will be able to provide the most appropriate care.	Standard practice	
3.11	Where no treatment or therapy is available/ recommended for their visual deficit, stroke survivors should be referred to a vision support service (e.g. Vision Australia, Guide Dogs NSW) and social worker to discuss available services and entitlements. *Rationale:* Vision support services and social workers are able to provide access to assistive technology, adaptive training and environmental modification as well as access to psychological and emotional support services. These services enhance the quality of life of stroke survivors with untreatable vision loss.	(Rowe, Hepworth, Howard, Hanna, and Helliwell 2020) (Sand et al. 2013)	N/A N/A
3.12	Discussions with the stroke survivor/ carer should be had to determine if referral to a social worker, stroke or vision support service, or access to a case manager (where available) would aid in managing their vision care and assist in accessing funding for disability support. *Rationale:* The multiplicity of health problems after stroke can be overwhelming for both the survivor and their carer(s). Assistance in	(Hanna, Mercer, and Rowe 2020) The PRECiS Study	N/A N/A

	managing appointments, care services and attaining funding can reduce the stress involved in this process and improve access to these services.		
3.13	Referrals to non-eye care specialists, namely occupational therapists and social workers, should be provided in the same instance as eye-specific referrals. *Rationale:* Services provided by other health professionals that support stroke survivors with vision loss are of equal importance to eye-specific care for successful recovery.	(Sand et al. 2013)	N/A
	Appropriateness of management		
3.14	Management of visual field loss should include promoting awareness of the field loss and compensatory strategies (e.g. visual scanning training, reading strategies, discussion and referral for assistive technology) by an eye care professional as well as environmental adaptations and mobility training guided by an occupational therapist or appropriate healthcare professional. Other options such as restitutive treatment should also be discussed with the patient with advice on effectiveness so they can make an informed decision should they wish to pursue. *Rationale:* There is little conclusive evidence to indicate the most effective treatment, however compensatory methods show task specific improvement and increase quality of life. Stroke survivors indicate a want to be informed on all options available.	(Hanna, Hepworth, and Rowe 2017) (Pollock et al. 2011b) (Howard and Rowe 2018) The PRECiS study	I I I N/A
3.15	Where double vision is the primary complaint of a strabismus or ocular motility issue, occlusion of one eye or Fresnel prisms should be suggested as a short term solution to aid rehabilitation. Long term management should be through referral to an ophthalmologist, neuro-ophthalmologist or orthoptist. *Rationale:* These treatment methods are the best supported by evidence and clinical practice at present.	(Hanna, Hepworth, and Rowe 2017) (Rowe 2017a) (Pollock et al. 2011a)	I N/A I
3.16	Reduced central vision should be referred to an optometrist to ensure refractive error is fully corrected AND ophthalmologist to investigate/ manage potential pathology. *Rationale:* Refractive error (particularly presbyopia) is a very common cause of reduced central vision in the age group most susceptible to stroke. All refractive error should be corrected as best as possible to enhance visual function. However, assessment by an ophthalmologist is necessary to identify and manage any additional pathology.	(Rowe 2017a)	N/A
3.17	Management of visual neglect should include promoting awareness of the area of neglect and cognitive rehabilitation (e.g. visual scanning training, reading strategies) by an eye care professional as well as environmental adaptations and mobility/ activity training guided by an occupational therapist. Other options should also be discussed with the patient with advice on effectiveness so that they can make an informed decision should they wish to pursue. *Rationale:* There is little conclusive evidence regarding the most effective treatment method, however compensatory strategies and training have been shown to be beneficial on standardised assessments. Providing information on different treatment options provides stroke survivors with hope and coping strategies during recovery and in their daily life.	(Hanna, Hepworth, and Rowe 2017) The PRECiS Study (Bowen et al. 2013)	I N/A I

4	**EDUCATION & INFORMATION** **Timing of information**		
4.1	All stroke survivors should be provided general information about stroke related symptoms/ conditions prior to discharge. *Rationale:* This will improve community awareness and alert stroke survivors/ their families to other possible symptoms of a second stroke.	The PRECiS Study	N/A
4.2	Where a visual deficit is identified, information should be provided at the time of diagnosis and prior to discharge. *Rationale:* The patient and/or carer is likely to have questions and concerns regarding their visual condition and these should be addressed immediately. However, the stroke survivor may not be able to understand/ retain this information at the time of diagnosis and so it should be made available to be them again at a later stage.	The PRECiS Study (Rowe 2017b) (Hanna, Mercer, and Rowe 2020) (Forster et al. 2012)	N/A N/A N/A I
	Specificity of information		
4.3	General information about how stroke can impact the eyes and vision should be provided to all stroke survivors in written form (e.g. pamphlet or fact sheet). *Rationale:* Stroke survivors are at high risk of suffering another stroke. They should be made aware of the visual symptoms of stroke so that they can be more easily identified and appropriate action taken should they ever occur.	The PRECiS Study	N/A
4.4	Stroke survivors with a visual deficit should be provided information about what their condition is, what area of the brain and visual system it relates to, the expected implications on functional vision, expected recovery, available management options, resources and support services. This should be included in writing in the patient's discharge summary or in the form of a take home report. *Rationale:* A clear understanding of the visual condition is important in reducing the anxiety associated with a new visual diagnosis. Clear information about management and recovery also helps to manage expectations and adaptation of the stroke survivor and their family.	The PRECiS Study (Rowe 2017b) (Hanna, Mercer, and Rowe 2020) (Forster et al. 2012)	N/A N/A N/A I
4.5	Referrals should be explained in regards to what condition is to be managed or what service provided by each professional the stroke survivor is referred to. *Rationale:* After stroke, a multitude of conditions are managed by a multidisciplinary team. Keeping track of what each referral is for can be confusing and overwhelming for the patient and/or carer and so clear explanation can help in prioritising and organising follow up.	The PRECiS Study	N/A
	Education/ training of stroke health professionals		
4.6	Non-eye specific health professionals should receive training relating to commonly used vision terminology, and visual conditions relating to stroke. *Rationale:* As stroke care requires a collaborative effort from a multi-disciplinary team, all members of the team should have a general understanding of basic visual terminology and common post-stroke visual conditions to aid communication and hence improve patient care.	The PRECiS Study (Rowe et al. 2013)	N/A N/A
4.7	Post-stroke vision assessment should be included in existing stroke pathways and/or protocols for all acute and rehabilitation services. *Rationale:* Where hospitals or rehabilitation facilities have a stroke	The PRECiS Study (Rowe et al. 2013)	N/A N/A

	protocol, vision assessment should be included so that there is consistency of care across all disciplines.		
4.8	Trained eye care professionals (e.g. orthoptists) should be included in the multi-disciplinary team of all stroke care facilities (acute and rehabilitation). *Rationale:* Vision is impacted in approximately 60% of stroke survivors and manifests as a wide range of abnormalities. This necessitates access to specialist vision care acutely as non-eye specific health professionals are often not confident in assessing/ treating visual conditions.	The PRECiS Study (Jones and Shinton 2006) (Rowe, Hepworth, Howard, Hanna, and Currie 2020)	N/A N/A II
4.9	Information regarding the visual condition of a stroke survivor, the implications and how to best manage these should be documented in the patients file and in discharge papers/ referrals for shared access between the multi-disciplinary team. *Rationale:* This information aids other health professionals in providing care/ rehabilitation in a manner that is appropriate for the patient's visual condition. It also ensures accurate and consistent information is given to the patient.	The PRECiS Study	N/A
	Education of carers/ family		
4.10	The stroke survivor's next of kin or carer, if applicable, should be educated on what to expect regarding the impact of the visual deficit on the survivor's daily function, how to best manage this, expected recovery and available resources/ services for management and support. *Rationale:* The stroke survivor is often not capable of retaining and relaying information about their own condition to their carer or family members and so this information should be given directly to the necessary people where possible.	The PRECiS Study	N/A

If you would like to talk to someone who is not connected with the research, you may contact the Research Ethics Officer on 02 9514 9772 or Research.ethics@uts.edu.au and quote this number [ETH20-5446]

PRECiS STUDY – Post stroke vision care pathway
Scoring Sheet

BPS Number	Score (1-9)	Comment(s)
1	PRE-HOSPITAL PATHWAYS	
1.1	9	
1.2	9	
1.3	9	
1.4	9	
2	SCREENING & ASSESSMENT	
2.1	9	
2.2	9	
2.3	9	
2.4	9	
2.5	9	
2.6	9	
2.7	9	
2.8	9	
2.9	9	
3	MANAGEMENT & REFERRAL	
3.1	9	
3.2	9	
3.3	9	
3.4	9	
3.5	9	
3.6	9	
3.7	9	
3.8	9	
3.9	9	
3.10	9	
3.11	9	

3.12	9	
3.13	9	
3.14	9	
3.15	9	
3.16	9	
3.17	9	
4	EDUCATION & INFORMATION	
4.1	9	
4.2	9	
4.3	9	
4.4	9	
4.5	9	
4.6	9	
4.7	9	
4.8	9	
4.9	9	
4.10	9	

General comments:

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PRECiS Study: Section 3

Stage 1 – Data Summary (for more detail see Appendix II)

The following data summary is based on the results of the PRECiS Study Stage 1 (exploratory). Please refer to this summary and Appendix II when seeking to verify references made to these findings throughout the consensus survey.

Stroke survivor survey data (n= 43)

Demographics

	Stroke survivors (*n*=43)
Mean Age in Years (range)	60 (23-88)
Sex n (%)	
Male	20 (46.5)
Female	22 (51.2)
Other	1 (2.3)
Remoteness index classification n (%)	
Major city	24 (55.8)
Inner regional	8 (18.6
Outer regional	11 (25.6)
Remote to Very Remote	nil
Type of stroke n (%)	
Haemorrhagic	12 (28.6)
Ischemic	28 (66.7)
Don't know	2 (4.8)

Visual conditions

	Yes	**No**
Felt vision/ eyes were affected by stroke (%)	87.8	12.2
New visual symptoms relating to stroke (%)	76.2	23.8
Formal diagnosis of stroke-related visual condition (%)	64.3	35.7
Pre-existing eye conditions (%)	38.1	61.9

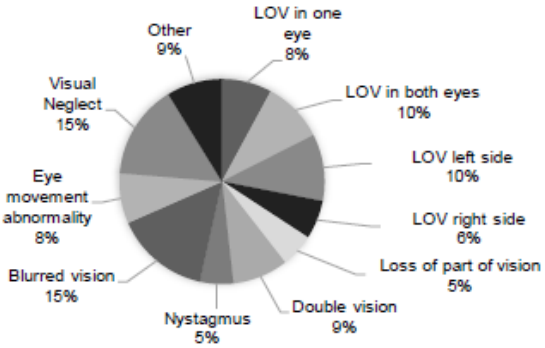


Fig. 1 – Stroke related eye conditions reported; LOV = loss of vision

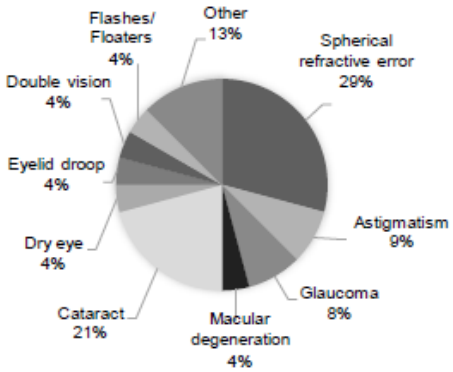


Fig. 2 – Pre-existing eye conditions reported

Vision Assessment
Over a quarter of stroke survivors did not have any vision assessment within six months of their stroke. Of those that did have a vision assessment, approximately half (51.6%) had the assessment within six weeks of their stroke. The majority of vision assessments took place in an external eye clinic (not within the treating hospital) and were performed by an orthoptist.

Management
Less than half of stroke survivors received a care plan upon discharge from the hospital that managed their stroke (46.3%), and of those that did have a plan, less than a third (31.6%) included management options for their visual condition(s). The vast majority received no treatment or assistance for their vision problems as an inpatient (88.1%). Nor were the majority (61.0%) referred by the treating hospital to an eye care professional by time of discharge. Similar trends occurred in rehabilitation hospitals or facilities where most stroke survivors received no treatment for their vision problems (78.3%) and no referral to an eye care professional (77.5%) during their stay or on discharge.

Provision of information
The majority of stroke survivors were not provided information about post-stroke vision problems (65.9%) nor provided with information about their specific vision problem (67.5%). Of those who were provided general information about post-stroke vision loss, this was most often verbal (42.9%) and provided by the treating stroke physician (50%), nurse (21.4%) or orthoptist (14.3%). For those who were provided information specific to their vision problems, this was most often verbal (53.8%) and provided by an orthoptist (38.5%), nurse (23.1%) or doctor (23.1%).

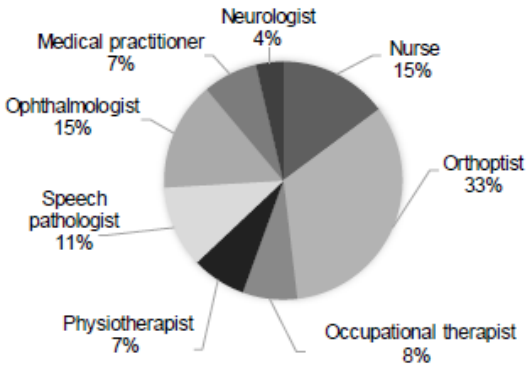
Barriers and unmet care needs
Most stroke survivors felt as though their vision care needs were not successfully met prior to discharge from hospital (60%) or by the care plan and/or referrals they received (61%). However, the majority of stroke survivors did not feel that there were barriers to them receiving appropriate vision care during their recovery (70%). Further exploration of experiences of 'satisfactory' and 'unsatisfactory' vision care, barriers and unmet needs was performed in the stroke survivor interviews. Most felt that their vision problems have had a moderate to significant impact on their daily life (78.4%), and on their overall success in rehabilitation (62.8%).

Health professional survey data (n= 27)

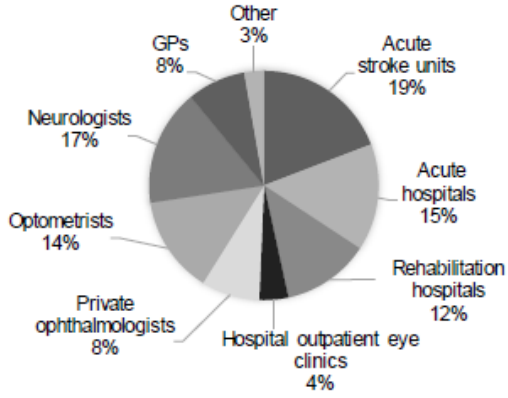
Care setting for health professionals *(may nominate more than one)*

Primary care	15	Acute	2	Outpatient	7	Public	12
Community care	6	Rehabilitation	8	Inpatient	4	Private	8
-	-	Mixed	11	Mixed	10	NGO	1

Role/ occupation:



Where are stroke patients referred from?



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Vision assessment
The vast majority of health professionals report that their workplace does not have a protocol or care plan that includes or is specific to vision problems after stroke (88.9%). Most health professionals (67%) reported that vision problems are often mentioned by stroke patients and that the most common are visual field loss, visual neglect and double vision. The health professional who typically carries out initial visual assessment is an orthoptist (44%) followed by occupational therapist (19%) and neurologist (15%). There is large variability in the vision tests and screening tools that are used for the vision assessment of stroke patients.

Information
Under half of health professionals report that information about post stroke vision problems is provided to patients routinely (40.7%), while several were not sure (18.5%). The most common post-stroke information provided related to driving regulations and specific information about the patient's individual vision problem. A significant number of health professionals report having an orthoptist as part of their multidisciplinary stroke team (40%), however, many report having no eye-care professional as part of their team, or weren't sure (30%). Others report that their multidisciplinary team (MDT) included an ophthalmologist (26%) or optometrist (4%).

Management
Most health professionals report providing treatment or management of vision problems within two weeks of stoke (67%), with the majority of these treatments being continued for as long as needed (80%). Management of vision problems was typically led by an Orthoptist (25%), Ophthalmologist (22%), Occupational therapist (22%), Stroke physician (13%), Neurologist (9%), Nurse (6%) or Physiotherapist (3%). Conditions such as visual field loss and visual neglect were more likely to receive management in-house or from the multidisciplinary stroke team compared to other conditions. Eye movement abnormalities and double vision were most likely to be referred to an orthoptist, while conditions such as reduced central vision, pupil defects, lid/ tear dysfunction or functional vision defects would be most likely referred to an ophthalmologist. Where in-house treatment was provided, this consisted primarily of visual scanning training for field loss and visual neglect, education for eye movement abnormalities and reduced central vision, and patching for double vision.

Barriers
Health professionals most frequently reported a lack of care protocol or management plan as the primary barrier they experience in the identification and/or management of post-stroke vision problems. They also perceived unidentified vision problems experienced by stroke survivors to be the primary barrier to patients receiving successful vision care.

When asked how the identification of post-stroke vision problems could be improved, health professionals felt that routine vision screening for all stroke patients was most important. Second to this was the use of a vision screening tool, followed by the inclusion of orthoptists on stroke units, having a standardised protocol with suggested tools, vision training for the MDT, timely referral to specialist vision services prior to discharge, increased resources including specialist staff, inclusion of vision care in the stroke pathway and increased awareness of post-stroke vision problems among the MDT and general public.

When asked how the management of post-stroke vision problems could be improved, most felt that a standardised referral or management protocol that the MDT were trained on would help. Equally reported was the need for established links/ access to specialist eye services prior to discharge from acute care. Other suggestions were the inclusion of orthoptists/ ophthalmology service onsite, increased vision training for the MDT, improved education and awareness of post-stroke vision problems amongst patients and staff, more research in the area, closer relationship between inpatient and community care to ensure follow up of visual problems, and clearer indications of what funding is available for different age groups.

Stroke survivor interview data (n=21); see next page…

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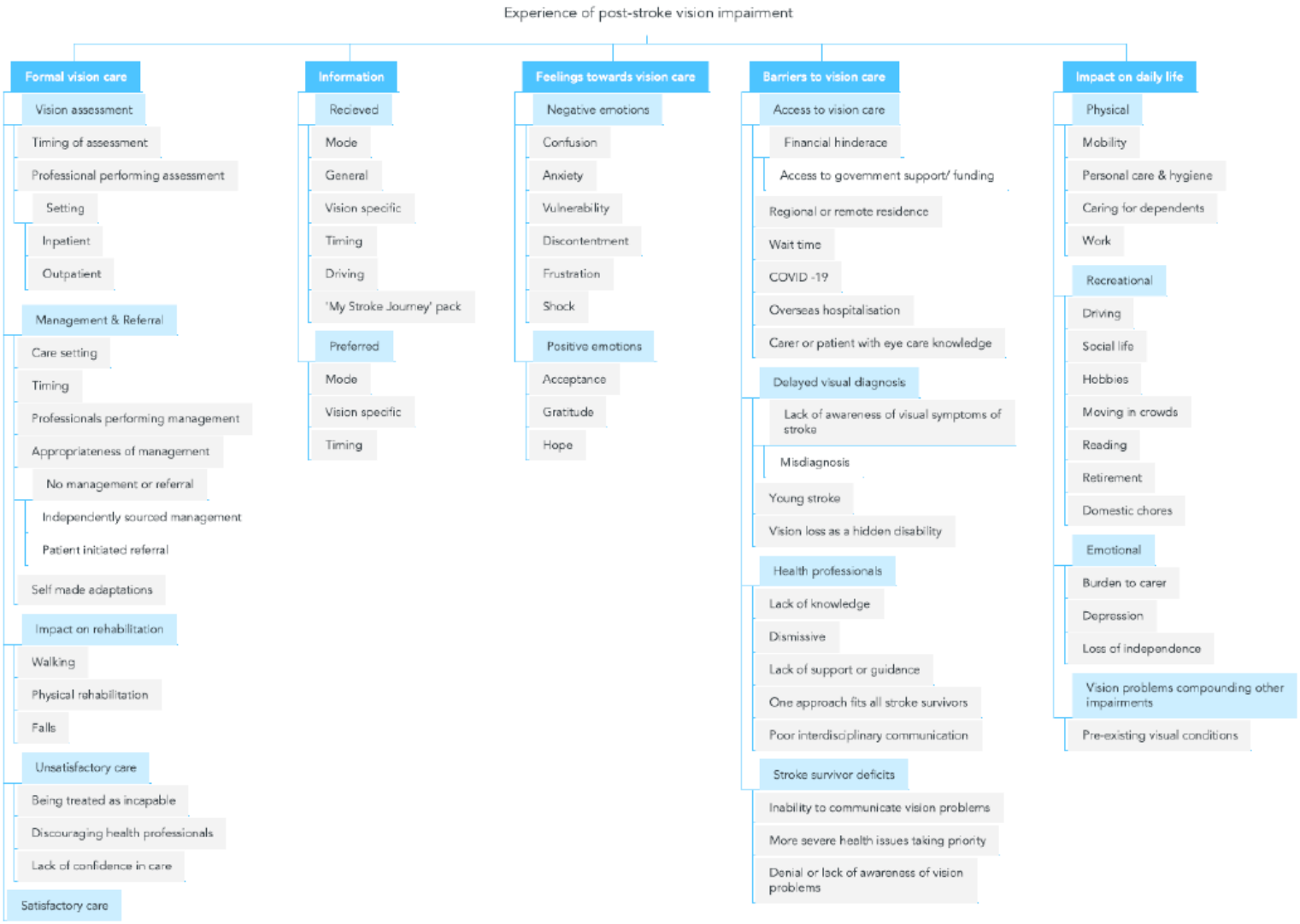


Fig 3. Summary of stroke survivor interview data: The five emerging themes from stroke survivor interview data and their related categories/ sub-categories as indicated by coding.
For more detail see Appendix II

11.11 SUMMARY OF EVIDENCE PROVIDED WITH BPS SURVEY

UTS UNIVERSITY OF TECHNOLOGY SYDNEY

PRECiS Study

Literature Summary: Stroke and vision disorders

Stroke related vision loss

In Australia, there are more than 100 stroke events every day.[1] Of these, up to 60% will result in some form of vision disorder.[2] Stroke can cause an array of visual disorders and it is common for stroke survivors to have some form of visual impairment in both acute and long-term stages of recovery.[3,4] Specifically, visual field loss (30-40%),[5,6] eye movement abnormalities (70%)[7,8] and visual processing disorders (80%) are among the most commonly reported visual problems following stroke.[4] Recovery of stroke-related visual impairment is variable depending on the type of deficit. Only an estimated 17% of visual field loss recovers completely over the first 3 months, while, 34% of visual perceptual disorders recover.[2] Eye movement abnormalities including cranial nerve palsies and gaze related defects occur frequently in brainstem and cerebellum strokes.[7,8] Most gaze defects only partially recover (66%) or do not recover at all (30%), over a 6 month period post-stroke.[7] For patients with ocular cranial nerve palsies, some recovery over 6-12 months after onset is expected although, recovery is most often partial (43%) with only approximately 22% recovering completely.[8]

In addition, as stroke occurs most often in the elderly with 71% aged over 65,[9] there is also a high prevalence of pre-existing eye conditions in this group. Such conditions include refractive error and age-related presbyopia (loss of accommodative ability) requiring optical correction, as well as, other pathological conditions causing visual impairment such as; macular degeneration, cataract and glaucoma. Many of these conditions require ongoing management by ophthalmologists to prevent further degeneration of vision. This complicates the ocular care of stroke survivors, which requires the detection of both pre-existing and newly acquired visual impairments for appropriate long-term care.

The impact of visual impairment in the community is known to be substantial. As well as significant direct and indirect costs,[10] visual impairment significantly impacts activities of daily living (ADLs) and is a barrier to patient independence in the community, increasing reliance on community support services and carers.[11-13] A recent systematic review reported that visual impairment in stroke survivors, substantially reduces quality of life (QoL), with a combination of central vision impairment and visual field loss reducing QoL more so than visual field loss alone.[14] A study conducted in the UK interviewed 35 stroke survivors with visual impairment and found that patient's reported a number of barriers to reintegration into the community resulting from their visual impairment including, inability to return to work, pursue hobbies or drive.[15] In addition to this, visual impairment is known to impact balance,[16] gait,[16] depression[12] and overall morbidity,[17,18] hence is an additional barrier to successful rehabilitation of stroke survivors.

Currently, there is very little evidence regarding the provision of post-stroke vision care in Australia and no evidence based guidelines specific to management of stroke related vision disorders. The Australian Clinical Guidelines for Stroke Management currently only contain limited information regarding vision, including recommendation for visual acuity and visual field testing and treatment options for visual inattention only.[19] Stage one of the PRECiS Study aimed to begin to address this by conducting an exploratory study of post-stroke care provision in NSW using surveys and interviews to determine current practices and identify potential shortcomings. The results of this study have been summarised in Appendix II. With the information collected, combined with existing evidence relating to best practice in the detection and management of stroke related vision disorders, a draft post-stroke vision care pathway has

been created (main document) and will be developed through a consensus study involving Australian stroke health care professionals. Table 1 and Table 2 contain a summary of the relevant evidence pertaining to the detection and management of the most commonly occurring stroke-related vision disorders.

Other considerations for stroke survivors with vision loss

When discussing care provision of vision impairment in stroke survivors it is important to consider the non-vision specific impacts on wellbeing and potential health inequalities for this population. Depression has been strongly linked to vision impairment[12] and stroke[20] independently. It is unsurprising that stroke survivors with vision loss often report experiencing depression at various points in their post-stroke life.[15] Qualitative studies with stroke survivors indicate a strong sense of multifaceted loss: loss of mobility, loss of identity, loss of confidence and loss of agency.[21] Several stroke survivors in Stage One of the current study said that they were advised of depression as a consequence of stroke but were often not provided referral to a psychologist or advised on organisations where emotional support could be obtained. This needs to be considered in the care provision of stroke survivors with vision impairment as mental health is an important facet of overall wellbeing and is crucial to support ongoing stroke recovery. In discussions of health inequalities within this population the primary issues related to patient – clinician power imbalance.[21] Specifically, lack of information transfer from clinician to patient, or inappropriate communication of information that made it difficult for the patient to understand and/or remember the information given to them about their condition.[15,21] There is also an issue around patient-centred stroke care where the stroke survivor does not always have an input into their rehabilitation regime and personal issues/ goals are not addressed. Where patients have some control over their rehabilitation goals, this improved the power imbalance felt by them in their recovery.[21] Stroke survivors also have to navigate the multiplicity of their health problems in attending several appointments at different locations and times while trying to overcome the disabilities acquired through stroke. For many this is only possible through the assistance of a carer or next of kin, and raises questions about inequalities experienced by those stroke survivors who do not have access to this kind of support. These concepts are reinforced through the data collected in Stage One of the PRECiS Study and shows that these issues translate into an Australian context of stroke care.

Consideration must also be given to the financial burden of having a stroke. Most stroke survivors suffer prolonged or permanent loss of income as a result of their stroke but also have increased expenses that are associated with their healthcare and recovery.[15,21] Some stroke survivors describe how this financial burden fed into their depression and loss of identity,[21] while others in the PRECiS study explain their financial circumstances as a barrier to attaining appropriate vision care. In Australia, the National Disability Insurance Scheme (NDIS) provides opportunity for Australians to access care services and support for a range of disabilities. However, navigating this system with existing disabilities can be difficult and guidance in this process is often required for successful utilisation of the service. The introduction of a social worker and/or case manager into the stroke care pathway may help negate some of these inequalities by helping to coordinate the ongoing care necessary for stroke recovery, as well as providing information and support in accessing funding and support services where possible. Limitations within the health system may not allow for staffing of this kind in all hospitals or rehabilitation facilities, however additional training and information for existing staff in the areas of funding and social support may allow for better transfer of information to stroke survivors and their carers.

Table 1. Detection of vision disorders in stroke survivors

Vision disorder	Associated symptoms	Gold standard assessment	Alternative assessment
Visual field loss	Loss of vision in one area, commonly half of the visual field or one quarter of the visual field. Other visual field defects can cause an overall restriction of the visual field or localised areas of loss in the periphery or centrally. Patients are typically aware of this loss if it does not occur in conjunction with neglect.	Quantitative perimetry assessment of full visual field: • Goldmann visual field • Octopus visual field Not appropriate for patients with communication and cognitive deficits or with severe fatigue. Requires patient to have significant sitting balance and operate a buzzer with one hand.	• Confrontation visual field – higher risk of bias, low sensitivity.[22,23] Detects hemianopic and quadrantic defects. NIHSS confrontation method (finger counting) shown to have 20% sensitivity and 98% specificity.[23] • Oculokinetic Perimetry (OKP) method – detects arcuate, quadrantic, hemianopic, altitudinal and nasal step defects, high sensitivity (94%) and portable.[24,25] Requires normal communication, cognition and attention. • Hemispheric stroke scale – stroke vision screening tool appropriate for aphasic patients, high correlation with Barthel index indicating high sensitivity overall.[26] • Checklist for vision problems post-stroke – stroke vision screening tool with 69% sensitivity when administered by an orthoptist and 17% by a non-orthoptist.[27] • VIS screening form – stroke vision screening tool with 92% sensitivity, reduced to 42% sensitivity and 52% specificity without patient reported symptoms.[28]
Reduced central vision	Reduced or blurred vision overall or centrally. It is important to note that a number of conditions can cause reduced visual acuity and reduced contrast sensitivity. Such conditions may be present prior to stroke and are common within populations over the age of 65 years.	Visual acuity testing using an EDTRS logMAR chart at distance (6m) and standardised near vision chart at 1/3m. Contrast sensitivity can be screened using a Pelli-Robson contrast chart or sinusoidal wave grating chart. Requires patients to be able to recognise letters or numbers as well as communicate verbally or through a matching card, and have a normal level of cognitive function.	• MIS Pocket Vision Guide – screening for near visual acuity appropriate for stroke population, authors strongly advise use of optical correction during testing to reduce false positive results.[28] • Assessments developed for pre-verbal children may help overcome issues of aphasia such as the Teller Acuity Test and Cardiff Acuity Test (CAT) by using principle of preferential looking. There is no evidence in stroke populations but the CAT has been found practical in older populations with dysphasia or cognitive impairment.[29] • VIS Screening form – tests for reduced visual acuity however sensitivity (92%) relies on patient reported symptoms.[28] • The Checklist for Vision Problems Post-stroke – tests for reduced visual acuity. Relies solely on patient responses to questioning.[27]
Visual neglect (inattention)	Lack of awareness of one side of the visual field (typically left side). Visual neglect can occur	Currently there is no 'gold standard' method of visual neglect assessment, however, a	A multitude of screening tools and test batteries for the assessment of visual neglect exist. Each have merits and limitations relating to their accuracy and suitability to testing in stroke populations.[29]

	in differing severities and may occur in conjunction with other forms of neglect e.g. personal, motor, auditory.	battery of at least three different tests is said to increase accuracy of testing.[29] For example: • Line bisection (using lines of 200mm length) • Cancellation tests (shape, letter, bell) • Figure copying Requires patients to hold and use a pen with one hand, have a level of cognition to understand instructions and recognise objects, have reasonable level of near vision.	Common limitations of these tools include time taken to complete, portability for use at bedside, cognitive and physical capability requirements as well as accuracy and sensitivity. Pen and paper tools such as line bisection, cancellation tests and figure copying are inexpensive, easy to administer at bedside and have reasonable sensitivity when administered correctly and collectively.[29] The Rivermead Behavioural Inattention (BIT) test encompasses all variants of inattention screening methods, however lengthy to perform and so difficult for stroke patients in the acute stage to complete.[30] Shorter alternatives have since been developed[29]: • Sunnybrook Neglect Assessment (SNAP) – faster than BIT with high reliability and validity, suitable for aphasic patients, requires handwriting and moderate cognition.[31] • Virtual Reality Diagnostic Test (VR-DiSTRO) – computer based, easy to complete, three times faster than BIT. Not able to performed at bedside and requires sitting balance.[32]
Other visual perception disorders	In addition to the more commonly acquired visual neglect, visual perceptual disorders can include Agnosia (inability to recognise objects/ faces), Alexia (inability to comprehend written language), visual hallucinations, impaired depth perception, colour vision disturbance and many others.	Currently there is no 'gold standard' assessment for visual perception disorders. Typical examination combines careful questioning of symptoms by a trained healthcare professional as well as utilisation of one or more screening tools.	• Mini Mental State Examination (MMSE) – cognitive impairment screening tool suitable for use in stroke patients, unable to screen for complex impairments such as visuospatial deficits.[33,34] • Montreal Cognitive Assessment (MoCA) – quick, suitable for bedside assessment with high sensitivity but 42% specificity.[35] • Oxford Cognitive Screen (OCS) – cognitive impairment screening tool that includes visual field, sentence reading, space and object asymmetry; sensitivity from 27-94%.[29,36] • Occupational Therapy Perceptual Screening Test (OT-APST) – includes agnosia, visuospatial relations. Found to be reliable but requires separate prior testing of visual acuity, tracking, visual fields and visual history in order to modify for patient needs.[37,38] • Leuven Perceptual Organisation Screening Test (L-POST) – freely available online and can be administered at bedside on laptop or tablet. Neglect friendly version (if patient is pre-diagnosed with neglect).[39] Shortened version piloted in sub sample of low ability patients (including small number of

			stroke survivors) showed 79% sensitivity and 54% specificity.[40] • Test of Visual Perceptual Skills (TVPS-3) – tests visual discrimination, visual memory, spatial relations, form constancy, visual figure and visual closure. Patients can respond without motor or verbal expression and suitable for those with reading difficulties. Some issues with test-retest reliability.[29,41]
Cranial nerve palsy or Gaze defect	Palsy of the cranial nerves three, four and six can cause misalignment of the eyes resulting in double vision impaired depth perception, balance issues and cosmetic misalignment of the eyes. Gaze defects may make patients unable to move their eyes in certain directions and cause impaired eye movement, double vision and make visual tasks that involve scanning and/or tracking difficult.	Orthoptic or ophthalmologist assessment to assess: • Ocular motility • Ocular alignment (cover test, prism bar cover test, Bielschowsky Head Tilt Test) • Diplopia • Vestibulo-ocular reflex Requires patient to have reasonable sitting balance, ability to communicate for some aspects of testing and adequate cognitive function to understand instructions.	• Ocular motility, as well as some diplopia and ocular alignment assessments can be performed at bedside by a trained eye care professional, this still requires the patient to be responsive and understand verbal instructions. • Hemispheric stroke scale – includes gaze/eye movement assessment, however, testing is only able to identify gaze palsies or conjugately deviated gaze.[26] • The Checklist for Vision Problems Post-stroke – includes questioning of ocular motility defects. Requires patients to be responsive and able to communicate.[27] • VIS Screening Form – includes ocular motility, however sensitivity is dependent on patient responses and so requires the patient to be able to communicate in order to maintain effectiveness.[28]
Vitreous or Retinal Haemorrhage	Vitreous or retinal haemorrhage may cause significantly reduced vision centrally or in the periphery.	Vitreous or retinal haemorrhage is diagnosed through dilated fundus examination using a slit lamp, fundus camera or Optical Coherence Tomography. Examination of this kind does not require the patient to be responsive or communicate. Portable slit lamps and fundus cameras are available, making it possible to perform such an assessment at bedside, however	While haemorrhages at the posterior of the eye are not uncommon in stroke patients, screening tools for this population do not typically test for retinal pathologies, with the exception of questioning previously diagnosed conditions. It would not be possible to formally diagnose these pathologies without viewing the fundus, with this type of formal assessment typically carried out by an ophthalmologist.

		this equipment is not widely used in hospitals. Assessment on more commonly used, fixed machinery would require good sitting balance and steady fixation.	
Pupil defects	Pupillary defects may cause blurred vision, sensitivity to light, generalised discomfort or may be asymptomatic.	Pupil defects can be assessed through observation of the eyes, and simple assessment using a small bright light to check direct and consensual response to light, and diagnose relative afferent pupillary defects using the swinging light test. These assessments do not require any verbal response from the patient and can be performed at bedside. In order to test accommodative response (fixation at near) the patient is instructed to change fixation from a distance target to a near target. This requires patient to be able to understand instructions but does not require verbal communication.	All pupil assessments can be performed quickly and easily at bedside by a trained healthcare professional. No verbal communication is required.
Nystagmus	Nystagmus typically causes blurred vision, unsteady fixation and may impair depth perception. In some cases, the eyes may appear to be constantly 'shaking'.	Nystagmus can typically be diagnosed from observation. Latent nystagmus may only be discovered when one eye is covered or when eyes are in a certain position of gaze. Assessment of nystagmus can be performed at bedside and does not usually require the patient to be able to communicate.	Assessment of nystagmus can be performed quickly and easily at bedside by a trained healthcare professional. No verbal communication is required by the patient. However, further investigation to inform management of nystagmus may require some level of responsiveness and patient communication.

Table 2. Management of stroke related vision disorders

Vision disorder	Short-term management	Long-term management
Visual field loss	• Education – information on how much of the visual field has been affected, what the implications are for functional vision, expected recovery and management/ support options available. This information should also be relayed to family and/or care providers. • Visual scanning – encouraging eye movements towards the area of loss to promote awareness. This can be done through specified training sessions using paper-based or computer based search tasks, and also incidentally during other rehabilitation activities. • Prisms – Pelli prisms may assist during rehabilitation to promote awareness of objects and obstacles in the area of loss.	• Pelli prisms – Fresnel prisms cut and placed on spectacle lenses above and/or below the pupil shift images from the area of loss into the seeing field. This substitutive treatment prompts patients to look toward the affected side and promote awareness.[42] Studies have shown that participants noted a positive difference when using Pelli prisms, particularly when walking.[43] • Visual scanning training – paper based or computer based training activities can help to compensate for the area of loss and improve performance of certain activities such as reading through increased speed and accuracy of eye movements.[44-46] There is currently no evidence to suggest that visual scanning training aids in reducing the area of loss.[47] Where recovery of visual field loss has been reported in prior studies, natural recovery of the visual field in early stages post-stroke cannot be ruled out.[47] Evidence suggests that training is task specific, hence improvements in reading are noted as a result of reading training but not eye search training and vice versa.[44,48] • Vision restoration treatment – light stimuli are presented at the border area of field loss to help promote expansion of the visual field.[49] Studies have reported an expansion of the visual field border of 1-11.3 degrees,[50,51] however eye movements were not recorded and so expansion due to eye movement cannot be ruled out. Where fixation was controlled, little to no change in the visual field was shown.[52,53] • Orientation and mobility training – training typically performed by occupational therapists or low vision specialists to help patients to use their intact senses as well as mobility aids to know where they are within their environment and navigate through it safely. • Vision aids – a multitude of vision aids exist to assist patients with visual field loss in activities of daily living such as reading, writing and cooking.

		• Environmental modification – assistance typically from an occupational therapist or low vision specialist on how to best modify the patient's home and/or work environment in a way that maximises their visual function and makes performing daily activities with their vision impairment easier and safer. Such modifications may include where their bed/ clothing and essential items are positioned, where they sit at the dinner table, positioning of computer screens and visual prompts.
Reduced central vision	• Education – inform patient and/ or care giver about the condition, the impact of this on functional vision, potential recovery and treatment options. This has been shown to reduce anxiety and stress around the vision loss during recovery. • Glasses/ update prescription – A common correctable cause of reduced central vision is refractive error. Checking and prescribing appropriate glasses is a simple and effective way of maximising visual function. • Environmental modification – use of appropriate lighting, colour and contrast in the patient's environment and during rehabilitation activities to maximise visual function.	• Ophthalmologist care provision – it is important that conditions are formally diagnosed, managed and monitored as necessary. • Visual aids – vision aids such as magnifiers, electronic vision and reading aids have been shown to improve quality of life for those with vision impairment. • Environmental modification – advice from an occupational therapist or low vision specialist can help to modify the patient's home and/or work environment in a way that maximises their visual function and makes performing daily activities with their vision impairment easier and safer. • Low vision support services – low vision services can provide necessary guidance on appropriate vision aids as well as provided training for things such as orientation and mobility training, daily living skills training, workplace training and support and falls prevention training. These services can also provide support in accessing government funding such as the NDIS. Explanation of these services and what they offer is important for patient understanding, increasing utilisation of these services and reducing stigma around low vision services.
Visual neglect (inattention)	• Education – information on the condition, what the implications are for functional vision and awareness, expected recovery and management/ support options available. This information should also be relayed to family and/or care providers. • Visual scanning – encouraging eye movements towards the area of loss to promote awareness. This can be done through specified training sessions using paper-based or	• Cognitive rehabilitation/ Perceptual retraining – Cognitive rehabilitation is a broad term used to describe a number of training strategies aimed at reducing the adverse effects cognitive impairment has on an individual's life. With regard to visual inattention, these therapies may include visual scanning training, feedback or cueing, mental practice and imagery, prims adaptation and hemifield patching. Cognitive rehabilitation may be considered restitutive or compensatory, whereby restitutive treatment is more often used in early stages of recovery where plasticity is

	computer based search tasks, and also incidentally during other rehabilitation activities.	considered greatest and compensatory techniques used later.[54] A Cochrane review showed significant improvement on standardised assessments following cognitive rehabilitation, however, when only high quality trials were included this effect was no longer significant.[47,54] ○ Hemifield eye patching and optokinetic stimulation – This is considered a restitutive therapy. Evidence shows equal amounts of improvement in neglect-related functional disability in both the control group and treatment group.[55] ○ Visual scanning training/ Smooth pursuit training – paper based and computer based visual scanning training are commonly prescribed treatments for visual neglect to promote compensatory eye movements into the area of neglect. There is some evidence to suggest that smooth pursuit training offers more improvement to visual and auditory outcomes than standard scanning therapy however there is a currently a lack of high quality evidence to support this.[47,56] ○ Prisms/ prism adaptation training – another compensatory therapy using prisms fit to spectacle lenses that shift the image from the area of neglect into the non-neglect field.[47] • Environmental modification – modifying the patients home and/or work environment to reduce the impact of neglect on their daily activities. Such modifications may include where their bed/ clothing and essential items are positioned, where they sit at the dinner table, positioning of computer screens and visual prompts. • Low vision support services – low vision services can provide necessary guidance on appropriate vision aids to better utilise the area of non-neglect, as well as provided training for things such as orientation and mobility training, daily living skills training, workplace training and support and falls prevention training. Such services can also provide guidance on how to attain funding through government initiatives such as the NDIS. Explanation of these services and what they offer is important for patient understanding, increasing utilisation of these services and reducing stigma around low vision services.

Other visual perception disorders	• Education – Patients report a benefit from formal diagnosis and recognition of their perceptual condition as well as advice on coping strategies.	There is a lack of high quality evidence regarding interventions for visual perceptual disorders with very few treatment options discussed in the literature.[47] Cross-modal word recognition training has been investigated in patients with alexia where single word were presented visually and vis audio simultaneously. Patients recognised words from the training program faster than untrained words, but this improvement was not maintained at follow up.[57]
Ocular motility defects	• Education – patients should receive information about their condition, what the implications are for functional vision, expected recovery and management options. • Patching – one eye is covered to eliminate diplopia caused by misalignment of the eyes. This improves mobility and reduced discomfort for the patient. • Fresnel prisms – cut and placed on spectacle lenses in the correct strength and direction can help to reduce or eliminate diplopia. The prism(s) act to shift the image seen by one eye enough so that the two eyes see overlapping images that can be fused, hence compensating for eye misalignment. Alternatively, prisms can be used to separate the images to an extent that one can be ignored and/or is less troublesome to the patient. • Alternative head posture – advice on adopting an alternative head posture in order to avoid the gaze position in which diplopia is present can help to reduce or eliminate double vision.	• Botulinum toxin – injected into specific eye muscles in order to restore balance to muscle actions and reduce symptoms of strabismus caused by cranial nerve palsies.[58] The effects last up to three months. • Prisms ground into glasses – if the use of Fresnel prisms has been successful in reducing or eliminating diplopia and the misalignment of the eye is stable, prisms can be incorporated into a pair of glasses for a more permanent management option. • Strabismus surgery – surgery performed on the eye muscles to realign the eyes can be performed once the condition is stable, however this treatment option is not typically suitable for torsional imbalances. • Orthoptic exercises – specific ocular motility problems such as convergence insufficiency and decompensating heterophorias can be treated through vergence exercises. This may help to eliminate symptoms such as diplopia and asthenopia.[59]
Vitreous or Retinal Haemorrhage	• Education – information should be provided on the condition, what the implications are for functional vision and treatment options. • Patching – occlusion of the affected eye may improve short term comfort to prevent competition of vision from affected eye.	• Ophthalmologist care provision – prompt assessment from an ophthalmologist will confirm the diagnosis and inform the patient of their treatment options. Some spontaneous recovery may occur depending on the cause and extent of the haemorrhage, and the patient should be informed on what treatment strategy is best suited to them. Other treatment options that can be provided by an ophthalmologist include: ○ Laser photocoagulation – to treat the abnormal vessel(s) in order to stop bleeding and prevent future bleeds in this area.

		○ Vitrectomy – removal of the vitreous humour to clear blood and allow light to pass through optics of the eye, restoring vision. ○ Anti-VEGF injections – treat abnormal vessels at the back of the eye that have caused bleeding and disruption of vision. This treatment is typically undergone over multiple sessions, with duration determined by individual response to treatment and stability of the condition.
Pupil defects	• Education – information should be provided on the condition, what the implications are for functional vision and management options available. • Glasses – vision can be maximised by ensuring the patient has glasses that are appropriate for their refractive error (if any). In the case of fixed, dilated pupils dimmer lighting or use of sunglasses may increase comfort.	Pupil defects are difficult to treat in isolation and need to be addressed in relation to the systemic cause of the defect. Formal assessment and management by an ophthalmologist and/or neurologist should be undertaken to ensure cause of the pupil abnormality (typically neurological) is addressed.
Nystagmus	• Education – information should be provided on the condition, its implications for functional vision and management options. • Prisms/ Alternative head posture – if the 'null point' or eye position in which nystagmus is minimised can be identified, the patient can be advised to adopt an alternative head posture or be fit with Fresnel prisms in order to keep their eyes in this position and reduce the visual impact of nystagmus.	• Formal investigation and management with ophthalmologist – important to diagnosis the type and cause of nystagmus and hence inform appropriate management strategies. ○ Pharmaceutical intervention – most often, pharmaceutical interventions are prescribed to manage nystagmus. Neurologists more commonly report prescribing Gabapentin and Baclofen to treat nystagmus.[60] Limited evidence is available regarding the treatment of nystagmus in stroke populations.[47,61] Trihexyphenidyl has been shown to have no effect on the velocity of nystagmus, while 3,4-diaminopyridine did have a significant effect but was not found when assessed in a sub-group of stroke patients.[61] ○ Other options such as botulinum toxin and paired high powered spectacle lenses with contact lenses have been trialled to stabilise nystagmus, however the effects have not been well tolerated as long term treatment methods.[62] • Low vision support services – low vision services can provide necessary guidance on appropriate vision aids that help utilise remaining vision in order to carry out daily activities with greater ease. They can also provide training as necessary in areas of orientation and mobility training, daily living skills
		training, workplace training and support and falls prevention training. These services can also provide support in accessing government funding such as the NDIS. Explanation of these services and what they offer is important for patient understanding, increasing utilisation of these services and reducing stigma around low vision services.

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11.12 ROUND 1 SUMMARY OF SCORES (EXAMPLE)

PRECiS Study

Consensus Survey Round 1: Personalised Summary of results

Below is a summary of the scores given for each best practice statement (BPS) in Round One. Your score and comments for each statement are highlighted in red. The comments of other respondents have not been provided.

Pre-hospital pathways:

BPS # **Comments:**

1.1

Score	9	8	7	6	5	4	3	2	1
Frequency	11	3	2	0	1	0	0	0	0

If a client is diagnosed with a visual impairment they should be required to attend an internal or external appropriate health professional before discharge from hospital

1.2

Score	9	8	7	6	5	4	3	2	1
Frequency	6	3	4	1	1	0	0	2	0

Even is provided via telemedicine.

1.3

Score	9	8	7	6	5	4	3	2	1
Frequency	12	4	1	0	0	0	0	0	0

Yes, not enough community clients are referred to the appropriate professionals.

1.4

Score	9	8	7	6	5	4	3	2	1
Frequency	11	5	1	0	0	0	0	0	0

More Vision assessments need to be completed by occupational therapists which cover this screening area of

Screening & Assessment

2.1

Score	9	8	7	6	5	4	3	2	1
Frequency	11	6	0	0	0	0	0	0	0

This is vital to success in rehab and should be addressed early in rehab.

2.2

Score	9	8	7	6	5	4	3	2	1
Frequency	8	7	0	0	0	0	1	1	0

Always!!

2.3

Score	9	8	7	6	5	4	3	2	1
Frequency	10	1	1	2	1	1	1	0	0

Every patient!!!

2.4

Score	9	8	7	6	5	4	3	2	1
Frequency	6	3	5	0	2	1	0	0	0

This is the case across the board and needs to occur more in practice.

2.5

Score	9	8	7	6	5	4	3	2	1
Frequency	14	1	2	0	0	0	0	0	0

2.6

Score	9	8	7	6	5	4	3	2	1
Frequency	12	4	1	0	0	0	0	0	0

2.7

Score	9	8	7	6	5	4	3	2	1
Frequency	13	4	0	0	0	0	0	0	0

2.8

Score	9	8	7	6	5	4	3	2	1
Frequency	12	3	1	0	1	0	0	0	0

Most definitely.

2.9

Score	9	8	7	6	5	4	3	2	1
Frequency	15	1	1	0	0	0	0	0	0

Management & Referral

3.1

Score	9	8	7	6	5	4	3	2	1
Frequency	9	4	2	1	1	0	0	0	0

3.2

Score	9	8	7	6	5	4	3	2	1
Frequency	10	3	3	0	1	0	0	0	0

These clients should not be discharged.

3.3

Score	9	8	7	6	5	4	3	2	1
Frequency	13	3	0	0	1	0	0	0	0

Not enough of this is happening

3.4

Score	9	8	7	6	5	4	3	2	1
Frequency	13	3	1	0	0	0	0	0	0

3.5

Score	9	8	7	6	5	4	3	2	1
Frequency	11	3	2	1	0	0	0	0	0

3.6

Score	9	8	7	6	5	4	3	2	1
Frequency	12	3	1	0	0	1	0	0	0

3.7

Score	9	8	7	6	5	4	3	2	1
Frequency	12	4	0	1	0	0	0	0	0

3.8

Score	9	8	7	6	5	4	3	2	1
Frequency	12	4	1	0	0	0	0	0	0

3.9

Score	9	8	7	6	5	4	3	2	1
Frequency	13	2	2	0	0	0	0	0	0

3.10

Score	9	8	7	6	5	4	3	2	1
Frequency	11	3	0	2	1	0	0	0	0

3.11

Score	9	8	7	6	5	4	3	2	1
Frequency	14	1	2	0	0	0	0	0	0

3.12

Score	9	8	7	6	5	4	3	2	1
Frequency	13	2	2	0	0	0	0	0	0

3.13

Score	9	8	7	6	5	4	3	2	1
Frequency	12	1	0	2	2	0	0	0	0

3.14

Score	9	8	7	6	5	4	3	2	1
Frequency	13	2	1	1	0	0	0	0	0

3.15

Score	9	8	7	6	5	4	3	2	1
Frequency	11	2	2	2	0	0	0	0	0

3.16

Score	9	8	7	6	5	4	3	2	1
Frequency	11	3	1	0	1	1	0	0	0

3.17

Score	9	8	7	6	5	4	3	2	1
Frequency	11	2	2	0	1	1	0	0	0

Education & Information

4.1

Score	9	8	7	6	5	4	3	2	1
Frequency	13	2	1	0	1	0	0	0	0

4.2

Score	9	8	7	6	5	4	3	2	1
Frequency	13	2	2	0	0	0	0	0	0

4.3

Score	9	8	7	6	5	4	3	2	1
Frequency	10	1	2	0	2	1	1	0	0

4.4

Score	9	8	7	6	5	4	3	2	1
Frequency	12	1	1	0	2	0	1	0	0

4.5

Score	9	8	7	6	5	4	3	2	1
Frequency	12	2	1	0	2	0	0	0	0

4.6

Score	9	8	7	6	5	4	3	2	1
Frequency	13	3	0	0	1	0	0	0	0

4.7

Score	9	8	7	6	5	4	3	2	1
Frequency	11	4	1	0	1	0	0	0	0

4.8

Score	9	8	7	6	5	4	3	2	1
Frequency	10	2	3	1	1	0	0	0	0

4.9

Score	9	8	7	6	5	4	3	2	1
Frequency	14	2	0	0	1	0	0	0	0

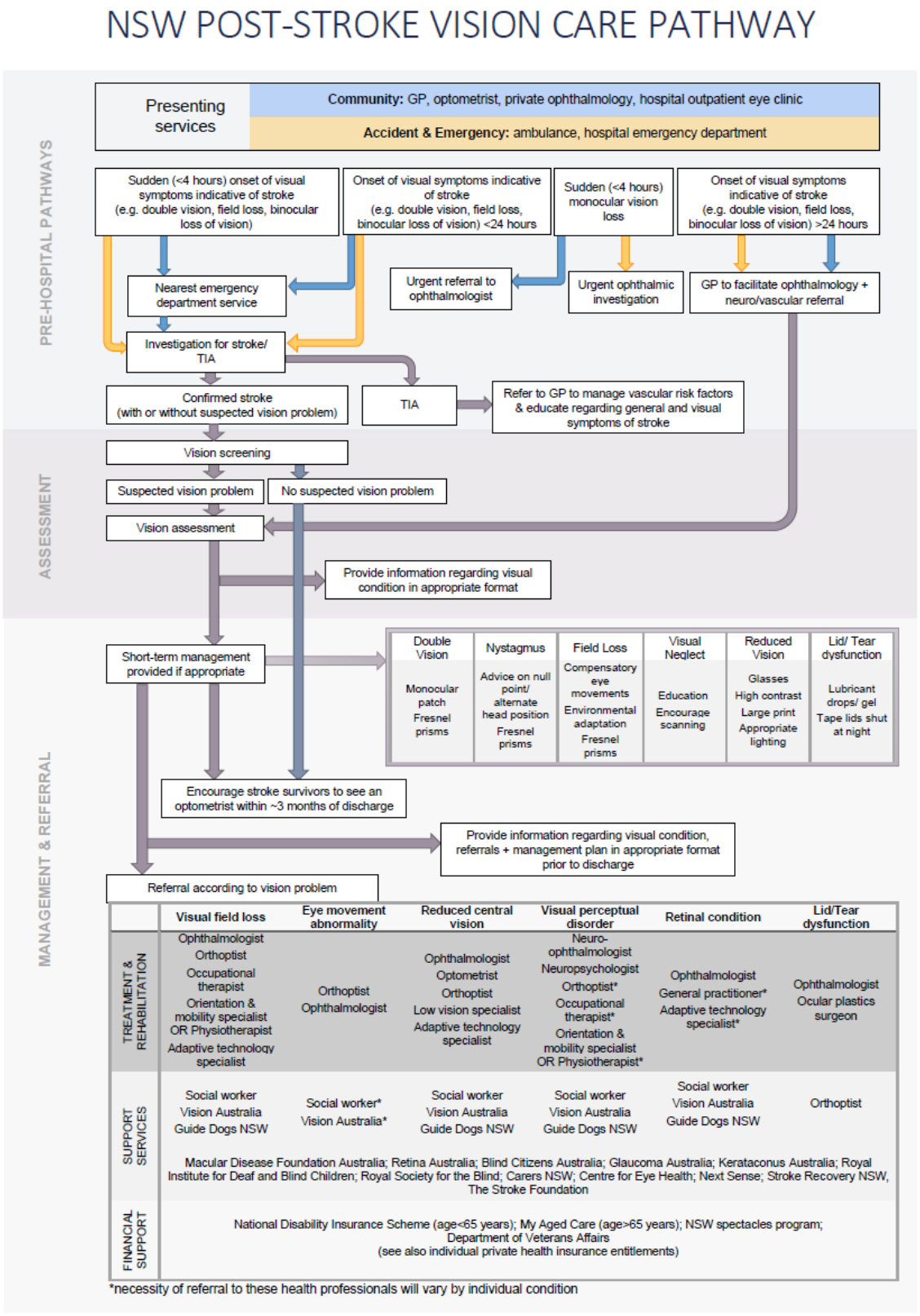
4.10

Score	9	8	7	6	5	4	3	2	1
Frequency	13	2	0	2	0	0	0	0	0

General comments:

Overall there is not enough in this field here in Australia and not enough support is provided.

11.13 ORIGINAL NSW POST-STROKE VISION CARE PATHWAY



11.14 ROUND 2 SUMMARY OF SCORES (EXAMPLE)

PRECiS Study

Consensus Survey Round 2: Personalised Summary of results

Below is a summary of the scores given for each best practice statement (BPS) in Round Two. Your score and comments for each statement are highlighted in red. The comments of other respondents have not been provided.

Pre-hospital pathways:

BPS # **Comments:**

1.1

Score	9	8	7	6	5	4	3	2	1
Frequency	9	4	0	0	0	0	0	0	0

1.2

Score	9	8	7	6	5	4	3	2	1
Frequency	6	7	0	0	0	0	0	0	0

1.3

Score	9	8	7	6	5	4	3	2	1
Frequency	12	1	0	0	0	0	0	0	0

1.4

Score	9	8	7	6	5	4	3	2	1
Frequency	11	2	0	0	0	0	0	0	0

Screening & Assessment

2.1

Score	9	8	7	6	5	4	3	2	1
Frequency	9	2	1	0	0	0	1	0	0

2.2

Score	9	8	7	6	5	4	3	2	1
Frequency	7	4	2	0	0	0	0	0	0

2.3

Score	9	8	7	6	5	4	3	2	1
Frequency	7	3	2	0	1	0	0	0	0

2.4

Score	9	8	7	6	5	4	3	2	1
Frequency	9	2	1	0	0	1	0	0	0

2.5

Score	9	8	7	6	5	4	3	2	1
Frequency	10	3	0	0	0	0	0	0	0

2.6

Score	9	8	7	6	5	4	3	2	1
Frequency	12	0	1	0	0	0	0	0	0

2.7

Score	9	8	7	6	5	4	3	2	1
Frequency	12	1	0	0	0	0	0	0	0

2.8

Score	9	8	7	6	5	4	3	2	1
Frequency	10	1	2	0	0	0	0	0	0

2.9

Score	9	8	7	6	5	4	3	2	1
Frequency	12	1	0	0	0	0	0	0	0

Management & Referral

3.1

Score	9	8	7	6	5	4	3	2	1
Frequency	10	3	0	0	0	0	0	0	0

3.2

Score	9	8	7	6	5	4	3	2	1
Frequency	10	3	0	0	0	0	0	0	0

3.3

Score	9	8	7	6	5	4	3	2	1
Frequency	11	1	0	0	1	0	0	0	0

3.4

Score	9	8	7	6	5	4	3	2	1
Frequency	11	2	0	0	0	0	0	0	0

3.5

Score	9	8	7	6	5	4	3	2	1
Frequency	10	3	0	0	0	0	0	0	0

3.6

Score	9	8	7	6	5	4	3	2	1
Frequency	9	4	0	0	0	0	0	0	0

3.7

Score	9	8	7	6	5	4	3	2	1
Frequency	11	2	0	0	0	0	0	0	0

3.8

Score	9	8	7	6	5	4	3	2	1
Frequency	9	4	0	0	0	0	0	0	0

3.9

Score	9	8	7	6	5	4	3	2	1
Frequency	10	3	0	0	0	0	0	0	0

3.10

Score	9	8	7	6	5	4	3	2	1
Frequency	8	1	2	0	1	0	1	0	0

3.11

Score	9	8	7	6	5	4	3	2	1
Frequency	10	2	0	0	1	0	0	0	0

3.12

Score	9	8	7	6	5	4	3	2	1
Frequency	10	3	0	0	0	0	0	0	0

3.13

Score	9	8	7	6	5	4	3	2	1
Frequency	10	3	0	0	0	0	0	0	0

3.14

Score	9	8	7	6	5	4	3	2	1
Frequency	9	4	0	0	0	0	0	0	0

3.15

Score	9	8	7	6	5	4	3	2	1
Frequency	9	4	0	0	0	0	0	0	0

3.16

Score	9	8	7	6	5	4	3	2	1
Frequency	10	3	0	0	0	0	0	0	0

3.17

Score	9	8	7	6	5	4	3	2	1
Frequency	9	4	0	0	0	0	0	0	0

Education & Information

4.1

Score	9	8	7	6	5	4	3	2	1
Frequency	12	1	0	0	0	0	0	0	0

4.2

Score	9	8	7	6	5	4	3	2	1
Frequency	12	1	0	0	0	0	0	0	0

Vision professionals may need to liaise with other team members such as speech pathologists for survivors to provide accessible information for a person with communication disability I know it is not about communication in itself, but I would really love to see a nod to awareness of that issue and our role in working in this area for the benefit of these patients.

4.3

Score	9	8	7	6	5	4	3	2	1
Frequency	11	2	0	0	0	0	0	0	0

4.4

Score	9	8	7	6	5	4	3	2	1
Frequency	12	1	0	0	0	0	0	0	0

4.5

Score	9	8	7	6	5	4	3	2	1
Frequency	11	2	0	0	0	0	0	0	0

4.6

Score	9	8	7	6	5	4	3	2	1
Frequency	10	2	1	0	0	0	0	0	0

4.7

Score	9	8	7	6	5	4	3	2	1
Frequency	11	2	0	0	0	0	0	0	0

4.8

Score	9	8	7	6	5	4	3	2	1
Frequency	9	2	2	0	0	0	0	0	0

4.9

Score	9	8	7	6	5	4	3	2	1
Frequency	12	1	0	0	0	0	0	0	0

4.10

Score	9	8	7	6	5	4	3	2	1
Frequency	11	2	0	0	0	0	0	0	0

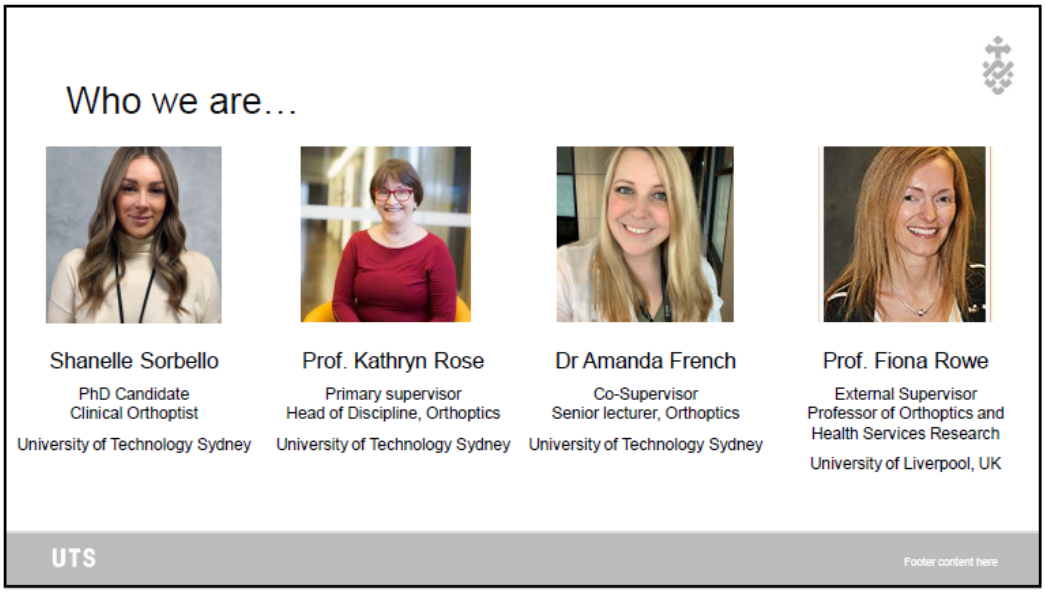
General comments:

this is a remarkable and import document. I would really appreciate that there is a little specificity about where people can get support for aphasia friendly materials through mention of SLP

11.15 Panel Meeting Introduction

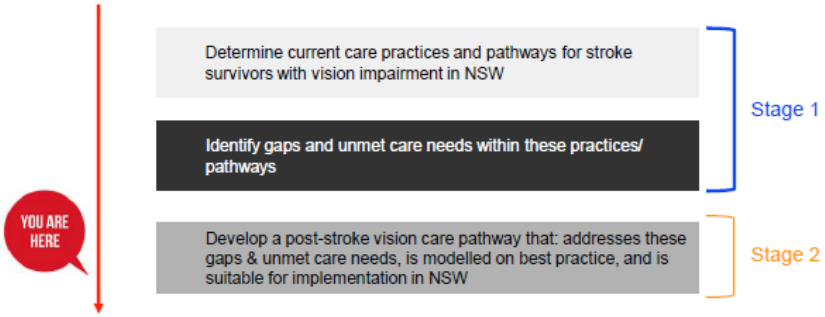


1



2

Study Aims:



3

Recap on relevant background information…

- Vision impairment is common after stroke (60% of stroke survivors), as are pre-existing eye conditions in the population most susceptible to stroke (aged >60 years)
- Lack of awareness amongst the general community and health professionals regarding visual symptoms of stroke is a known problem for timely diagnosis
  - Particularly in occipital strokes and in younger stroke victims
- Gaps & unmet care needs identified in Stage 1:
  - Unstandardised practices in assessment, management and information provision between care facilities → relates to a lack of protocol/ guidelines + access to specialist staff
  - Lack of timely and appropriate assessment
  - Lack of specific information delivered in an appropriate format & time frame
  - Lack of acute management for vision problems impacting overall rehabilitation
  - Lack of visual rehabilitation options and/or referral provided
  - Delayed access to care causing prolonged burden of impairment

4

What we will be discussing today…

- In the last round of consensus survey, all best practice statements (BPS) were deemed ***appropriate*** with ***strong agreement*** amongst the group
- The structure and content of the **NSW post-stroke vision care pathway**
  - Is it reflective of the BPS previously agreed upon by the group?
  - Is it comprehensive and appropriate?
  - Is it clear and easy to follow?
- After discussion (and amendment) of each section you will be asked to rate the appropriateness of that section using the Zoom polling function



5

What is expected in the rating process?

Open discussion

Please feel free to share your opinions, refer to the evidence & BPS, propose changes, agree or disagree. It's just a conversation!

Determining appropriateness

After discussion and any amendments made for each section (as agreed upon by the group), I will open a live poll for rating & share the results.
Your score will not be identifiable by others in the meeting.

As you are all familiar with the BPS we will only be allowing a short time for scoring once the poll is open.



6

Reminder about *'appropriateness'*…

Definition:

"the expected health benefit (e.g. increased life expectancy, relief of pain, reduction in anxiety, improved functional capacity) exceeds the expected negative consequences (e.g. mortality, morbidity, anxiety, pain, time lost from work) by a sufficiently wide margin that the procedure is worth doing, exclusive of cost."

- Brook et al, 1986



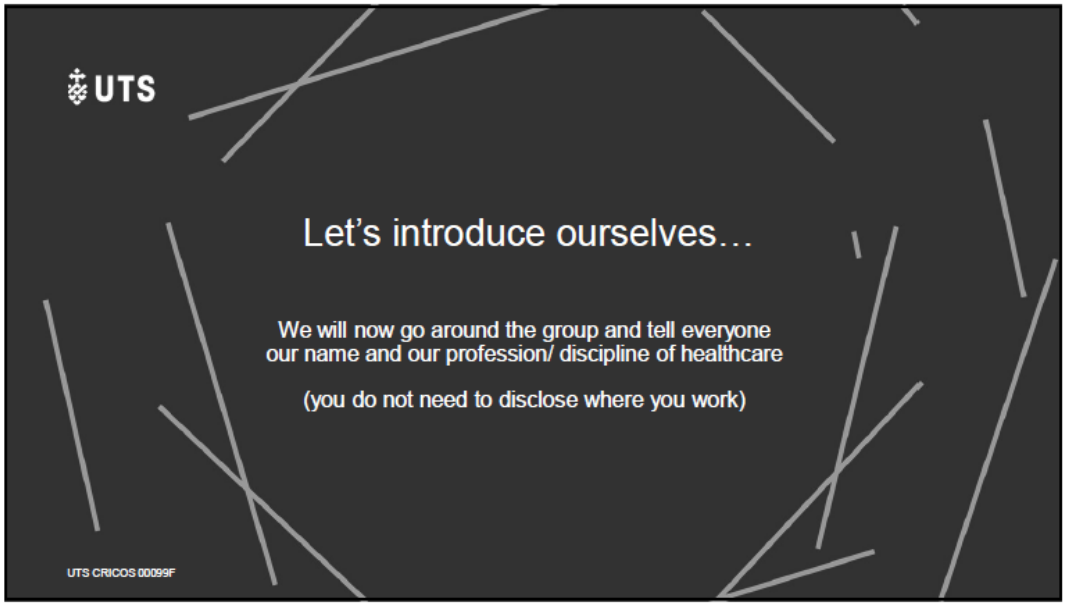
Highly Appropriate ***Highly Inappropriate***

7

A few ground rules…

1. Be polite ☺ *(no profanities or personal criticism)*
2. Try to avoid talking over others
   (we know this can be tricky on Zoom, but as a rule of thumb, wait until a person has finished speaking before you start)
   i. If you are struggling to find an opportunity to speak, you can use the 'raise hand' function (bottom of your screen: Reactions > Raise hand)
3. The content of this meeting as well as the identities of those involved is CONFIDENTIAL.
   i. There should not be others listening in at your home/ office while the meeting is taking place
   ii. The meeting content and participants should not be discussed with others after the meeting concludes except for with the research team should you wish to debrief or raise an issue.
4. There are no 'right' or 'wrong' points, so feel free to discuss and make suggestions.
5. Keep in mind the purpose of the discussion and this study, as well as the relevant evidence.

8


UTS
Let's introduce ourselves…
We will now go around the group and tell everyone our name and our profession/ discipline of healthcare
(you do not need to disclose where you work)
UTS CRICOS 00099F

9

11.16 Panel Meeting Discussion Summary

UTS UNIVERSITY OF TECHNOLOGY SYDNEY

THE PRECIS STUDY

NSW POST-STROKE VISION CARE PATHWAY: DEVELOPMENT & EVALUATION

ROUND 3: CONSENSUS STUDY

So far in this consensus study, two rounds of survey have been completed in which you have rated the appropriateness of a series of 'Best Practice Statements' relating to the vision care of stroke survivors in NSW.

In the previous round of this consensus study, all best practice statements (BPS) were deemed ***appropriate with agreement from all participants*** (see Document 1). From these statements, a 'NSW post-stroke vision care pathway' has been created (see Section 2).

On the 19th of August, 2021 a Panel Meeting took place with seven stroke healthcare professionals who participated in the previous rounds of the consensus study. The primary focus of discussion was the structure and content of the diagrammatic pathway (Section 2).

The pathway was discussed section by section with specific reference to:

1. How well it reflects the Best Practice Statements previously agreed upon by the group
2. If it is comprehensive and appropriate
3. If it is clear and easy to interpret

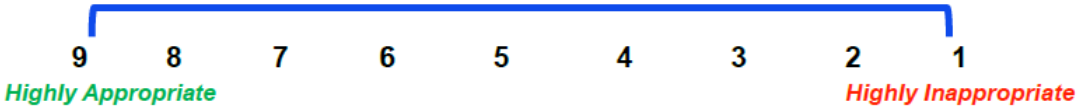
Below (Section 3) is a summary of the outcomes of the meeting for each section, including main points of discussion, proposed changes and final ratings.

We ask that you **review this information for each section and provide your own rating** of appropriateness for each section of the pathway. Your rating should be based on the modified version which includes the proposed changes agreed upon at the Panel Meeting. We also encourage you to add your own comments and/or thoughts regarding the pathway and discussion points using the comment section.

A REMINDER ABOUT THE RATING PROCESS:

Discussion and rating should be made in relation to an AVERAGE patient presenting to an AVERAGE hospital or clinical setting.

A rating of *9 = **highly appropriate**, 1 = **highly inappropriate***



A procedure or practice is deemed appropriate based on the following definition:

> "the expected health benefit (e.g. increased life expectancy, relief of pain, reduction in anxiety, improved functional capacity) exceeds the expected negative consequences (e.g. mortality, morbidity, anxiety, pain, time lost from work) by a sufficiently wide margin that the procedure is worth doing, exclusive of cost."
>
> *- Brook et al, 1986*

Here we have provided a DropBox link where you can access the previously referenced supporting documents (summary of PRECiS Study Stage 1 Results, literature review, systematic review) should you wish to access these and refamiliarize yourself with the relevant background information.

SECTION 3: SUMMARY OF MEETING DISCUSSION & OUTCOMES + RATING

Please read the discussion points for each section and review the proposed changes before providing your score (1-9) and comments.

PATHWAY SECTION 1: MODES OF PRESENTATION

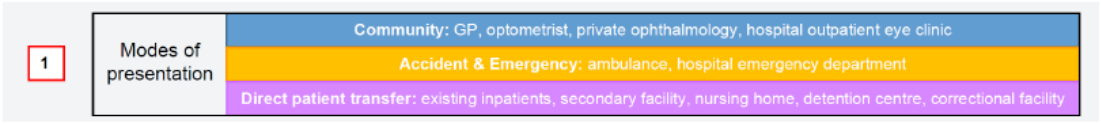
ORIGINAL:



SUMMARY OF DISCUSSION:

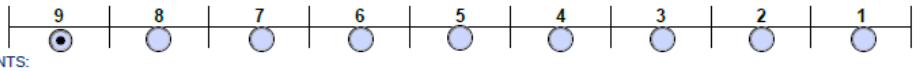
- All agreed that the modes of presentation currently listed should remain
- Existing patients in hospital (inpatients in other wards, having procedures performed) may end up having a stroke or displaying signs/ symptoms of stroke
  - This mode of presentation is not covered
  - They would likely bypass the emergency department and so the pathway that follows would differ
  - As these patients are already under the care/supervision of health professionals, the symptoms may not necessarily be self reported by rather noticed by those caring for them
- The same might apply for patients who are transferred from another hospital/ secondary facility/ nursing home/ detention centres and prisons
- This mode of presentation should be added under a new category 'Direct patient transfer', should have a different colour and join the pathway at 'investigation for stroke/TIA'

PROPOSED CHANGES:



With the proposed changes all participants deemed this section **appropriate with agreement.**

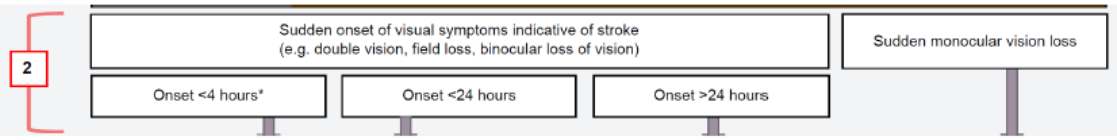
PLEASE PROVIDE YOUR SCORE FOR SECTION 1:



COMMENTS:

PATHWAY SECTION 2: PRESENTING SYMPTOMS

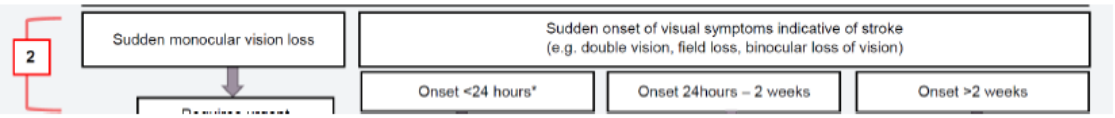
ORIGINAL:



SUMMARY OF DISCUSSION:

- All agreed that the presenting symptoms listed were appropriate and reflective of the best practice statements
- Time frame <4 hours:
  - The <4 hours time frame seems unnecessary and potentially beyond the scope of this pathway as one intended for vision problems. This is based on the eligibility criteria for thrombolysis, which is already highlighted and rationalised in the BPS.
  - The suggested action for <4 hours and <24 hours is referral to nearest emergency department so would be appropriate to group these into one, with a footnote explaining the eligibility criteria for thrombolysis as <4 hours
- Time frame >24 hours:
  - Between 24 hours and 1-2 weeks post onset of stroke symptoms, patients may still be at risk of worsening (e.g. secondary stroke or progression to complete stroke in the case of Carotid Artery dissections.
  - Unsure on exact time frame (whether 1 or 2 weeks is more appropriate) but 24hours is definitely too soon to rely on GP referral for neurovascular care. This process is too slow and often results in delays of up to 21 days or more.
  - Propose a new category 'onset >24 hours but less than 1 week' (would need to check the evidence/ get stroke physician opinion on end point) and have these patients referred to a rapid access TIA or stroke centre
  - Beyond this end point (1-2) weeks it would them be appropriate to have referral through GP

PROPOSED CHANGES:



- The evidence suggests that in most cases of carotid artery dissection, progression to complete stroke occurs within 5-10 days. Hence, the new category proposed was 'onset 24hours – 2 weeks'
  Reference: Guillon B, Lévy C, Bousser MG. Internal carotid artery dissection: an update. Journal of the neurological sciences. 1998 Jan 8;153(2):146-58.
- The best practice statements were updated to be reflective of these changes:

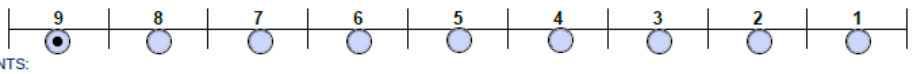
1.3 Patients that present to their general practitioner, community vision service, or hospital outpatient clinic with sudden onset of visual signs/symptoms (onset <24 hours) indicative of stroke (e.g. double vision, field loss, binocular loss/significant reduction of vision) and unexplained by identifiable pathology should be referred to nearest emergency department. Sudden monocular vision loss should be urgently referred to an ophthalmologist if cause is undetermined.
Rationale: Eligibility for intravenous thrombolysis is time sensitive (≤4 hours). Hence, if visual symptoms of stroke are misdiagnosed initially, the opportunity to prevent permanent loss of function may be lost. Stroke with visual deficits as the primary symptom are a risk for delayed diagnosis due to lack of awareness regarding visual consequences of stroke/ TIA. Sudden monocular loss of vision can be caused by pathologies such as Wet AMD and retinal vein occlusions, therefore requires further ophthalmic investigation to rule out ocular pathology.

1.4 Patients presenting to emergency services (emergency department, ambulance) with sudden onset of visual signs/symptoms (onset <24 hours) indicative of stroke (e.g. double vision, field loss, binocular loss of vision) should be investigated for stroke/ TIA. Vision assessment should be performed for sudden monocular vision loss to determine necessity of stroke/TIA investigation. Where an eye care professional is not available, this should be performed by a stroke health professional trained in vision assessment.
Rationale: Eligibility for intravenous thrombolysis is time sensitive (≤4 hours). Hence, if visual symptoms of stroke are misdiagnosed initially, the opportunity to prevent permanent loss of function may be lost. Sudden monocular loss of vision can be caused by pathologies such as Wet AMD and retinal vein occlusions, therefore requires further ophthalmic investigation to rule out ocular pathology.

1.5 Patients that present to community or emergency services with sudden onset of visual signs/symptoms (onset >24hours but less than 2 weeks) indicative of stroke (e.g. double vision, field loss, binocular loss/significant reduction of vision) and unexplained by identifiable pathology should be referred to nearest stroke/TIA rapid access centre for investigation.
Rationale: In some circumstances, such as minor stroke or carotid artery dissection, initial symptoms are isolated and/or minor which often results in delayed presentation to health services. These patients are at heightened risk of recurrent stroke and/or progression to completed stroke and require urgent investigation and management. Most carotid artery dissections progress to completed stroke within 5-10 days.

With the proposed changes all participants deemed this section **appropriate with agreement.**

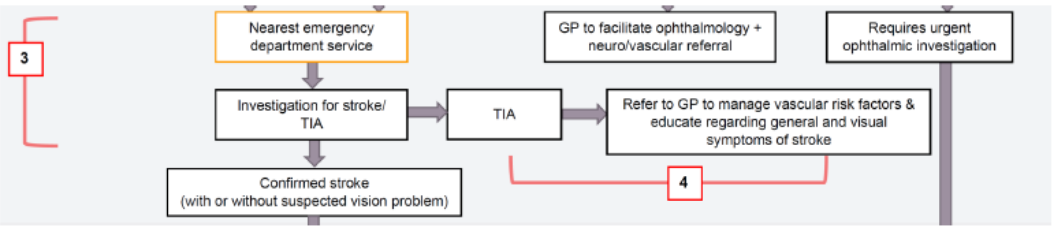
PLEASE PROVIDE YOUR SCORE FOR SECTION 2:



COMMENTS:

PATHWAY SECTION 3: SUGGESTED ACTION

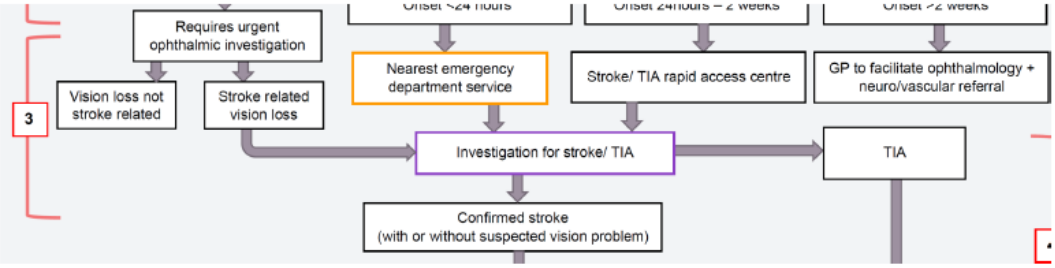
ORIGINAL:



DISCUSSION SUMMARY:

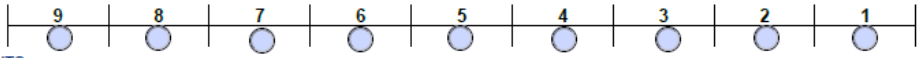
- For those with monocular vision loss who require urgent ophthalmic investigation, if they are found to have vision loss as a result of retinal artery or retinal vein occlusion they need to go back into the stroke pathway
  - There should be two outcomes resulting from 'urgent ophthalmic investigation': 'stroke related vision loss' which relates to conditions such as retinal artery and vein occlusions, and 'vision loss not stroke related' which relates to other eye conditions such as wet macular degeneration.

PROPOSED CHANGES:



With the proposed changes all participants deemed this section **appropriate with agreement.**

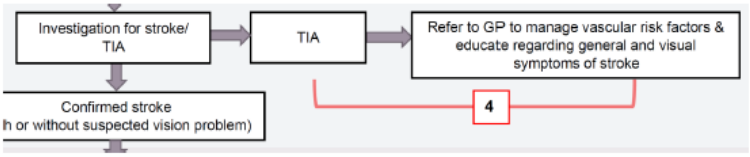
PLEASE PROVIDE YOUR SCORE FOR SECTION 3:



COMMENTS:

PATHWAY SECTION 4: TIA

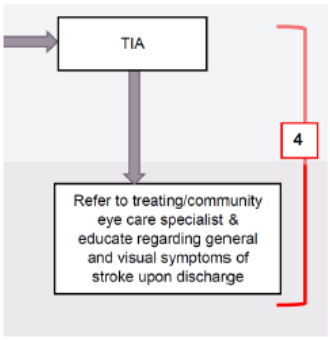
ORIGINAL:



DISCUSSION SUMMARY:

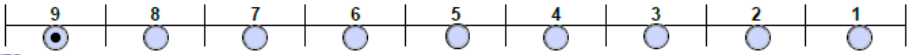
- TIA patients still tend to spend quite a bit of time in hospital, perhaps should still follow stroke pathway as there is not much difference between the two except that they are not in hospital for as long
    - There was some disagreement about this among the group as most felt that TIA should be distinguished from stroke because by being transient in nature it is not in fact considered a stroke
        - Also, by definition, the resulting signs/symptoms of a TIA are not permanent and so don't require the same process in terms of management
        - More appropriate that they are referred to someone in the community (treating eye care specialist or optometrist to ensure there are no pre-existing or ongoing eye conditions)
        - Perhaps referral part should be moved further down the pathway (out of 'Pre-hospital pathways' section) to better reflect the timing in which this usually occurs. Most TIA patients are admitted for some period of time.
- Management of vascular risk factors may not be necessary to include in this pathway as it is outside the scope of what is intended as a 'vision' pathway
- Important to keep part about education on general and visual symptoms of stroke as TIA patients are at greater risk of stroke

PROPOSED CHANGES:



With the proposed changes all participants deemed this section **appropriate with agreement.**

PLEASE PROVIDE YOUR SCORE FOR SECTION 4:

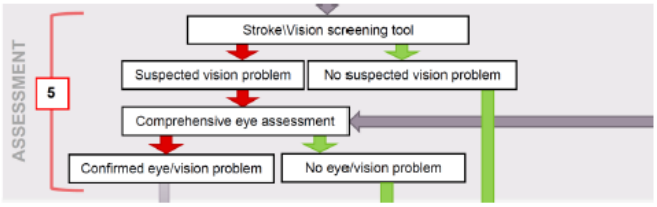


COMMENTS:

more helpful for eye problems

PATHWAY SECTION 5: ASSESSMENT

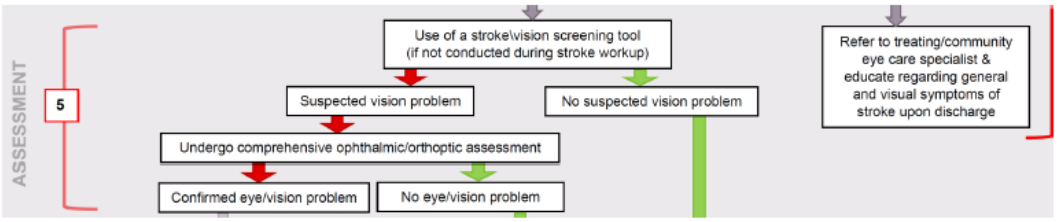
ORIGINAL:



DISCUSSION SUMMARY:

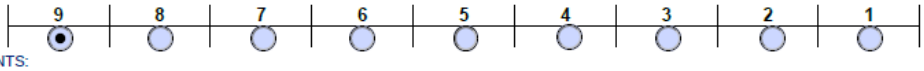
- There may be a need for some delegation of tasks in this section so that it is not by passed due to uncertainty in terms whose responsibility it is
  - This is outlined in the BPS and the pathway is intended for use in conjunction with the BPS
    - Does need to made clear that a comprehensive assessment is one performed by an eye care professional
    - Differentiates this from screening which can be done by any member of the stroke team. This is particularly important when considering rural/regional areas of NSW where access to specialist eye care is unlikely to be available on the stroke ward. It should be clear that screening using a validated tool can and should be done by any member of the team.
  - Perhaps include 'call to action' wording such as 'conduct stroke vision screening' and/or 'refer for/undergo comprehensive assessment'
- Sometimes vision screening is done as part of the stroke assessment, perhaps this should be included to prevent double up/ waste of resources
  - Stroke 'workup' is more appropriate and commonly used language in hospitals
    - Better describes the extensive nature of various types of assessments performed in diagnosis of stroke

PROPOSED CHANGES:



With the proposed changes all participants deemed this section **appropriate with agreement.**

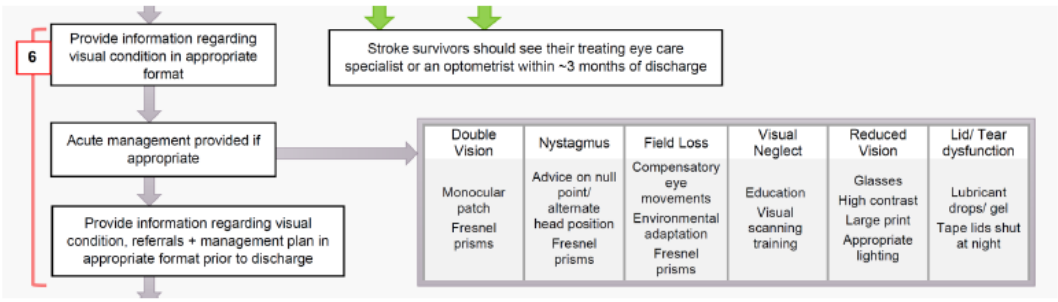
PLEASE PROVIDE YOUR SCORE FOR SECTION 5:



COMMENTS:

PATHWAY SECTION 6: SHORT TERM/ ACUTE MANAGEMENT

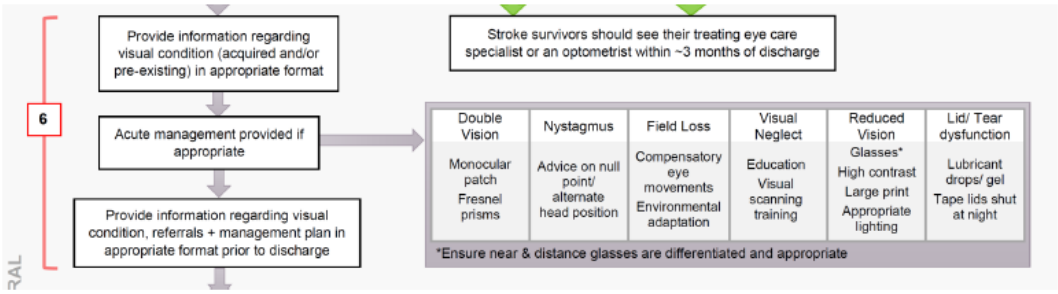
ORIGINAL:



DISCUSSION SUMMARY:

- There may be a need to distinguish pre-existing and acquired visual conditions
  - Pathway covers both – unlikely to change the pathway by making a distinction
  - This may be made clearer with the inclusion/ mention of pre-existing conditions somewhere in the early stages of management
    - Suggested: provide information regarding pre-existing and stroke related visual condition(s) in appropriate format
- Fresnel prisms not commonly used in the acute management of visual field loss – increases confusion and not well accepted by patient, particularly if there are also cognitive deficits
  - Similar discussion around the appropriateness of Fresnel prisms for acute management of nystagmus
  - Group suggested to remove Fresnel prisms from both categories
- There are often issues around the use of glasses for inpatients: glasses are not with them or have been lost, health professionals send patient for assessments and rehabilitation activities with the wrong pair of glasses (when using different glasses for near and distance fixation)
  - Group agreed that this is a commonly occurring issue
  - Suggested: add foot note to the table which explains importance of the patient having the correct prescription glasses and that near/ distance glasses are differentiated (to the patient and the health professionals providing care)
  - May also be necessary to reflect this in the BPS

PROPOSED CHANGES:

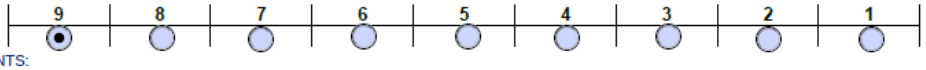


3.7 Management of pre-existing conditions through the use of glasses, drops and/or medications, should be continued and monitored appropriately for the entirety of their inpatient recovery and continued into their community care through appropriate referral.
Rationale: Pre-existing eye conditions can negatively impact the recovery and rehabilitation of a stroke survivor and may worsen if left untreated for a period of time (e.g. Glaucoma, Wet AMD).

3.19 Where glasses are currently used by the stroke survivor or deemed necessary through vision assessment, these should be made available to the patient as soon as practicable. It should be made clear to the patient, as well as their treating health professionals, what distance or tasks the glasses are to be used for e.g. distance viewing, reading, or both.
Rationale: There is a high incidence of presbyopia and other refractive errors amongst stroke survivors. Access and appropriate use of prescribed glasses is important for the general functioning and participation in rehabilitation activities of the stroke survivor.

With the proposed changes all participants deemed this section **appropriate with agreement.**

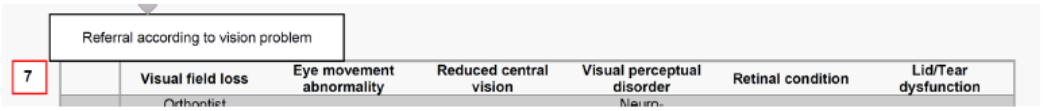
PLEASE PROVIDE YOUR SCORE FOR SECTION 6:



COMMENTS:

PATHWAY SECTION 7: CATEGORIES OF VISION PROBLEMS

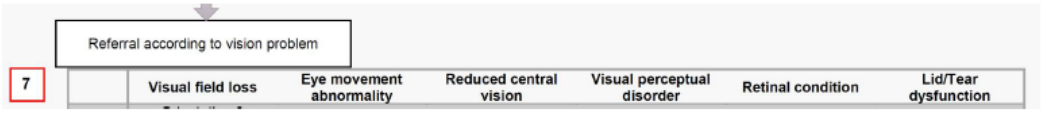
ORIGINAL:



DISCUSSION SUMMARY:

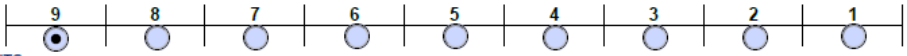
- All agreed that the included categories of eye/vision problems were appropriate and reflective of the BPS.
- No changes were proposed.

PROPOSED CHANGES:



All participants deemed this section **appropriate with agreement.**

PLEASE PROVIDE YOUR SCORE FOR SECTION 7:



COMMENTS:

PATHWAY SECTION 8: REFERRAL FOR MANAGEMENT/ REHABILITATION

ORIGINAL:

		Visual field loss	Eye movement abnormality	Reduced central vision	Visual perceptual disorder	Retinal condition	Lid/Tear dysfunction
7							
8	TREATMENT & REHABILITATION	Orthoptist Occupational therapist Ophthalmologist Low vision specialist Orientation & mobility specialist OR Physiotherapist Adaptive technology specialist	Orthoptist Ophthalmologist	Ophthalmologist Low vision specialist Orthoptist Optometrist Adaptive technology specialist	Neuro-ophthalmologist Neuropsychologist Orthoptist* Low vision specialist Occupational therapist* Orientation & mobility specialist OR Physiotherapist*	Ophthalmologist Low vision specialist General practitioner* Adaptive technology specialist*	Ophthalmologist Ocular plastics surgeon

DISCUSSION SUMMARY:

- Regarding treatment and rehabilitation for visual field defects:
  - Physiotherapists and orientation and mobility specialists should be moved higher up the list as they are very important in terms of addressing balance and mobility issues
    - Potentially more important than eye care specialists as there is not much that can be done for these conditions in terms of treatment and by this stage the condition has already been diagnosed
    - Suggested to put them up the top
    - Need to separate physiotherapists and orientation + mobility specialists as they are quite different, will not necessarily get the same services/ treatment from the two
  - Should there be information included regarding the management strategies used?
    - Many stroke health professionals are not aware of the visual scanning training programmes available for visual field loss and patients are often quite upset if they are not informed about these options early on (despite the mixed evidence on effectiveness)
    - If included for visual field defects, the management strategies/ techniques for all conditions would have to be listed and may be too much detail for the pathway itself. These strategies are already outline in the BPS
      - Suggested to reference the corresponding BPS number in the table or as a footnote.
- There is a role for physiotherapists and/or orientation + mobility specialists in the management of eye movement abnormalities (e.g. nystagmus/ gaze palsies) particularly regarding balance issues
  - They should be included in this category
- Need to have a greater presence of optometry in this section
  - Especially when considering rural/regional communities as they are often the only or most accessible eye care professionals in these areas
    - this is mentioned in the BPS, may need to consider making this more clear
    - we should be providing all appropriate options for patients so that they can make the decision of where/whom they seek care from
    - suggested to include optometrist for eye movement abnormality and lid/tear dysfunction
- including general practitioner under retinal condition is not necessary
  - while they may be managing the associated systemic risk factors that accompany retinal conditions (e.g. diabetic retinopathy, retinal artery and vein occlusion, hypertensive retinopathy) they do not manage the eye condition itself
    - is outside the scope of this pathway
    - suggest removing GP from this category, enough to state this in the BPS

PROPOSED CHANGES:

Referral according to vision problem
IMPORTANT: see BPS Section 3

	Visual field loss	Eye movement abnormality	Reduced central vision	Visual perceptual disorder	Retinal condition	Lid/Tear dysfunction
TREATMENT & REHABILITATION	Orientation & mobility specialist Occupational therapist Physiotherapist Orthoptist Ophthalmologist Low vision specialist Adaptive technology specialist	Orthoptist Ophthalmologist Optometrist* Orientation & mobility specialist* Physiotherapist*	Ophthalmologist Low vision specialist Orthoptist Optometrist Adaptive technology specialist	Neuro-ophthalmologist Neuropsychologist Orthoptist* Low vision specialist Occupational therapist* Orientation & mobility specialist OR Physiotherapist*	Ophthalmologist Low vision specialist Adaptive technology specialist*	Ophthalmologist Ocular plastics surgeon

With the proposed changes all participants deemed this section **appropriate with agreement.**

PLEASE PROVIDE YOUR SCORE FOR SECTION 8:

9 8 7 6 5 4 3 2 1

COMMENTS:

PATHWAY SECTION 9: SUPPORT SERVICES

ORIGINAL:

9	SUPPORT SERVICES	Social worker Vision Australia Guide Dogs NSW	Social worker* Vision Australia*	Social worker Vision Australia Guide Dogs NSW	Social worker Vision Australia Guide Dogs NSW	Social worker Macular Disease Foundation Australia Retina Australia Vision Australia Guide Dogs NSW	Orthoptist Optometrist
		Blind Citizens Australia; Glaucoma Australia; Kerataconus Australia; Royal Institute for Deaf and Blind Children; Royal Society for the Blind; Carers NSW; Centre for Eye Health; Next Sense; Stroke Recovery NSW, The Stroke Foundation					

This section was not discussed during the panel meeting due to time constraints.

PLEASE PROVIDE YOUR SCORE FOR SECTION 9:

9 ● 8 ○ 7 ○ 6 ○ 5 ○ 4 ○ 3 ○ 2 ○ 1 ○

COMMENTS:

this seems appropriate from my experience

PATHWAY SECTION 10: FINANCIAL SUPPORT SERVICES

ORIGINAL:

10	FINANCIAL SUPPORT	National Disability Insurance Scheme (age<65 years); My Aged Care (age>65 years); NSW spectacles program; Department of Veterans Affairs (see also individual private health insurance entitlements)

This section was not discussed during the panel meeting due to time constraints.

PLEASE PROVIDE YOUR SCORE FOR SECTION10:

9 ● 8 ○ 7 ○ 6 ○ 5 ○ 4 ○ 3 ○ 2 ○ 1 ○

COMMENTS:

PATHWAY SECTION 11: OVERALL STRUCTURE/ FLOW

ORIGINAL:

Please see Document 2 (sent by email).

This section was not discussed during the panel meeting due to time constraints.

PLEASE PROVIDE YOUR SCORE FOR SECTION 3:

9 ● 8 ○ 7 ○ 6 ○ 5 ○ 4 ○ 3 ○ 2 ○ 1 ○

COMMENTS:

Thank you for completing the final round of evaluation for the NSW Post-stroke Vision Care Pathway!

If you wish to raise any queries or concerns, please contact: shanelle.sorbello@student.uts.edu.au

11.17 Stroke Survivor Feedback Survey

Feedback Questions:

In your opinion, does the pathway and best practice statements (above) cover the various ways that stroke patients with visual symptoms might present to healthcare services? If not, please provide an explanation or example of what may have been missed.

Thrombolysis is a type of clot-dissolving therapy that is used for ischemic strokes. It allows blood flow to return to the blocked vessel(s) that cause this type of stroke, and if successful, can prevent permanent deficits or significantly reduce their severity. In most cases, the treatment can only be given within 4.5 hours of stroke onset. Do you feel that it is important to highlight this timeframe in the NSW post-stroke vision care pathway (page 1)?
Please explain why or why not.

In your opinion, do you feel that eye-care specialists such as Orthoptists and/or Ophthalmologists should be part of the stroke team in acute (hospital stroke wards/ inpatient services) and rehabilitation stroke facilities?
Please explain why or why not.

Do you feel that the short-term management strategies, such as those listed in the pathway and best practice statements (above), would be beneficial to stroke survivors with vision problems while they are in hospital?
Please explain why or why not.

Do you feel that the use of this pathway (page 1) or a similar set of guidelines would have better helped to meet your post-stroke vision care needs?
Please explain why or why not.

Do you have any other feedback you wish to provide on the NSW post stroke vision care pathway or related best practice statements?

11.18 Round Two Consensus Survey including revised BPS following Round 1



Returning?

A A A

The PRECiS Study - Consensus Survey 2

About this survey:

This survey aims to build consensus on a number of best practice statements (BPS) regarding the vision care of stroke survivors in NSW, Australia. These statements will form the basis of a 'post-stroke vision care pathway' created for implementation in Australian stroke care facilities as a means of improving and standardising post-stroke vision care. The statements were gathered from existing literature as well as from data gathered in Stage One of the PRECiS Study (see Appendix I and II).

This is the ***second round*** of consensus survey in this study. You have been sent a personalised summary of the results of Round One, that indicates the frequency of scores given by respondents for each BPS. This summary also indicates your own score and comments for each BPS for your own comparison.

Survey information and instructions:

As in Round 1, the first column of the document below contains the number of each BPS listed. A list of BPS can be found in the second column of the document below, with the respective rationale written below each statement. **Modifications to each statement and/or it's rationale based on comments from Round 1 have been indicated in blue.**

Below each statement, you will find the survey results from Round 1 indicating the collective appropriateness rating according to the median score and the dispersion of scores.

Definitions of Levels of Appropriateness:

- **Appropriate:** median score of 7-9, without disagreement
- **Uncertain:** median score of 4-6 OR any median with disagreement
- **Inappropriate:** median score of 1-3, without disagreement

The ***mean absolute deviation from the median (MAD) has been provided for your information***. However, following the RAND/UCLA Appropriateness Method for a group of this size, agreement or disagreement has been determined by the following rule:

The BPS is rated with disagreement if IPR>IPRAS where,
IPR = interpercentile range of 0.3-0.7 for each score set
IPRAS = interpercentile range adjusted for symmetry required for disagreement

If you wish to have more information on how these calculations were performed, please see the RAND/UCLA Appropriateness Method User's Manual, Chapter 8.

What you need to do...

Use the information available to give each BPS a score from 1-9. When scoring each BPS, a single value from 1 to 9 should be indicated. A score of 1 indicates that the BPS is highly inappropriate and ***a score of 9 indicates that the BPS is highly appropriate***. You are asked to rate each statement according to your own clinical judgement, considering the implications of the BPS on an average patient within an average stroke care setting. You should NOT consider cost implications when making your judgement on each BPS. A BPS is considered 'appropriate' if:

"the expected health benefit (e.g. increased life expectancy, relief of pain, reduction in anxiety, improved functional capacity) exceeds the expected negative consequences (e.g. mortality, morbidity, anxiety, pain, time lost from work) by a sufficiently wide margin that the procedure is worth doing, exclusive of cost." *(Brook et al, 1986)*

Comments can be provided on each BPS if you think the statement needs revision, restructuring, if the statement should be split or combined with another, or if you think an additional statement should be included. General comments can also be provided about the collection of statements at the end.

All background information including literature reviews, appendices & full text articles used in Round One are still available from:

https://www.dropbox.com/sh/sdw1o71cu1y16ut/AAD7lEWaUvm0AJgnkpKwxQ2wa?dl=0

If you have any questions about how to complete the survey or the contents of the survey and it's supporting documents, please contact Shanelle Sorbello (UTS) using the details below:

E: shanelle.sorbello@uts.edu.au **T:** +61

This survey will close at **10pm July 24, 2021**.

Please provide your contact details below:

This will be used to send consensus results from this round of survey back to you and invite you to participate in the final focus group.

First Name:
* must provide value

Discipline/ Role in stroke care:
* must provide value

E-mail:
* must provide value

Telephone: *(optional)*

1. PRE-HOSPITAL PATHWAYS

1.1 COMMUNITY AWARENESS

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

Orthoptists, optometrists and ophthalmologists as well as other stroke health professionals should endeavour to raise community awareness of visual stroke symptoms. In doing so, an attempt should be made to distinguish migraine with visual aura from stroke with visual complications.

Rationale: *Visual symptoms of stroke are not well recognised within the community and so may result in delayed contact of health services. Where possible, stroke related visual problems should be distinguished from migraine related visual symptoms to prevent unwarranted presentation and increased burden to frontline services.*

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	9	0	1	7.6

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

1.1 Comments:

Expand

1.2 Training should be provided to general practitioners, accident and emergency personnel and other 'first point of care' professionals regarding differentiating diagnosis of migraine with visual aura, drug overdose and stroke, particularly in younger people. This training should be provided by an eye care professional such as an orthoptist or ophthalmologist or by the assigned stroke educator.

Rationale: *Stroke with primarily visual symptoms are often misdiagnosed initially as migraine with aura. In younger people specifically, misdiagnosis of drug overdose also occurs. This happens due to a lack of awareness and training on visual stroke symptoms.*

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	8	1	2	6.9

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

1.2 Comments:

Expand

1.3 REFERRAL PROCESS

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

Patients that present to their general practitioner, community vision service, or hospital outpatient clinic with sudden onset of visual symptoms (onset < 4 hours) indicative of stroke (e.g. double vision, field loss, binocular loss of vision) and unexplained by identifiable pathology should be referred to nearest emergency department. Sudden monocular vision loss should be urgently referred to an ophthalmologist if cause is undetermined.

Rationale: *Stroke with visual deficits as the primary symptom are a risk for delayed diagnosis due to lack of awareness regarding visual consequences of stroke/ TIA. Sudden monocular loss of vision can be caused by pathologies such as Wet AMD and retinal vein occlusions, therefore requires further ophthalmic investigation to rule out ocular pathology.*

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	9	0	0.2	8.2

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

1.3 Comments:

Expand

1.4 Patients presenting to emergency services (emergency department, ambulance) with sudden onset of visual symptoms (onset < 4 hours) indicative of stroke (e.g. double vision, field loss, binocular loss of vision) should be investigated for stroke/ TIA. Vision assessment should be performed for sudden monocular vision loss to determine necessity of stroke/TIA investigation. Where an eye care professional is not available, this should be performed by a stroke health professional trained in vision assessment.

Rationale: *Eligibility for intravenous thrombolysis is time sensitive. Hence, if visual symptoms of stroke are misdiagnosed initially, the opportunity to prevent permanent loss of function may be lost. Sudden monocular loss of vision can be caused by pathologies such as Wet AMD and retinal vein occlusions, therefore requires further ophthalmic investigation to rule out ocular pathology.*

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	9	0	1	7.6

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

◯ 9 ◯ 8 ◯ 7 ◯ 6 ◯ 5
◯ 4 ◯ 3 ◯ 2 ◯ 1

reset

1.4 Comments:

Expand

2. SCREENING & ASSESSMENT

2.1 TIMING OF ASSESSMENT

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

Vision screening, including objective measures, should be provided to all stroke patients within 2 weeks of regained consciousness, OR before rehabilitation activities begin.

Rationale: *Visual deficits can complicate rehabilitation (e.g. physical rehabilitation, occupational therapy training, communication training). Strategies to minimise the impact of vision loss on these rehabilitation activities can be utilised if both the patient and other health professionals are aware of the deficits and informed on how to manage them. Objective measures of visual function should be used in screening as many stroke survivors do not or cannot report visual symptoms.*

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	9	0	1	7.6

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

2.1 Comments:

Expand

2.2 Where vision screening indicates the need for further vision assessment, this should ideally take place before rehabilitation activities begin or in the early stages of rehabilitation. However, rehabilitation activities should not be delayed if patient is awaiting vision assessment due to service limitations.

Rationale: *Visual deficits can complicate rehabilitation (e.g. physical rehabilitation, occupational therapy training, communication training). Strategies to minimise the impact of vision loss on these rehabilitation activities can be utilised if both the patient and other health professionals are aware of the deficits and informed on how to manage them.*

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	8	1	1	7.6

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

2.2 Comments:

Expand

2.3 All stroke survivors should be encouraged to have an optometry assessment at their earliest convenience post-discharge using appropriate rationale to explain the potential benefits.

Rationale: *Most stroke survivors are within the age group prone to presbyopia and other age related visual conditions. Hence vision may be compromised even if there is no obvious visual deficit. Having an optometry assessment will ensure refractive error is corrected and age related pathologies identified/ managed, which will help ease their reintegration into the community.*

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	9	0	2.2	6.7

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

2.3 Comments:

Expand

2.4 HEALTH PROFESSIONAL(S) PERFORMING ASSESSMENT

Where an orthoptist is not available for initial vision assessment, the use of a suitable, validated vision screening tool(s) for stroke survivors (e.g. VISA, Vision defect in stroke screening tool) by non-eye care specialists should be supplemented with appropriate training and education around how to administer and interpret results of the tool. Training should be provided by an eye care professional and may be performed remotely via video conference or online material to improve access.

Rationale: *Non-eye care professionals have been shown to be less accurate/effective at administering vision screening tools than eye specialist health professionals. However, when appropriate training and education is provided, there is significant improvement. Access to specialist services and training is particularly limited in regional and remote areas of Australia. Remote/ online training services may improve access in these areas.*

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	8	1	2	6.9

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

2.4 Comments:

Expand

2.5 Stroke survivors suspected of having visual deficits, who report visual deficits, or show potential visual deficits as a result of screening should be referred for assessment by an orthoptist or ophthalmologist as appropriate for the condition. Where this is not possible within a reasonable timeframe, such as in some rural areas of Australia, consultation via telehealth and/or liaison between local treating health professional(s) and a specialist eye professional should be arranged.

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

Rationale: *Accurate assessment, diagnosis and explanation of visual deficits can only be provided by eye specialist health professionals. Ophthalmologists and orthoptists have the required training to identify and manage stroke related visual deficits. Access to these services in rural Australia may be improved via telehealth and ongoing remote cooperation between rural stroke services and specialist eye care services.*

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	9	0	0	8.4

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

2.5 Comments:

Expand

2.6 EXECUTION OF ASSESSMENT

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

All stroke survivors should have an assessment of visual acuity wearing the appropriate glasses, to check their ability to read newspaper text and see distant objects clearly.

Rationale: *The ability to read at near and distance is an important functional aspect of vision for everyday life. Reduced visual acuity in one or both eyes may be indicative of several pathologies and provides crucial information when forming a visual diagnosis.*

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	9	0	0.2	8.2

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

2.6 Comments:

Expand

2.7 All stroke survivors should have an examination for the presence of visual field deficit (e.g. hemianopia) and eye movement disorders (e.g. strabismus and motility deficits).

Rationale: *Visual field defects and eye movement disorders are the most common visual consequences of stroke and have a severe impact on a survivor's visual function. Consensus has been previously established in a UK study regarding inclusion of visual field and eye motility assessment in the vision screening of stroke survivors.*

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	9	0	0	8.4

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

2.7 Comments:

Expand

2.8 All stroke survivors should be screened for visual neglect and/or visual perception disorders at the time of vision assessment or perceptual assessment. If a disorder is suspected, an appropriate battery of tests should be used to confirm diagnosis.

Rationale: *Visual neglect is a common consequence of stroke and has a severe impact on a survivor's visual function. It can also occur in conjunction with other visual and perceptual deficits after stroke and so should be accurately diagnosed through a battery of tests. Visual perceptual disorders are less common but are also less likely to be reported by stroke survivors and have a significant impact of their quality of life.*

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	9	0	0.2	8.2

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

2.8 Comments:

Expand

2.9 Vision screening should include vision history (with carer present if necessary) to identify any pre-existing vision conditions. Where possible and necessary to aid diagnosis/ referral, ophthalmic history should be sourced from previously seen ophthalmologist or optometrist.

Rationale: *Pre-existing vision conditions may explain visual complaints and require ongoing management throughout the patient's rehabilitation in order to reduce impact on recovery.*

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	9	0	0	8.4

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

2.9 Comments:

Expand

3. MANAGEMENT & REFERRAL

3.1 TIMING OF MANAGEMENT & REFERRAL

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

The orthoptist or health professional responsible for providing vision care should initiate management and referrals for visual deficits based on the patient's needs, readiness for information and capacity for participation in these services based on their clinical judgement and discussion with the stroke survivor and/or their family/ informal caregiver.

Rationale: *Due to the varying severity of stroke and individual personalities/ circumstances, stroke survivors and their carers may be ready to participate in vision management at different times, with some visual conditions requiring more immediate treatment than others. An appropriate balance between clinical necessity and stroke survivor capacity needs to be determined in order for treatment to be most effective.*

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	9	0	1	7.6

*** Median absolute deviation**
**** Interpercentile range**
***** Interpercentile range adjusted for symmetry**

Therefore, deemed appropriate with agreement.

* must provide value

3.1 Comments:

Expand

3.2 Where a visual deficit is found through screening, or by report of the patient/ carer/ other health professional, there should be immediate (or as soon as practicable) referral to an orthoptist or ophthalmologist as appropriate. Where access to an orthoptist or ophthalmologist is limited, referral to an eye care professional should be made in order to confirm diagnosis and provide appropriate management or referral.

Rationale: *Immediate referral allows the visual condition to be investigated and diagnosed in a timely manner. This enables time sensitive treatment to be provided as necessary, as well as clarity for the patient and other treating health professionals regarding their condition.*

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	9	0	1	7.6

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

3.2 Comments:

Expand

3.3 Where short-term management (e.g. advice, patching, Fresnel prisms) is appropriate and available, this should be provided as soon as it becomes beneficial for the stroke survivor.

Rationale: *Simple interventions such as advice (on gaze or head position) or patching/ Fresnel prisms for double vision can be quickly and easily administered and may provide significant improvement to comfort and functionality.*

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	9	0	0	8.4

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

3.3 Comments:

Expand

3.4 If a visual deficit is found that has a known treatment/ intervention available, referral to the appropriate health professional should be made immediately (or as soon as practicable in the context of inpatient care).

Rationale: *Immediate referral allows for intervention to be provided promptly, minimising the impact of the visual deficit on overall recovery. It also provides clear understanding of where and how to seek treatment, should the patient wish to pursue it at a later time.*

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	9	0	0	8.4

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

3.4 Comments:

Expand

3.5 If a visual deficit is found that does not have a known treatment/ intervention available, but can be managed or better adapted to through therapy and/or training, there should be a referral provided at the time the stroke survivor is physically and cognitively able to participate in said management OR ondischarge.

Rationale: *Commencement of therapy/ training is not appropriate until the stroke survivor is able to understand and participate to an extent that is beneficial to their condition. However, patients should not be discharged without receiving referral.*

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	9	0	1	7.6

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

3.5 Comments:

Expand

3.6 If a visual deficit is found that does not have any known treatment/ intervention or therapy/ training that is appropriate, referral to a vision support service and/or social worker should be provided as soon as practicable and must be provided before discharge.

Rationale: *Referral to support services at the time of diagnosis and/ or before discharge ensures the patient and their family have clear information about the long term help available to them and where to obtain it. Social workers can also provide patient and caregivers with emotional support and facilitate access to mental health services where necessary.*

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	9	0	0.2	8.2

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

3.6 Comments:

Expand

3.7 APPROPRIATENESS OF REFERRAL

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

Where pharmacological or surgical intervention is available/ recommended for their visual deficit, stroke survivors should be referred to an ophthalmologist.
Rationale: Specialist eye care that requires pharmacological and/or surgical intervention can only be administered by an ophthalmologist.

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	9	0	0.2	8.2

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

3.7 Comments:

Expand

3.8 Where therapeutic training and/or compensatory management options are available/ recommended for their visual deficit, stroke survivors should be referred to an orthoptist and/or occupational therapist trained in vision management and/or low vision orientation and mobility specialist.

Rationale: *Orthoptists and health professionals such as occupational therapists/ orientation and mobility specialists with vision specific training have the specialist knowledge to provide therapeutic training, and educate on compensatory strategies relating to post-stroke visual deficits.*

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	9	0	0.2	8.2

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

3.8 Comments:

Expand

3.9 Where optical correction (such as glasses and/ or long term prisms) is available/ recommended for their visual deficit, stroke survivors should be referred to an optometrist. Prescription of prisms may require consultation with an orthoptist or ophthalmologist.

Rationale: *Optometrists have the specialist knowledge to provide optical correction for age related and stroke related vision problems.*

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	9	0	0	8.4

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

3.9 Comments:

Expand

3.10 Visual perceptual deficits should be referred to a neuro-ophthalmologist and social worker. In some cases, referral to a neuropsychologist and vision support services may also be appropriate.

Rationale: *Visual perceptual deficits are a less common visual occurrence and so are not as widely understood. Neuro- ophthalmologists work specifically with neurological vision loss, and so will be able to provide the most appropriate care. Often, management options for these conditions are limited and so appropriate referral for compensatory management and support services are required.*

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	9	0	1	7.6

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

3.10 Comments:

Expand

3.11 Where no treatment or therapy is available/ recommended for their visual deficit, stroke survivors should be referred to a vision support service (e.g. Vision Australia, Guide Dogs NSW) and social worker to discuss available services and entitlements. When referring to vision support services, it is important to ensure referral requirements have been met prior to discharge (e.g. vision assessment by an ophthalmologist for some services).

Rationale: *Vision support services and social workers are able to provide access to assistive technology, adaptive training and environmental modification as well as access to psychological and emotional support services. These services enhance the quality of life of stroke survivors with untreatable vision loss.*

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	9	0	0	8.4

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

3.11 Comments:

Expand

3.12 Discussions with the stroke survivor/ carer should be had to determine if referral to a social worker, stroke or vision support service, or access to a case manager (where available) would aid in managing their vision care and assist in accessing funding for disability support.

Rationale: *The multiplicity of health problems after stroke can be overwhelming for both the survivor and their carer(s). Assistance inmanaging appointments, care services and attaining funding can reduce the stress involved in this process and improve access to these services.*

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	9	0	0	8.4

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

3.12 Comments:

Expand

3.13 Referrals to non-eye care specialists, namely occupational therapists, social workers, counsellors, orientation and mobility specialists and/or adaptive technology specialists should be provided in the same instance as eye-specific referrals as appropriate for the condition.

Rationale: *Services provided by other health professionals that support stroke survivors with vision loss are of equal importance to eye-specific care for successful recovery.*

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	9	0	0.2	8.2

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

3.13 Comments:

Expand

3.14 APPROPRIATENESS OF MANAGEMENT

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

Management of visual field loss should include promoting awareness of the field loss and compensatory strategies (e.g. visual scanning training, reading strategies, discussion and referral for assistive technology) by an eye care professional as well as environmental adaptations and mobility training guided by an occupational therapist and/or orientation and mobility specialist. Other options such as restitutive treatment should also be discussed with the patient with advice on effectiveness so they can make an informed decision should they wish to pursue.

Rationale: *There is little conclusive evidence to indicate the most effective treatment, however compensatory methods show task specific improvement and increase quality of life. Stroke survivors indicate a want to be informed on all options available.*

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	9	0	0	8.4

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

3.14 Comments:

Expand

3.15 Where double vision is the primary complaint of a strabismus or ocular motility issue, occlusion of one eye or Fresnel prisms should be suggested as a short term solution to aid rehabilitation. This should be facilitated by an orthoptist, ophthalmologist or health professional trained on how to appropriately prescribe these treatments. Long term management should be through referral to an ophthalmologist, neuro- ophthalmologist or orthoptist.

Rationale: *These treatment methods are the best supported by evidence and clinical practice at present. Short term management strategies need to be administered appropriately in order to be effective and hence should be facilitated by a trained eye care professional.*

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	9	0	1	7.6

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

3.15 Comments:

Expand

3.16 Reduced central vision should be referred to an ophthalmologist to investigate/ manage potential pathology. If uncorrected refractive error is the determined cause of reduced vision, onward referral to an optometrist may then be necessary.

Rationale: *Refractive error (particularly presbyopia) is a very common cause of reduced central vision in the age group most susceptible to stroke. All refractive error should be corrected as best as possible to enhance visual function. However, assessment by an ophthalmologist is necessary to identify and manage any potential pathology.*

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	9	0	1	7.6

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

3.16 Comments:

Expand

3.17 Management of visual neglect should include promoting awareness of the area of neglect and cognitive rehabilitation (e.g. visual scanning training, reading strategies) by an eye care professional as well as environmental adaptations and mobility/ activity training guided by an occupational therapist, physiotherapist or orientation and mobility specialist as appropriate. Other options should also be discussed with the patient with advice on effectiveness so that they can make an informed decision should they wish to pursue.
Rationale: *There is little conclusive evidence regarding the most effective treatment method, however compensatory strategies and training have been shown to be beneficial on standardised assessments. Providing information on different treatment options provides stroke survivors with hope and coping strategies during recovery and in their daily life.*

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	9	0	1	7.6

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

3.17 Comments:

Expand

4. EDUCATION & INFORMATION

4.1 TIMING OF INFORMATION

All stroke survivors should be provided general information about symptoms that may indicate stroke as well as conditions that occur as a consequence of stroke prior to discharge.
Rationale: *This will improve community awareness and alert stroke survivors/ their families to other possible symptoms of a second stroke.*

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	9	0	0	8.4

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

4.1 Comments:

Expand

4.2 Where a visual deficit is identified, information should be provided at the time of diagnosis and prior to discharge in an appropriate format (e.g. aphasia friendly, large print, audio).

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

Rationale: *The patient and/or carer is likely to have questions and concerns regarding their visual condition and these should be addressed immediately. However, the stroke survivor may not be able to understand/ retain this information at the time of diagnosis and so it should be made available to be them again at a later stage.*

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	9	0	0	8.4

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

4.2 Comments:

Expand

4.3 SPECIFICITY OF INFORMATION

General information about how stroke can impact the eyes and vision should be provided to all stroke survivors in an appropriate format that can be accessed repeatedly (e.g. large print/ aphasia friendly pamphlet, electronic document or media file).

Rationale: *Stroke survivors are at high risk of suffering another stroke. They should be made aware of the visual symptoms of stroke so that they can be more easily identified and appropriate action taken should they ever occur. Take-home information can be readily accessed by patients and carers at any time, ensuring accurate information relay.*

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	9	0	2	6.9

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

4.3 Comments:

Expand

4.4 Stroke survivors with a visual deficit should be provided information about what their condition is, what area of the brain and visual system it relates to, the expected implications on functional vision, expected recovery, available management options, resources and support services. This should be worded in lay terms that can be easily understood by non-medical personnel and provided in an appropriate format for the patient as an addition to discharge documents.

Rationale: *A clear understanding of the visual condition is important in reducing the anxiety associated with a new visual diagnosis. Clear information about management and recovery also helps to manage expectations and adaptation of the stroke survivor and their family.*

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	9	0	0.2	8.2

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

4.4 Comments:

Expand

4.5 Referrals should be explained in regards to what condition is to be managed or what service provided by each professional the stroke survivor is referred to. This may be provided through direct communication with the patient's nominated general practitioner (GP), in which case the patient/ carer should be notified that they can access this information through their GP.

Rationale: *After stroke, a multitude of conditions are managed by a multidisciplinary team. Keeping track of what each referral is for can be confusing and overwhelming for the patient and/or carer and so clear explanation can help in prioritising and organising follow up.*

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	9	0	0.2	8.2

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

4.5 Comments:

Expand

4.6 EDUCATION/ TRAINING OF STROKE HEALTH PROFESSIONALS

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

Non-eye specific health professionals should receive training relating to commonly used vision terminology, and visual conditions relating to stroke.

Rationale: *As stroke care requires a collaborative effort from a multi- disciplinary team, all members of the team should have a general understanding of basic visual terminology and common post-stroke visual conditions to aid communication and hence improve patient care.*

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	9	0	0	8.4

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

4.6 Comments:

Expand

4.7 Post-stroke vision assessment should be included in existing stroke pathways and/or protocols for all acute and rehabilitation services. ***Rationale:*** *Where hospitals or rehabilitation facilities have a stroke protocol, vision assessment should be included so that there is consistency of care across all disciplines.*

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	9	0	1	7.6

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

4.7 Comments:

Expand

4.8 Trained eye care professionals (e.g. orthoptists) should be included in the multi-disciplinary team of all stroke care facilities (acute and rehabilitation).

Rationale: Vision is impacted in approximately 60% of stroke survivors and manifests as a wide range of abnormalities. This necessitates access to specialist vision care acutely as non-eye specific health professionals are often not confident in assessing/ treating visual conditions.

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	9	0	1.2	7.5

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

4.8 Comments:

Expand

4.9 Information regarding the visual condition of a stroke survivor, the implications (including driving and return to work requirements) and how to best manage these should be documented in the patients file and in discharge papers/ referrals for shared access between the multi-disciplinary team.
Rationale: *This information aids other health professionals in providing care/ rehabilitation in a manner that is appropriate for the patient's visual condition. It also ensures accurate and consistent information is given to the patient.*

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	9	0	0	8.4

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

4.9 Comments:

Expand

4.10 EDUCATION OF CARERS/ FAMILY

○ 9 ○ 8 ○ 7 ○ 6 ○ 5
○ 4 ○ 3 ○ 2 ○ 1

reset

The stroke survivor's next of kin or carer, if applicable, should be educated on what to expect regarding the impact of the visual deficit on the survivor's daily function, how to best manage this, expected recovery and available resources/ services for management and support. Information on carer support services should also be provided.

Rationale: *The stroke survivor often requires support in retaining and relaying information about their own condition to their carer/s or family members and so this information should also be given directly to the necessary people where possible. The health and well-being of caregivers is also an important aspect of care provision that should be addressed.*

Round 1 Scores:

n	Median	MAD*	IPR**	IPRAS***
17	9	0	0	8.4

* Median absolute deviation
** Interpercentile range
*** Interpercentile range adjusted for symmetry

Therefore, deemed appropriate with agreement.

* must provide value

4.10 Comments:

Expand

5 GENERAL COMMENTS:

Expand

11.19 REVISED BPS FOLLOWING ROUND 2

BEST PRACTICE STATEMENTS

1 Pre-Hospital Pathways

Community awareness

1.1 Orthoptists, optometrists and ophthalmologists as well as other stroke health professionals should endeavour to raise community awareness of visual stroke symptoms. In doing so, an attempt should be made to distinguish migraine with visual aura from stroke with visual complications.
Rationale: Visual symptoms of stroke are not well recognised within the community and so may result in delayed contact of health services. Where possible, stroke related visual problems should be distinguished from migraine related visual symptoms to prevent unwarranted presentation and increased burden to frontline services.

1.2 Training should be provided to general practitioners, accident and emergency personnel, nurses and other 'first point of care' professionals regarding differentiating diagnosis of migraine with visual aura, drug overdose and stroke, particularly in younger people. This training should be provided by an eye care professional such as an orthoptist or ophthalmologist or by the assigned stroke educator.
Rationale: Stroke with primarily visual symptoms is often misdiagnosed initially as migraine with aura. In younger people specifically, misdiagnosis of drug overdose also occurs. This happens due to a lack of awareness and training on visual stroke symptoms.

Referral process

1.3 Patients that present to their general practitioner, community vision service, or hospital outpatient clinic with sudden onset of visual symptoms (onset <4 hours) indicative of stroke (e.g. double vision, field loss, binocular loss/significant reduction of vision) and unexplained by identifiable pathology should be referred to nearest emergency department. Sudden monocular vision loss should be urgently referred to an ophthalmologist if cause is undetermined.
Rationale: Stroke with visual deficits as the primary symptom are a risk for delayed diagnosis due to lack of awareness regarding visual consequences of stroke/ TIA. Sudden monocular loss of vision can be caused by pathologies such as Wet AMD and retinal vein occlusions, therefore requires further ophthalmic investigation to rule out ocular pathology.

1.4 Patients presenting to emergency services (emergency department, ambulance) with sudden onset of visual symptoms (onset <4 hours) indicative of stroke (e.g. double vision, field loss, binocular loss of vision) should be investigated for stroke/ TIA. Vision assessment should be performed for sudden monocular vision loss to determine necessity of stroke/TIA investigation. Where an eye care professional is not available, this should be performed by a stroke health professional trained in vision assessment.
Rationale: Eligibility for intravenous thrombolysis is time sensitive. Hence, if visual symptoms of stroke are misdiagnosed initially, the opportunity to prevent permanent loss of function may be lost. Sudden monocular loss of vision can be caused by pathologies such as Wet AMD and retinal vein occlusions, therefore requires further ophthalmic investigation to rule out ocular pathology.

2 Screening and Assessment

Timing of assessment

2.1 Vision screening, including objective measures, should be provided to all stroke patients within 2 weeks of regained consciousness, OR before rehabilitation activities begin. However, rehabilitation activities should not be delayed if patient is awaiting vision assessment due to service limitations.
Rationale: Visual deficits can complicate rehabilitation (e.g. physical rehabilitation, occupational therapy training, communication training). Strategies to minimise the impact of vision loss on these rehabilitation activities can be utilised if both the patient and other health professionals are aware of the deficits and informed on how to manage them. Objective measures of visual function should be used in screening as many stroke survivors do not or cannot report visual symptoms.

2.2 Where vision screening indicates the need for further vision assessment, this should ideally take place before rehabilitation activities begin or in the early stages of rehabilitation. However, rehabilitation activities should not be delayed if patient is awaiting vision assessment due to service limitations.
Rationale: Visual deficits can complicate rehabilitation (e.g. physical rehabilitation, occupational therapy training, communication training). Strategies to minimise the impact of vision loss on these rehabilitation activities can be utilised if both the patient and other health professionals are aware of the deficits and informed on how to manage them.

2.3 All stroke survivors should be encouraged to have an optometry assessment at their earliest convenience post-discharge with appropriate explanation regarding the potential benefits.
Rationale: Most stroke survivors are within the age group prone to presbyopia and other age-related visual conditions. Hence vision may be compromised even if there is no obvious visual deficit. Having an optometry assessment will ensure refractive error is corrected and age-related pathologies identified/ managed, which will help ease their reintegration into the community.

Health professional(s) performing assessment

2.4 Where an orthoptist is not available for initial vision assessment, the use of a suitable, validated vision screening tool(s) for stroke survivors (e.g. VISA, Vision defect in stroke screening tool) by non-eye care stroke health professional should be supplemented with appropriate training and education around how to administer and interpret results of the tool. Training should be provided by an eye care professional and may be performed remotely via video conference or online material to improve access.
Rationale: Non-eye care professionals have been shown to be less accurate/effective at administering vision screening tools than eye specialist health professionals. However, when appropriate training and education is provided, there is significant improvement. Access to specialist services and training is particularly limited in regional and remote areas of Australia. Remote/ online training services may improve access in these areas.

2.5 Stroke survivors suspected of having visual deficits, who report visual deficits, or show potential visual deficits as a result of screening should be referred for assessment by an orthoptist or ophthalmologist as appropriate for the condition. Where this is not possible within a reasonable timeframe, such as in some rural areas of Australia, consultation via telehealth and/or liaison between local treating health professional(s) and a specialist eye professional should be arranged.
Rationale: Accurate assessment, diagnosis and explanation of visual deficits can only be provided by eye specialist health professionals. Ophthalmologists and orthoptists have the required training to identify and manage stroke related visual deficits. Access to these services in rural Australia may be improved via telehealth and ongoing remote cooperation between rural stroke services and specialist eye care services.

Execution of assessment

2.6 All stroke survivors should have an assessment of monocular and binocular visual acuity wearing the appropriate glasses, to check their ability to read newspaper text and see distant objects clearly.
Rationale: The ability to read at near and distance is an important functional aspect of vision for everyday life. Reduced visual acuity in one or both eyes may be indicative of several pathologies and provides crucial information when forming a visual diagnosis.

2.7 All stroke survivors should have an examination for the presence of visual field deficit (e.g. hemianopia) and eye movement disorders (e.g. strabismus and motility deficits).
Rationale: Visual field defects and eye movement disorders are the most common visual consequences of stroke and have a severe impact on a survivor's visual function. Consensus has been previously established regarding the inclusion of visual field and eye motility assessment in the vision screening of stroke survivors in the UK.

2.8 All stroke survivors should be screened for visual neglect and/or visual perception disorders at the time of vision assessment or perceptual assessment. If a disorder is suspected, an appropriate battery of tests should be used to confirm diagnosis.
Rationale: Visual neglect is a common consequence of stroke and has a severe impact on a survivor's visual function. It can also occur in conjunction with other visual and perceptual deficits after stroke and so should be accurately diagnosed through a battery of tests. Visual perceptual disorders are less common but are also less likely to be reported by stroke survivors and have a significant impact of their quality of life.

2.9 Vision screening should include vision history (with carer present if necessary) to identify any pre-existing vision conditions. Where possible and necessary to aid diagnosis/ referral, ophthalmic history should be sourced from previously seen ophthalmologist or optometrist.
Rationale: Pre-existing vision conditions may explain visual complaints and require ongoing management throughout the patient's rehabilitation in order to reduce impact on recovery and prevent regression of ocular conditions e.g. glaucoma.

PRECIS STUDY MANUAL

3 Management and referral

Timing of management/ referral

3.1 The orthoptist or health professional responsible for providing vision care should initiate management and referrals for visual deficits based on the patient's needs, readiness for information and capacity for participation in these services based on their clinical judgement and discussion with the stroke survivor and/or their family/ informal caregiver.
Rationale: Due to the varying severity of stroke and individual personalities/ circumstances, stroke survivors and their carers may be ready to participate in vision management at different times, with some visual conditions requiring more immediate treatment than others. An appropriate balance between clinical necessity and stroke survivor capacity needs to be determined for treatment to be most effective.

3.2 Where a visual deficit is found through screening, or by report of the patient/ carer/ other health professional, there should be immediate (or as soon as practicable) referral to an orthoptist or ophthalmologist as appropriate. Where access to an orthoptist or ophthalmologist is limited, referral to an eye care professional (such as an optometrist) should be made in order to confirm diagnosis and provide appropriate management or referral.
Rationale: Immediate referral allows the visual condition to be investigated and diagnosed in a timely manner. This enables time sensitive treatment to be provided as necessary, as well as clarity for the patient and other treating health professionals regarding their condition.

3.3 Where short-term management (e.g. advice, patching, Fresnel prisms) is appropriate and available, this should be provided as soon as it becomes beneficial for the stroke survivor by a health professional with appropriate training in how to administer the required management. In areas of limited access to specialist eye care services, advice on these management strategies should be facilitated through telehealth.
Rationale: Simple interventions such as advice (on gaze or head position) or patching/ Fresnel prisms for double vision can be quickly and easily administered and may provide significant improvement to comfort and functionality.

3.4 If a visual deficit is found that has a known treatment/ intervention available, referral to the appropriate health professional should be made immediately (or as soon as practicable in the context of inpatient care).
Rationale: Immediate referral allows for intervention to be provided promptly, minimising the impact of the visual deficit on overall recovery. It also provides clear understanding of where and how to seek treatment, should the patient wish to pursue it at a later time.

3.5 If a visual deficit is found that does not have a known treatment/ intervention available, but can be managed or better adapted to through therapy and/or training, there should be a referral provided at the time the stroke survivor is physically and cognitively able to participate in said management OR on discharge.
Rationale: Commencement of therapy/ training is not appropriate until the stroke survivor is able to understand and participate to an extent that is beneficial to their condition. However, patients should not be discharged without receiving referral.

3.6 If a visual deficit is found that does not have any known treatment/ intervention or therapy/ training that is appropriate, referral to a vision support service and/or social worker should be provided as soon as practicable and must be provided before discharge.
Rationale: Referral to support services at the time of diagnosis and/ or before discharge ensures the patient and their family have clear information about the long term help available to them and where to obtain it. Social workers can also provide patient and caregivers with emotional support and facilitate access to mental health services where necessary.

Appropriateness of referral

3.7 Where pharmacological or surgical intervention is available/ recommended for their visual deficit, stroke survivors should be referred to an ophthalmologist.
Rationale: Specialist eye care that requires pharmacological and/or surgical intervention can only be administered by an ophthalmologist.

3.8 Where therapeutic training and/or compensatory management options are available/ recommended for their visual deficit, stroke survivors should be referred to an orthoptist and/or occupational therapist trained in vision management and/or low vision orientation and mobility specialist.
Rationale: Orthoptists and health professionals such as occupational therapists/ orientation and mobility specialists with vision specific training have the specialist knowledge to provide therapeutic training and educate on compensatory strategies relating to post-stroke visual deficits.

3.9 Where optical correction (such as glasses and/ or long-term prisms) is available/ recommended for their visual deficit, stroke survivors should be referred to an optometrist. Prescription of prisms may require consultation with an orthoptist or ophthalmologist.
Rationale: Optometrists have the specialist knowledge to provide optical correction for age related and stroke related vision problems.

3.10 Visual perceptual deficits should be referred to a neuro-ophthalmologist and social worker. In some cases, referral to a neuropsychologist and vision support services may also be appropriate. These patients may also benefit from therapeutic training and/or compensatory management options (see 3.8).
Rationale: Visual perceptual deficits are a less common visual occurrence and so are not as widely understood. Neuro- ophthalmologists work specifically with neurological vision loss, and so will be able to provide the most appropriate care. Often, management options for these conditions are limited and so appropriate referral for compensatory management and support services are required.

3.11 Where no treatment or therapy is available/ recommended for their visual deficit, stroke survivors should be referred to a vision support service (e.g. Vision Australia, Guide Dogs NSW) and social worker to discuss available services and entitlements. When referring to vision support services, it is important to ensure referral requirements have been met prior to discharge (e.g. vision assessment by an ophthalmologist for some services).
Rationale: Vision support services and social workers are able to provide access to assistive technology, adaptive training and environmental modification as well as access to psychological and emotional support services. These services enhance the quality of life of stroke survivors with untreatable vision loss.

3.12 Discussions with the stroke survivor/ carer should be had to determine if referral to a social worker, stroke or vision support service, or access to a case manager (where available) would aid in managing their vision care and assist in accessing funding for disability support.
Rationale: The multiplicity of health problems after stroke can be overwhelming for both the survivor and their carer(s). Assistance in managing appointments, care services and attaining funding can reduce the stress involved in this process and improve access to these services.

3.13 Referrals to non-eye care specialists, namely occupational therapists, social workers, counsellors, orientation and mobility specialists and/or adaptive technology specialists should be provided in the same instance as eye- specific referrals as appropriate for the condition. Such referrals should include comprehensive information about the patient's visual, physical and cognitive condition.
Rationale: Services provided by other health professionals that support stroke survivors with vision loss are of equal importance to eye-specific care for successful recovery.

Appropriateness of management

3.14 Management of visual field loss should include promoting awareness of the field loss and compensatory strategies (e.g. visual scanning training, reading strategies, discussion and referral for assistive technology) by an eye care professional as well as environmental adaptations and mobility training guided by an occupational therapist and/or orientation and mobility specialist. Other options such as restitutive treatment should also be discussed with the patient with advice on effectiveness so they can make an informed decision should they wish to pursue.
Rationale: There is little conclusive evidence to indicate the most effective treatment, however compensatory methods show task specific improvement and increase quality of life. Stroke survivors indicate a want to be informed on all options available.

3.15 Where double vision is the primary complaint of a strabismus or ocular motility issue, occlusion of one eye or Fresnel prisms should be suggested as a short-term solution to aid rehabilitation. This should be facilitated by an orthoptist, ophthalmologist or health professional trained on how to appropriately prescribe these treatments. Long term management should be through referral to an ophthalmologist, neuro- ophthalmologist or orthoptist.
Rationale: These treatment methods are the best supported by evidence and clinical practice at present. Short term management strategies need to be administered appropriately in order to be effective and hence should be facilitated by a trained eye care professional.

3.16 Reduced central vision should be referred to an ophthalmologist to investigate/ manage potential pathology. If uncorrected refractive error is the determined cause of reduced vision, onward referral to an optometrist may then be necessary.
Rationale: Refractive error (particularly presbyopia) is a very common cause of reduced central vision in the age group most susceptible to stroke. All refractive error should be corrected as best as possible to enhance visual function. However, assessment by an ophthalmologist is necessary to identify and manage any potential pathology.

3.17 Management of visual neglect should include promoting awareness of the area of neglect and cognitive rehabilitation (e.g. visual scanning training, reading strategies) by an eye care professional as well as environmental adaptations and mobility/ activity training guided by an occupational therapist, physiotherapist or orientation and mobility specialist as appropriate. Other options should also be discussed with the patient with advice on effectiveness so that they can make an informed decision should they wish to pursue.
Rationale: There is little conclusive evidence regarding the most effective treatment method, however compensatory strategies and training have been shown to be beneficial on standardised assessments. Providing information on different treatment options provides stroke survivors with hope and coping strategies during recovery and in their daily life.

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4 Education and information

Timing of information

4.1 All stroke survivors should be provided general information about symptoms that may indicate stroke as well as conditions that occur as a consequence of stroke, including those specific to vision, prior to discharge.
Rationale: This will improve community awareness and alert stroke survivors/ their families to other possible symptoms of a second stroke.

4.2 Where a visual deficit is identified, information should be provided at the time of diagnosis and prior to discharge in an appropriate format (e.g. aphasia friendly, large print, audio). Liaison with a speech pathologist may be necessary to facilitate information provision that is appropriate and accessible.
Rationale: The patient and/or carer is likely to have questions and concerns regarding their visual condition and these should be addressed immediately. However, the stroke survivor may not be able to understand/ retain this information at the time of diagnosis and so it should be made available to be them again at a later stage.

Specificity of information

4.3 General information about how stroke can impact the eyes and vision should be provided to all stroke survivors in an appropriate format that can be accessed repeatedly (e.g. large print/ aphasia friendly pamphlet, electronic document or media file). Liaison with a speech pathologist may be necessary to facilitate information provision that is appropriate and accessible.
Rationale: Stroke survivors are at high risk of suffering another stroke. They should be made aware of the visual symptoms of stroke so that they can be more easily identified and appropriate action taken should they ever occur. Take-home information can be readily accessed by patients and carers at any time, ensuring accurate information relay.

4.4 Stroke survivors with a visual deficit should be provided information about what their condition is, what area of the brain and visual system it relates to, the expected implications on functional vision, expected recovery, available management options, resources and support services. This should be worded in lay terms that can be easily understood by non-medical personnel and provided in an appropriate format for the patient as an addition to discharge documents.
Rationale: A clear understanding of the visual condition is important in reducing the anxiety associated with a new visual diagnosis. Clear information about management and recovery also helps to manage expectations and adaptation of the stroke survivor and their family.

4.5 Referrals should be explained in regard to what condition is to be managed or what service provided by each professional the stroke survivor is referred to. This may be provided through direct communication with the patient's nominated general practitioner (GP), in which case the patient/ carer should be notified that they can access this information through their GP.
Rationale: After stroke, a multitude of conditions are managed by a multidisciplinary team. Keeping track of what each referral is for can be confusing and overwhelming for the patient and/or carer and so clear explanation can help in prioritising and organising follow up.

Education/ training of stroke health professionals

4.6 Non-eye specific health professionals should receive training relating to commonly used vision terminology, and visual conditions relating to stroke.
Rationale: As stroke care requires a collaborative effort from a multi- disciplinary team, all members of the team should have a general understanding of basic visual terminology and common post-stroke visual conditions to aid communication and hence improve patient care.

4.7 Post-stroke vision assessment should be included in existing stroke pathways and/or protocols for all acute and rehabilitation services.
Rationale: Where hospitals or rehabilitation facilities have a stroke protocol, vision assessment should be included so that there is consistency of care across all disciplines.

4.8 Trained eye care professionals (e.g. orthoptists) should be included in the multi-disciplinary team of all stroke care facilities (acute and rehabilitation).
Rationale: Vision is impacted in approximately 60% of stroke survivors and manifests as a wide range of abnormalities. This necessitates access to specialist vision care acutely as non-eye specific health professionals are often not confident in assessing/ treating visual conditions.

4.9 Information regarding the visual condition of a stroke survivor, the implications (including driving and return to work requirements) and how to best manage these should be documented in the patients file and in discharge papers/ referrals for shared access between the multi-disciplinary team.
Rationale: This information aids other health professionals in providing care/ rehabilitation in a manner that is appropriate for the patient's visual condition. It also ensures accurate and consistent information is given to the patient.

Education of carers/ family

4.10 The stroke survivor's next of kin or carer, if applicable, should be educated on what to expect regarding the impact of the visual deficit on the survivor's daily function, how to best manage this, expected recovery and available resources/ services for management and support. Information on carer support services should also be provided.
Rationale: The stroke survivor often requires support in retaining and relaying information about their own condition to their carer/s or family members and so this information should also be given directly to the necessary people where possible. The health and well-being of caregivers is also an important aspect of care provision that should be addressed.

Abbreviations:

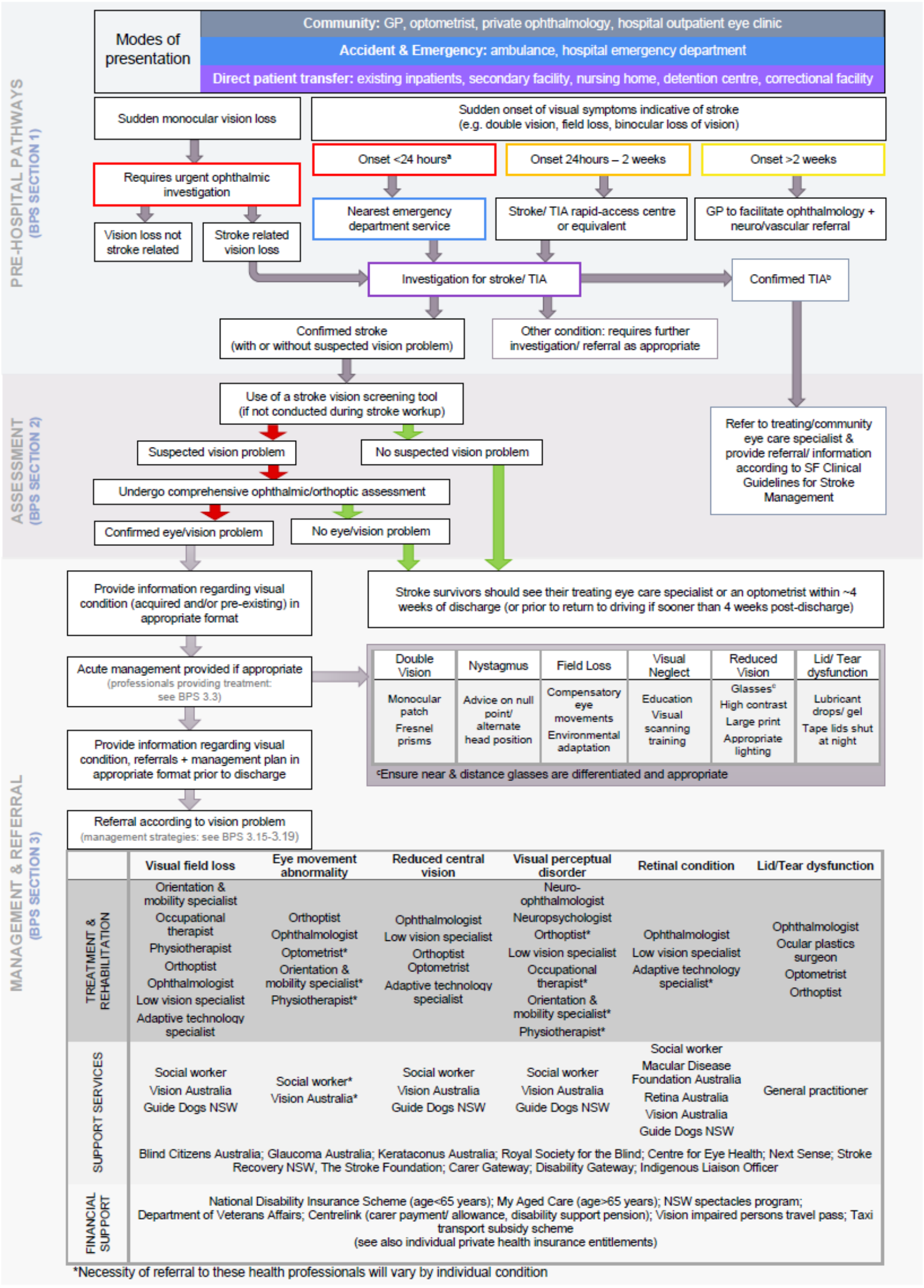
AMD = age related macular degeneration

TIA = transient ischemic attack

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11.20 Final NSW Post-stroke Vision Care Framework (including revised pathway & BPS) following Round Three

This pathway should be used in conjunction with the best practice statements for post-stroke vision care in NSW (Section 2).



[a]Patients presenting within 4.5 hours of ischemic stroke may be eligible for thrombolysis and/or other reperfusion therapies up to 24hours post onset.
[b]TIA is confirmed if symptoms are fully resolved within 24 hours
GP = general practitioner; TIA = transient ischemic attack, SF = Stroke Foundation.

BEST PRACTICE STATEMENTS

1 Pre-Hospital Pathways

Community awareness

1.1 Orthoptists, optometrists and ophthalmologists as well as other stroke health professionals should endeavour to raise community awareness of visual stroke symptoms. In doing so, an attempt should be made to distinguish migraine with visual aura (typically resolving within 60 minutes) from stroke with visual complications (duration more than 60 minutes).
Rationale: Visual symptoms of stroke are not well recognised within the community and so may result in delayed contact of health services. Where possible, stroke related visual problems should be distinguished from migraine related visual symptoms to prevent misdiagnosis, unwarranted presentation and increased burden to frontline services.

1.2 Training should be provided to general practitioners, accident and emergency personnel, nurses and other 'first point of care' professionals regarding differentiating diagnosis of migraine with visual aura, drug overdose and stroke, particularly in younger people. This training should be provided by an eye care professional such as an orthoptist or ophthalmologist or by the assigned stroke educator.
Rationale: Stroke with primarily visual symptoms is often misdiagnosed initially as migraine with aura. In younger people specifically, misdiagnosis of drug overdose also occurs. This happens due to a lack of awareness and training on visual stroke symptoms.

Referral process

1.3 Patients that present to their general practitioner, community vision service, or hospital outpatient clinic with sudden onset of visual signs/symptoms (onset <24 hours) indicative of stroke (e.g. double vision, field loss, binocular loss/significant reduction of vision) and unexplained by identifiable pathology should be referred to nearest emergency department. Sudden monocular vision loss should be urgently referred for ophthalmic investigation if cause is undetermined.
Rationale: Eligibility for intravenous thrombolysis is time sensitive (≤4.5 hours). Hence, if visual symptoms of stroke are misdiagnosed initially, the opportunity to prevent permanent loss of function may be lost. Stroke with visual deficits as the primary symptom are a risk for delayed diagnosis due to lack of awareness regarding visual consequences of stroke/ TIA. Sudden monocular loss of vision can be caused by pathologies such as Wet AMD and retinal vein occlusions, therefore requires further ophthalmic investigation to rule out non-stroke related pathology.

1.4 Patients presenting to emergency services (emergency department, ambulance) with sudden onset of visual signs/symptoms (onset <24 hours) indicative of stroke (e.g. double vision, field loss, binocular loss of vision) should be investigated for stroke/ TIA. Ophthalmic assessment should be performed for sudden monocular vision loss to determine necessity of stroke/TIA investigation. Where an eye care professional is not available, this should be performed by a stroke health professional trained in vision assessment or sent for alternative stroke investigation.
Rationale: Eligibility for intravenous thrombolysis is time sensitive (≤4.5 hours). Hence, if visual symptoms of stroke are misdiagnosed initially, the opportunity to prevent permanent loss of function may be lost. Sudden monocular loss of vision can be caused by pathologies such as Wet AMD and retinal vein occlusions, therefore requires further ophthalmic investigation to rule out non-stroke related pathology.

1.5 Patients that present to community or emergency services with sudden onset of visual signs/symptoms (onset >24hours but less than 2 weeks) indicative of stroke (e.g. double vision, field loss, binocular loss/significant reduction of vision) and unexplained by identifiable pathology should be referred to nearest stroke/TIA rapid access centre or equivalent for investigation.
Rationale: In some circumstances, such as minor stroke or carotid artery dissection, initial symptoms are isolated and/or minor which often results in delayed presentation to health services. These patients are at heightened risk of recurrent stroke and/or progression to completed stroke and require urgent investigation and management. Most carotid artery dissections progress to completed stroke within 5-10 days. Referral via a general practitioner has been shown to cause a delay in access to specialist services of up to 21 days and hence is inappropriate for individuals within this heightened risk category.

2 Screening and Assessment

Timing of assessment

2.1 Vision screening, including objective measures, should be provided to all stroke patients within 2 weeks of regained consciousness, OR before rehabilitation activities begin. However, rehabilitation activities should not be delayed if patient is awaiting vision assessment due to service limitations.
Rationale: Visual deficits can complicate rehabilitation (e.g. physical rehabilitation, occupational therapy training, communication training). Strategies to minimise the impact of vision loss on these rehabilitation activities can be utilised if both the patient and other health professionals are aware of the deficits and informed on how to manage them. Objective measures of visual function should be used in screening as many stroke survivors do not or cannot report visual symptoms.

2.2 Where vision screening indicates the need for further vision assessment, this should ideally take place before rehabilitation activities begin or in the early stages of rehabilitation. However, rehabilitation activities should not be delayed if patient is awaiting vision assessment due to service limitations.
Rationale: Visual deficits can complicate rehabilitation (e.g. physical rehabilitation, occupational therapy training, communication training). Strategies to minimise the impact of vision loss on these rehabilitation activities can be utilised if both the patient and other health professionals are aware of the deficits and informed on how to manage them.

2.3 All stroke survivors should be encouraged to have an eye/vision assessment at their earliest convenience post-discharge (or prior to return to driving if they wish to continue driving after the recommended non-driving period) with appropriate explanation regarding the potential benefits.
Rationale: Most stroke survivors are within the age group prone to presbyopia and other age-related visual conditions. Hence vision may be compromised even if there is no obvious visual deficit. Having a vision assessment will ensure refractive error is corrected and age-related pathologies identified/ managed, which will help ease their reintegration into the community and ensure a safe return to driving if intended. The recommended non-driving period after stroke is 4 weeks for private license holders and 3 months for commercial license holders.

Health professional(s) performing assessment

2.4 Where an orthoptist is not available for initial vision screening, the use of a suitable, validated vision screening tool(s) for stroke survivors (e.g. VISA, Vision Defect in Stroke Screening Tool) by non-eye care stroke health professional should be supplemented with appropriate training and education around how to administer and interpret results of the tool. Training should be provided using the associated education materials for the tool or by an eye care professional. Training may be performed remotely via video conference or online material to improve access.
Rationale: Non-eye care professionals have been shown to be less accurate/effective at administering vision screening tools than eye specialist health professionals. However, when appropriate training and education is provided, there is significant improvement. Access to specialist services and training is particularly limited in regional and remote areas of Australia. Remote/ online training services may improve access and facilitate vision screening in these areas.

2.5 Stroke survivors suspected of having visual deficits, who report visual deficits, or show potential visual deficits as a result of screening should be referred for assessment by an orthoptist or ophthalmologist as appropriate for the condition. Where this is not possible within a reasonable timeframe, such as in some rural areas of Australia, consultation via telehealth and/or liaison between local treating health professional(s) (e.g. an Optometrist) and a specialist eye professional should be arranged.
Rationale: Accurate assessment, diagnosis and explanation of visual deficits can only be provided by eye specialist health professionals. Ophthalmologists and orthoptists have the required training to identify and manage stroke related visual deficits. Access to these services in rural Australia may be improved via telehealth and ongoing remote cooperation between rural stroke services, local optometrists and specialist eye care services.

Execution of assessment

2.6 Vision screening should include vision history (with carer present if necessary) to identify any pre-existing vision conditions. Where possible and necessary to aid diagnosis/ referral, ophthalmic history should be sourced from previously seen ophthalmologist or optometrist.
Rationale: Pre-existing vision conditions may explain visual complaints and require ongoing management throughout the patient's rehabilitation in order to reduce impact on recovery and prevent regression of ocular conditions e.g. glaucoma.

2.7 All stroke survivors should have an assessment of monocular and binocular visual acuity wearing the appropriate glasses, to check their ability to read newspaper text and see distant objects clearly.
Rationale: The ability to read at near and distance is an important functional aspect of vision for everyday life. Reduced visual acuity in one or both eyes may be indicative of several pathologies and provides crucial information when forming a visual diagnosis.

2.8 All stroke survivors should have an examination for the presence of visual field deficit (e.g. hemianopia) and eye movement disorders (e.g. strabismus and motility deficits).
Rationale: Visual field defects and eye movement disorders are the most common visual consequences of stroke and have a severe impact on a survivor's visual function. Consensus has been previously established regarding the inclusion of visual field and eye motility assessment in the vision screening of stroke survivors in the UK.

2.9 All stroke survivors should be screened for visual neglect and/or visual perception disorders at the time of vision assessment or perceptual assessment. If a disorder is suspected, an appropriate battery of tests should be used to confirm diagnosis.
Rationale: Visual neglect is a common consequence of stroke and has a severe impact on a survivor's visual function. It can also occur in conjunction with other visual and perceptual deficits after stroke and so should be accurately diagnosed through a battery of tests. Visual perceptual disorders are less common but are also less likely to be reported by stroke survivors and have a significant impact of their quality of life.

3 Management and referral

Timing of management/ referral

3.1 The orthoptist or health professional responsible for providing vision care should initiate management and referrals for visual deficits based on the patient's needs, readiness for information and capacity for participation in these services based on their clinical judgement and discussion with the stroke survivor and/or their family/ informal caregiver.
Rationale: Due to the varying severity of stroke and individual personalities/ circumstances, stroke survivors and their carers may be ready to participate in vision management at different times, with some visual conditions requiring more immediate treatment than others. An appropriate balance between clinical necessity and stroke survivor capacity needs to be determined for treatment to be most effective.

3.2 Where a visual deficit is found through screening, or by report of the patient/ carer/ other health professional, there should be immediate (or as soon as practicable) referral to an orthoptist or ophthalmologist as appropriate. Where access to an orthoptist or ophthalmologist is limited, referral to an eye care professional (such as an optometrist) should be made in order to confirm diagnosis and provide appropriate management or referral.
Rationale: Immediate referral allows the visual condition to be investigated and diagnosed in a timely manner. This enables time sensitive treatment to be provided as necessary, as well as clarity for the patient and other treating health professionals regarding their condition.

3.3 Where short-term management (e.g. advice, patching, Fresnel prisms) is appropriate and available, this should be provided as soon as it becomes beneficial for the stroke survivor by a health professional with appropriate training in how to administer the required management. In the case of specialised treatments (e.g. Fresnel prisms, occlusion, prescription of ocular lubricants) this should be administered by an eye care professional. In areas of limited access to specialist eye care services, facilitation of these management strategies should be made possible through telehealth where appropriate.
Rationale: Simple interventions such as advice (on gaze or head position) or patching/ Fresnel prisms for double vision can be quickly and easily administered and may provide significant improvement to comfort and functionality. Many of these management strategies require eye-care specific expertise and hence require an eye care professional to administer them to ensure safety and effectiveness.

3.4 Management of pre-existing conditions through the use of glasses, drops and/or medications, should be continued and monitored appropriately for the entirety of their inpatient recovery and continued into their community care through appropriate referral.
Rationale: Pre-existing eye conditions can negatively impact the recovery and rehabilitation of a stroke survivor and may worsen if left untreated for a period of time (e.g. Glaucoma, Wet AMD).

3.5 If a visual deficit is found that has a known medical treatment/ intervention available, referral to the appropriate health professional should be made immediately (or as soon as practicable in the context of inpatient care).
Rationale: Immediate referral allows for intervention to be provided promptly, minimising the impact of the visual deficit on overall recovery. It also provides clear understanding of where and how to seek treatment, should the patient wish to pursue it at a later time.

3.6 If a visual deficit is found that does not have a known medical treatment/ intervention available, but can be managed or better adapted to through therapy and/or training, there should be a referral provided at the time the stroke survivor is physically and cognitively able to participate in said management OR on discharge.
Rationale: Commencement of therapy/ training is not appropriate until the stroke survivor is able to understand and participate to an extent that is beneficial to their condition. However, patients should not be discharged without receiving referral.

3.7 If a visual deficit is found that does not have any (or limited) known medical treatment/ intervention or therapy/ training that is appropriate, referral to a vision support service and/or social worker should be provided as soon as practicable and must be provided before discharge.
Rationale: Referral to support services at the time of diagnosis and/ or before discharge ensures the patient and their family have clear information about the long term help available to them and where to obtain it. Social workers can also provide patient and caregivers with emotional support, advise on financial support and facilitate access to mental health services where necessary. The inclusion of a social worker and/or case manager from the early stages of management can improve patient access to support services and reduce anxiety around management plans/ reintegration into the community.

Appropriateness of referral

3.8 Where pharmacological or surgical intervention is available/ recommended for their visual deficit, stroke survivors should be referred to an ophthalmologist.
Rationale: Specialist eye care that requires pharmacological and/or surgical intervention can only be administered by an ophthalmologist.

3.9 Where therapeutic training and/or compensatory management options are available/ recommended for their visual deficit, stroke survivors should be referred to an orthoptist and/or occupational therapist trained in vision management and/or a low vision specialist and/or an orientation and mobility specialist. In some cases, referral to a physiotherapist may also be appropriate (e.g. to assist with balance issues caused by vision problem).
Rationale: Orthoptists and health professionals such as occupational therapists, low vision specialists, orientation and mobility specialists with vision specific training have the specialist knowledge and qualifications to provide therapeutic training and educate on compensatory strategies relating to post-stroke visual deficits.

3.10 Where optical correction (such as glasses and/ or long-term prisms) is available/ recommended for their visual deficit, stroke survivors should be referred to an optometrist. Prescription of prisms may require consultation with an orthoptist or ophthalmologist.
Rationale: Optometrists have the specialist knowledge and qualifications to provide optical correction for age related and stroke related vision problems.

3.11 Visual perceptual deficits should be referred to a neuro-ophthalmologist and social worker. In some cases, referral to a neuropsychologist and vision support services may also be appropriate. These patients may also benefit from therapeutic training and/or compensatory management options (see 3.9).
Rationale: Visual perceptual deficits are a less common visual occurrence and so are not as widely understood. Neuro- ophthalmologists work specifically with neurological vision loss, and so will be able to provide the most appropriate care. Often, management options for these conditions are limited and so appropriate referral for compensatory management and support services are required.

3.12 Where no (or limited) treatment or therapy is available/ recommended for their visual deficit, stroke survivors should be referred to a vision support service (e.g. Vision Australia, Guide Dogs NSW) and social worker to discuss available services and entitlements. When referring to vision support services, it is important to ensure referral requirements have been met prior to discharge (e.g. vision assessment by an ophthalmologist for some services).
Rationale: Vision support services and social workers are able to provide access to assistive technology, adaptive training and environmental modification as well as access to psychological, emotional and financial support services. These services enhance the quality of life of stroke survivors with incurable vision loss.

3.13 Discussions with the stroke survivor/ carer should be had to determine if referral to a social worker, stroke or vision support service, or access to a case manager (where available) would aid in managing their vision care and assist in their reintegration into the community and/or accessing funding.
Rationale: The multiplicity of health problems after stroke can be overwhelming for both the survivor and their carer(s). Assistance in managing appointments, care services and attaining funding can reduce the stress involved in this process and improve access to these services.

3.14 Referrals to non-eye care specialists, namely occupational therapists, social workers, counsellors, orientation and mobility specialists, physiotherapists and/or adaptive technology specialists should be provided in the same instance as eye- specific referrals as appropriate for the condition. Such referrals should include comprehensive information about the patient's visual, physical and cognitive condition.
Rationale: Services provided by other health professionals that support stroke survivors with vision loss are of equal importance to eye-specific care for successful recovery.

Appropriateness of management

3.15 Where glasses are currently used by the stroke survivor or deemed necessary through vision assessment, these should be made available to the patient as soon as practicable. It should be made clear to the patient, as well as their treating health professionals, what distance or tasks the glasses are to be used for e.g. distance viewing, reading, or both.
Rationale: There is a high incidence of presbyopia and other refractive errors amongst stroke survivors. Access and appropriate use of prescribed glasses is important for the general functioning and participation in rehabilitation activities of the stroke survivor.

3.16 Management of visual field loss should include promoting awareness of the field loss and compensatory strategies (e.g. visual scanning training, reading strategies, discussion and referral for assistive technology) by an eye care professional as well as environmental adaptations and mobility training guided by an occupational therapist and/or orientation and mobility specialist. Other options such as restitutive treatment should also be discussed with the patient, with information on effectiveness/supporting evidence, so they can make an informed decision should they wish to pursue.
Rationale: There is little conclusive evidence to indicate the most effective treatment for visual field loss, however compensatory methods show task specific improvement and increased quality of life. Stroke survivors indicate a want and feel it is their right to be informed on all options available.

3.17 Where double vision is the primary complaint of a strabismus or ocular motility issue, occlusion of one eye or Fresnel prisms should be suggested as a short-term solution to aid rehabilitation (see also 3.3). Long term management should be through referral to an ophthalmologist, neuro- ophthalmologist or orthoptist and may include surgical or pharmacological intervention, long-term prisms, or other strategies as appropriate for the condition.

Rationale: These treatment methods are the best supported by evidence and clinical practice at present. Short term management strategies need to be administered appropriately in order to be effective and hence should be facilitated by a trained eye care professional.

3.18 Reduced central vision should be referred to an ophthalmologist to investigate/ manage potential pathology. If uncorrected refractive error is the determined cause of reduced vision, onward referral to an optometrist may then be necessary.
Rationale: Refractive error (particularly presbyopia) is a very common cause of reduced central vision in the age group most susceptible to stroke. All refractive error should be corrected as best as possible to enhance visual function. However, assessment by an ophthalmologist is necessary to identify and manage any potential pathology.

3.19 Management of visual neglect should include promoting awareness of the area of neglect and cognitive rehabilitation (e.g. visual scanning training, reading strategies) by an eye care professional as well as environmental adaptations and mobility/ activity training guided by an occupational therapist, physiotherapist or orientation and mobility specialist as appropriate. Other options should also be discussed with the patient with advice on effectiveness/supporting evidence so that they can make an informed decision should they wish to pursue.
Rationale: There is little conclusive evidence regarding the most effective treatment method for visual neglect, however compensatory strategies and training have been shown to be beneficial on standardised assessments. Providing information on all available treatment options provides stroke survivors with hope and coping strategies during recovery and in their daily life.

4 Education and information

Timing of information

4.1 All stroke survivors should be provided general information about symptoms that may indicate stroke as well as conditions that occur as a consequence of stroke, including those specific to vision, prior to discharge.
Rationale: This will improve community awareness and alert stroke survivors/ their families to other possible symptoms of a second stroke.

4.2 Where a visual deficit is identified, information should be provided at the time of diagnosis and prior to discharge in an appropriate format (e.g. aphasia friendly, large print, audio). Liaison with a speech pathologist may be necessary to facilitate information provision that is appropriate and accessible.
Rationale: The patient and/or carer is likely to have questions and concerns regarding their visual condition and these should be addressed immediately. However, the stroke survivor may not be able to understand/ retain this information at the time of diagnosis and so it should be made available to be them again at a later stage.

Specificity of information

4.3 General information about how stroke can impact the eyes and vision should be provided to all stroke survivors in an appropriate format that can be accessed repeatedly (e.g. large print/ aphasia friendly pamphlet, electronic document or media file). Liaison with a speech pathologist may be necessary to facilitate information provision that is appropriate and accessible.
Rationale: Stroke survivors are at high risk of suffering another stroke. They should be made aware of the visual symptoms of stroke so that they can be more easily identified and appropriate action taken should they ever occur. Take-home information can be readily accessed by patients and carers at any time, ensuring accurate information relay.

4.4 Stroke survivors with a visual deficit should be provided information about what their condition is, what area of the brain and visual system it relates to, the expected implications on functional vision, expected recovery, available management options, resources and support services. This should be worded in lay terms that can be easily understood by non-medical personnel and provided in an appropriate format for the patient as an addition to discharge documents.
Rationale: A clear understanding of the visual condition is important in reducing the anxiety associated with a new visual diagnosis. Clear information about management and recovery also helps to manage expectations and adaptation of the stroke survivor and their family.

4.5 Referrals should be explained in regard to what condition is to be managed or what service is provided by each professional the stroke survivor is referred to. This may be provided through direct communication with the patient's nominated general practitioner (GP), in which case the patient/ carer should be notified that they can access this information through their GP.
Rationale: After stroke, a multitude of conditions are managed by a multidisciplinary team. Keeping track of what each referral is for can be confusing and overwhelming for the patient and/or carer and so clear explanation can help in prioritising and organising follow up. GPs are easily accessible and are crucial in facilitating overall management once the stroke survivor returns to the community.

Education/ training of stroke health professionals

4.6 Non-eye specific health professionals should receive training relating to commonly used vision terminology, and visual conditions relating to stroke.
Rationale: As stroke care requires a collaborative effort from a multi- disciplinary team, all members of the team should have a general understanding of basic visual terminology and common post-stroke visual conditions to aid communication and hence improve patient care.

4.7 Post-stroke vision assessment should be included in existing stroke pathways and/or protocols for all acute and rehabilitation services.
Rationale: Where hospitals or rehabilitation facilities have a stroke protocol, vision assessment should be included so that there is consistency of care across all disciplines.

4.8 Trained eye care professionals (e.g. orthoptists) should be included in the multi-disciplinary team of all stroke care facilities (acute and rehabilitation).
Rationale: Vision is impacted in approximately 60% of stroke survivors and manifests as a wide range of abnormalities. This necessitates access to specialist vision care acutely and in rehabilitation, as non-eye specific health professionals are often not confident or not adequately trained in assessing/ treating visual conditions.

4.9 Information regarding the visual condition of a stroke survivor, the implications (including driving and return to work requirements) and how to best manage these should be documented in the patients file and in discharge papers/ referrals for shared access between the multi-disciplinary team.
Rationale: This information aids other health professionals in providing care/ rehabilitation in a manner that is appropriate for the patient's visual condition. It also ensures accurate and consistent information is given to the patient.

Education of carers/ family

4.10 The stroke survivor's next of kin or carer, if applicable, should be educated on what to expect regarding the impact of the visual deficit on the survivor's daily function, how to best manage this, expected recovery and available resources/ services for management and support. Information on carer support services (e.g. Carer Gateway) should also be provided.
Rationale: The stroke survivor often requires support in retaining and relaying information about their own condition to their carer/s or family members and so this information should also be given directly to the necessary people where possible. The health and well-being of caregivers is also an important aspect of care provision that should be addressed.

Abbreviations:

AMD = age related macular degeneration

TIA = transient ischemic attack

GP = general practitioner

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ORIGINAL ARTICLE

Meeting the need for post-stroke vision care in Australia: a scoping narrative review of current practice

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ABSTRACT

Purpose: Determine current vision care pathways and practices for stroke survivors in Australia and internationally, focusing on identifying reoccurring gaps in these pathways and unmet care needs.
Method: A scoping narrative review was conducted to identify literature related to post-stroke vision care practices and perspectives of patients and health professionals.
Results: A total of 16193 articles were retrieved and 28 deemed eligible for inclusion. Six were Australian, 14 from the UK, four from the USA, and four from within Europe. Post-stroke vision care is largely unstandardized, with substantial inconsistency in the use of vision care protocols, who executes them and at what point in post-stroke care they are utilised. Health professionals and stroke survivors expressed that unmet care needs were primarily a result of lack of education and awareness regarding post-stroke eye problems. Other gaps in care pathways related to the timing of vision assessment, provision of ongoing support, and the integration of eye-care specialists into the stroke team.
Conclusion: Further research is needed into current Australian post-stroke vision care to accurately assess whether the needs of stroke survivors are being met. Available evidence indicates that in Australia, there is a requirement for well-defined protocols for vision screening, education, management, and referral of stroke survivors.

> IMPLICATIONS FOR REHABILITATION

- Post-stroke vision care in Australia is unstandardised, which may cause inequities in vision care provision to Australian stroke survivors in different regions and/or care facilities.
- Education and training pertaining to stroke-related vision conditions for stroke healthcare professionals and the inclusion of eye-care professionals in stroke care teams is likely to improve gaps in care practice/pathways identified in the current evidence base.
- Management of stroke-related visual conditions should be inclusive of detailed information provision that is specific to the patients condition(s) and circumstances, as well as ongoing, long-term management strategies/support services to better aid stroke survivor"s reintegration into the community.

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Stroke; vision rehabilitation; Australian healthcare; care pathways; visual impairment

Introduction

Stroke is the second leading cause of cardiovascular death in Australia [1]. Despite a proportional decrease in stroke events, the actual number of stroke events has increased, which may in part be attributed to Australia's ageing population [2]. There are approximately 37 000 stroke events occurring in Australia each year [1]. Evidence indicates that 60% of people with stroke will experience some form of visual impairment [3]. As stroke most commonly occurs in those aged 65 years and over [1], there is also likely to be a high prevalence of pre-existing age-related eye conditions within this population of stroke survivors. This includes common age-related eye conditions such as cataracts, glaucoma, macular degeneration and presbyopia. For stroke survivors, these conditions will be compounded by the presence of stroke-related visual deficits, severely impacting rehabilitation and daily life activities [3,4]. There is a strong correlation between visual impairment and increased depression [4], falls risk [5–7] and overall morbidity [8,9]. Reports from stroke survivors also indicate that their visual impairment resulted in a number of barriers to reintegration into the community [10,11]. These included an inability to return to work [10,11], pursue hobbies such as reading [10], and driving [10,11]. This indicates that visual impairment can be a hindrance to the successful rehabilitation of stroke survivors and resumption of independent living if not adequately addressed.

The most commonly reported post-stroke vision problems are visual field loss, eye movement abnormalities and visual processing disorders, including hemispatial neglect. There is some recovery expected post-stroke, however, the degree tends to vary depending on the type of vision problem and severity of the stroke. Only approximately 17% of visual field loss recovers completely over the first 3 months post-stroke, while up to 34% of visual processing disorders have been found to recover in this time [12]. Eye movement abnormalities, such as most gaze defects

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only partially recover or do not recover at all in the six-month period after stroke [13]. For patients with ocular cranial nerve palsies, some recovery over a period of 6-12 months after onset is expected, although recovery is often partial, with only approximately 22% recovering completely [14].

While there is no cure for some visual deficits caused by stroke, there are several management techniques and services available that have been proven to effectively reduce their burden of them. The primary complaint of eye movement abnormalities such as cranial nerve palsies, gaze palsies and vergence disorders is usually diplopia. Simple management techniques such as correctly occluding one eye, the use of prisms or the adoption of an adaptive head posture to relieve diplopia are commonly used for these conditions [13,15]. If deviations of this kind persist beyond the expected point of recovery, surgical intervention or use of Botulinum toxin to alter eye muscle actions may be appropriate. While these methods have not been systematically investigated within stroke survivors specifically, the available literature indicates the wide use and efficacy of these treatment options in adult strabismic populations [16,17]. Similar methods can be beneficial in some cases, to manage nystagmus, with the use of pharmacological agents such as Gabapentin and Baclofen being more common [18].

For visual field loss, one of the common management techniques used is visual scanning training [15,19]. Such training is often administered through electronic programs but can also be taught using non-computerised scanning techniques and environmental cues. It is a form of compensatory therapy that aims to improve the frequency, speed and accuracy of eye movements into the affected visual field [20,21]. Peli prisms are also used for management of visual field loss as a means of shifting images from an area of field loss into the part of the visual field that is seeing [22]. This promotes awareness of objects in the area of vision loss and prompts/cues eye movement in that direction [22]. Another technique, visual restoration therapy (VRT) uses light stimuli at the border of the visual field defect with the aim of slowly expanding the visual field [23]. The available evidence on VRT suggests there is little to no change in the size of visual fields from this treatment and as such it is not commonly used in practice [23,24].

Similarly, visual scanning training is often used to treat visual neglect with varying levels of success [25]. Other reported methods of treatment for this condition include perceptual retraining, typoscopes, and hemifield eye patching [15,26]. However, little evidence is available regarding their success in stroke patients. Better reported is the recommendation of daily living training and the provision of aids and modifications. Services such as Guide Dogs Australia and Vision Australia can facilitate this kind of training and offer support to those with vision impairments to obtain appropriate aids and advice. Conversely, other vision-specific treatments such as patching, prisms, visual adaptation, and orthoptic training would typically be delivered by an orthoptist, ophthalmologist or at times an occupational therapist or specialised nurse. A range of health professionals can also provide the necessary information to stroke survivors about their vision problems, what to expect, and what services might be available. Despite the range of services and treatment options available to stroke survivors with vision impairment, post-stroke vision care is scarcely addressed in Australian national stroke guidelines.

The Australian Clinical Guidelines for Stroke Management is a living document that is continuously updated and revised based on the most current evidence, however, these guidelines currently only contain limited information regarding vision, including recommendations for visual acuity and visual field testing and treatment options for visual inattention only [27]. Some Australian states have their own stroke-specific guidelines, and of those that do, most do not address vision at all [28,29]. South Australia Health"s Stroke Management Procedures and Protocols (2019) states that occupational therapists or physiotherapists should provide rehabilitation for functional vision loss, compensatory skills for visual field loss, visual acuity, and eye movement disorders [29], most of which would be outside their scope of practice. The named therapies are visual training, visual scanning, and use of prisms, as well as the requirement to facilitate early referral to neurological vision specialists [29]. The lack of guidance specific to post-stroke vision care makes it difficult to know if stroke survivors in Australia are getting the vision care they need to best facilitate their recovery and return to the community. As such, the aim of this review is to identify existing literature relating to current post-stroke vision care pathways and practices are in Australia and identify reoccurring gaps and unmet care needs within them.

Methods

A scoping review was planned to collate and examine evidence relating to vision care pathways and practices for stroke survivors in Australia and secondly, in countries with similar healthcare structures. This method of review was deemed most suitable to determine the extent, range, and nature of research on this topic, as no previous reviews have been conducted in the context of Australian healthcare [30]. Due to the limited amount of evidence available on this topic and the nature of available evidence, the results of the review were outlined and discussed using a hybrid scoping-narrative review style.

A care pathway was defined as a process through which stroke survivors were assessed, managed and/or referred for their vision problems. Countries of a similar healthcare structure were defined as developed countries with stroke-specific services available. This review was carried out according to the PRISMA-ScR [31] guidelines.

Inclusion and exclusion criteria for studies

Types of studies

Studies were eligible for inclusion in the review if they provided information on post-stroke vision care practices or any stage of the post-stroke vision care pathway and were published in English. Studies included were: systematic reviews, cohort studies, observational studies, retrospective medical file reviews, randomised controlled trials and controlled trials. Case studies were not included, as they refer to isolated scenarios rather than widely utilised practices or pathways. Scoping of the literature revealed no evidence relevant to the topic published in Australia prior to 2008, hence studies conducted prior to this were excluded. For consistency, international studies published prior to 2008 were also excluded and it is noted that they may be an outdated representation of current healthcare practices. Studies were also excluded if they were conducted in developing countries under the assumption that results would vary greatly from Australian healthcare practices.

Types of participants

We included studies of participants of all ages who were found to have visual complications following stroke. Studies relating to children (under 18 years) were analysed separately to those with adult (18 years and over) participants, as the care pathways are

likely to differ based on the legal requirements for providing medical care to minors. Studies including participants of mixed health conditions were included if results for stroke survivors could be adequately differentiated. Studies with populations of health professionals who provide stroke care were also included.

Search methods and databases

A systematic search strategy was used to search the following key electronic databases:

- PubMed (2008- January 2022)
- Cochrane Library (2008- January 2022)
- MEDLINE (2008- January 2022)
- EMBASE (2008- January 2022)
- Australian Orthoptic Journal (2008- January 2022)

As the primary aim of this review is to identify literature relating to Australian post-stroke vision care pathways and practices, other international Orthoptic Journals were not included in the search. Search terms included a variety of MESH terms and alternatives relating to stroke, vision impairment, and care provision. The complete search strategy for the PubMed database is provided as an example in Figure 1. Manual search of reference lists from relevant Australian articles was also conducted. [Figure 1 near here]

Study selection

Titles and abstracts returned from the search were independently reviewed by two authors (SS, SL) using the predetermined inclusion criteria. If a study could not be properly evaluated based on the title and abstract alone, the full paper was obtained. Full papers were also obtained for the studies deemed eligible for inclusion. A second review of all full paper articles was then conducted to determine those studies eligible for inclusion. Where disagreements on the inclusion/exclusion of studies occurred between reviewing authors, a third author was to review these articles, and inclusion was based on the majority decision.

Data collection

Data extraction forms were designed to capture key study elements, and to inform quality assessment and categorisation. Further information collected included data pertaining to post-stroke vision care practices and pathways at each stage of care.

Data analysis

Data analysis was inductive and largely descriptive due to the emerging nature of the review topic and variable study types included. This resulted in a hybrid style scoping-narrative review. Care pathways are likely to differ between countries, healthcare models and time, making accurate synthesis of such data difficult. The variability of study types also produces different types of data (qualitative and quantitative) and so a thematic and descriptive approach was deemed the most appropriate. Data extracted was grouped according to the areas of post-stroke vision care. Descriptive statistics relevant to each stage of care were then collated and where possible, information on Australian post-stroke vision care was discussed in relation to that provided in other jurisdictions.

Results

Figure 2 illustrates the results of the search. A total of 28 articles met the inclusion criteria for this review, with no disagreements on the inclusion of studies between reviewing authors. Of the studies included, eight were cross-sectional studies, nine were cohort studies (both retrospective and prospective), five were qualitative studies, one was a mixed method study, three were multicentre prospective studies as well as one consensus study and one audit report. [Figure 2 near here] Studies varied in objectives, with most aiming to describe and appraise vision care provision for stroke survivors within specific regions or amongst specific professional groups. Other studies sought to explore the experience and perspectives of post-stroke vision care for stroke survivors, their carers, and health professionals. [Figure 2 near here]

The countries from which data was collected included Australia ($n=6$), the UK ($n=14$), USA ($n=4$), Finland ($n=1$), Denmark ($n=1$), Germany ($n=1$) and Norway ($n=1$). Of the studies included 15 provided information on vision screening and assessment of stroke survivors, 16 included information regarding management and referral, six included information relevant to education and information dissemination and 11 discussed perceptions of care and/or barriers to care.

Care provision

Screening & assessment

The available evidence indicates that the timing of vision screening and assessment of stroke survivors is of key importance to the quality of overall post-stroke vision care. The Vision in Stroke (VIS) study (2006–2016) surveying outpatients with stroke found that the median duration from stroke onset to initial eye examination was 22 days among stroke patients in 20 acute Trust hospitals in the UK [32]. More recently (2014–2015), further UK research on the Impact of Vision Impairment after Stroke (IVIS) study, interviewed 24 stroke health professionals working in integrated stroke/vision services. These interviews revealed that there was an aim to undertake an initial vision assessment within one week of stroke onset/admission [33]. However, in a slightly earlier study by the same group, a survey of 548 stroke health professionals indicated that only 41% reported assessing vision within one week of admission to the stroke unit [3,34]. In a similar survey of orthoptists across 16 different countries, approximately half (55.6%) stated that the first vision assessment was performed within 4 weeks of admission [35]. However, reports from stroke survivors indicated a delay in assessment, with many experiencing late or no referral to vision services [3,10].

Advanced search:
Search #1 – (stroke[MeSH Terms]) OR (stroke rehabilitation[MeSH Terms])
Search #2 – (vision disorders[MeSH Terms]) OR (visual impairment[MeSH Terms]) OR (eye disease[MeSH Terms])
Search #3 - #1 AND #2 Filters: from 2008 – present

Figure 1. Example search strategy for PubMed database.

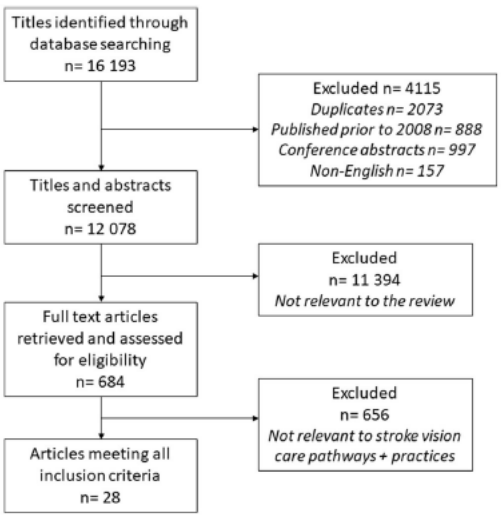


Figure 2. Flowchart demonstrating the pathway for included articles.

There is a large amount of variability in reports of how vision screening is performed. Orthoptists report most frequently testing visual acuity, using standardised letter charts, visual fields, ocular alignment and ocular movements when assessing stroke survivors [35]. From reports of stroke health professionals in the UK, 22% use a screening tool to test vision, 39.5% tested visual acuity (method unspecified), 57.7% tested visual fields, 48.5% assessed ocular movements, and 58.5% tested functional vision [3,34]. When vision screening was performed by an occupational therapist, this consisted of visual attention and scanning testing, visual field assessment and visual tracking [36,37] or use of an occupational therapist vision screening tool [38]. Another group of health professionals within a Danish stroke vision team, described by Norup et al. [37], variously assessed cranial nerve function, neuro-ophthalmic reflexes, eye movements, visual fields and inattention (neurologist); balance, gait/posture, eye movements, hand-eye coordination, ability to measure distance, vestibular-ocular reflex, hemianopia, diplopia and neglect (physiotherapist); visuoperceptual and visuo-spatial difficulties (neuropsychologist) [37].

When determining which health professional typically performs vision screening and assessment, each study illustrated different protocols indicative of the structure of the respective hospital departments/units. In the UK, orthoptists reported that the first vision assessment for stroke survivors was usually performed by an orthoptist (87%) in the eye clinic (78.6%) [35]. In all but one National Health Service (NHS) Trust surveyed by Rowe and colleagues (2013), stroke survivors had initial screening performed by a stroke team who had been trained by an orthoptist. Similar referral protocols were followed by other stroke services, whereby any need for secondary vision assessment was referred to an orthoptist [33] or other eye-care professionals [38].

Studies conducted in Australia found that vision assessment by non-orthoptic health professionals identified only 17% of the ocular conditions detected by an orthoptic assessment [39,40]. This improved to detection of 62% of all ocular conditions [39] and a sensitivity of 67% [41] with the use of a vision screening tool. It was also found that the availability of hospital on-site outpatient eye care did not significantly increase the number of ocular problems detected in stroke survivors when compared to those hospitals without any ophthalmology services [40].

Management & referral

Reports from both orthoptists [42] and occupational therapists [36] in Scotland indicated that only 14% and 9%, respectively, had vision protocol or management plans specific to stroke patients in their stroke unit. In the UK, 13/14 NHS Trusts indicated that they use a standardised screening and referral form for post-stroke vision care [3]. There were also notable differences in referral patterns and the health professionals involved in post-stroke vision care between countries. Stroke services within the UK often had orthoptic-led post-stroke vision care services [33,42,43] or the capacity to refer directly to an orthoptist when visual problems are suspected [3,44]. In the Danish service model described by Norup et al. [37] stroke patients with visual deficits that affect daily living (e.g. visual field loss, loss of vision and eye movement abnormalities) were referred to an OT. Stroke patients with vision problems affecting balance and mobility were referred to a physiotherapist, and those with visuo-perceptual or visuo-spatial issues were referred to a neuropsychologist [37].

An American study interviewed stroke survivors and their carers, who reported that they either saw an ophthalmologist, occupational therapist or "other" unidentified care provider for their visual concerns [45]. Ophthalmologists were seen for the provision of magnifiers, glasses or patching/occlusion. Occupational therapists addressed visual concerns with scanning, gaming, and eye-hand coordination activities, while other healthcare professionals provided compensation techniques and therapy [45,46]. Australian studies were conducted across a select number of stroke facilities across Sydney [39–41], and so could not provide generalisable information on referral patterns or which health professionals were typically involved in post-stroke vision care. However, when the management of vision problems by orthoptists was compared to non-orthoptic inpatient staff in the participating stroke services, orthoptists more frequently provided referrals and intervention to stroke patients [40,41].

Provision of treatment was also highly variable in all studies. Orthoptists (65.2%) [35] and other health professionals (46.5%) [34] would only occasionally treat stroke patients who had an eye condition but without visual symptoms. However, when asked about the provision of treatment for stroke survivors with vision problems, most occupational therapists (75%) report providing treatment within 6 weeks of stroke [36]. It should be noted that the occupational therapists participating in this survey indicated similar frequency of use of the same treatment methods across all categories of visual conditions, suggesting that treatment did not vary according to the specific vision problem.

Interviews with stroke survivors in the UK suggest that the majority did not receive any treatment or ongoing community support for their vision problems [3,10,11,47]. The most common types of treatment provided across studies were functional and vision advice [34,35,42,48] and scanning and or reading strategies [34,37,48]. Other treatment options provided were prisms for diplopia [35], monocular patching [35,45], prism adaptation [37,48], and magnifiers/low vision aids [45]. Studies that examined the provision of post-stroke vision care by orthoptists demonstrated more frequent use of management strategies such as feedback and advice, occlusion, lid taping, driver standard management, visual scanning, convergence training, and recommendation for adaptive technologies/low vision aids [40,49]. Approximately half

of the participating services in UK studies also keep a database of all referrals to ensure all patients receive appropriate assessment and follow-up [3,33].

Education & information

The education of healthcare professionals and the provision of vision-specific information to stroke survivors is a recurrent theme in the literature [3,11,33–36,47]. Health professionals from integrated stroke and vision services in the UK highlighted accurate and ongoing vision training for multi-disciplinary members of the stroke team as important for quality of service [33]. Of 548 stroke health professionals surveyed in the UK, 20% rated their knowledge of visual problems as fairly poor or very poor [3] while 24% of Scottish occupational therapists report having no specific training on post-stroke vision problems [36]. This suggests that approximately one in five health professionals within the UK tasked with providing vision care to stroke survivors do not have the appropriate knowledge base and/or training to do so. This is reiterated in the experience of stroke survivors in Norway and the UK, where they reported a lack of awareness among healthcare professionals [11,47] and inappropriate solutions suggested for their vision problems [11].

Stroke survivors in the UK also report that the provision of information about their vision problems was related to the knowledge and experience of their treating health professionals [10,12,47]. Where these were non-eye care trained staff, little to no information was provided [47]. Similarly, stroke survivors in Norway report poor information provision, particularly relating to vision rehabilitation options and support services [11]. The majority of orthoptists (85.9%) do provide patients with visual information sheets [35], however, a study of UK stroke health professionals (mixed disciplines) showed that 33.5% did not provide visual information sheets [34]. In addition to providing vision information sheets, half of the participating services in the UK study by Rowe et al. [33] provided lay summaries to the stroke team as well as to patients and carers. These summaries included information about the patient"s vision problem, treatment needed and provided, as well as required follow-up [33].

Reported barriers & unmet care needs

Stroke survivors and health professionals alike report a number of barriers to accessing and providing appropriate post-stroke vision care. Stroke survivors in the UK and Norway identify visual impairment as a "hidden disability", making it difficult to obtain adequate vision care in acute or rehabilitative stroke care setting [10,11]. Stroke survivors in general, reported experiencing a general lack of awareness and support amongst health care professionals relating to their post-stroke vision problems, coupled with poor provision of information about vision in general and support services [3,10,11,44,47].

Stroke health services often do not have access to vision care specialists in the stroke unit and deemed a lack of funding as one of the primary barriers to providing this service [3,33,42]. A lack of funding was also said to impact capacity for orthoptic cover when services relied on a single orthoptist or eye care professional [33]. Where services are only able to provide one session per week, there was a perceived risk of missing patients and not being able to screen all patients in a timely manner [33]. Other factors deemed important by health professionals to the success of stroke vision services were adequate training of multi-disciplinary team members [3,33], use of a standardised protocols or management plans [34,36,42] and support from stroke physicians [33].

There is also evidence of a lack of awareness about stroke-related vision problems amongst the general community and health professionals when investigating pre-hospital pathways for stroke sufferers. A study by Aroor et al. [50] found that amongst the stroke sufferers that did not have any symptoms relating to the F.A.S.T. pneumonic, 40% had visual presenting symptoms. Of the 14.1% of patients with missed stroke diagnosis according to F.A.S.T., 9.7% could have been identified with the inclusion of balance and vision screening [50]. Raty et al. [51] found that 11.4% of occipital stroke patients with isolated visual symptoms were frequently misdiagnosed and/or frequently arrived to ED through at least 2 points of care (27.3%). As such, these patients are more likely present to emergency services outside of the 4.5-h eligibility window for IV thrombolysis [51]. Stroke survivors themselves also report being unaware of vision symptoms as part of the stroke syndrome [11] and attributing them to other causes [10,11,52].

Other barriers identified by focus groups of stroke survivors and health professionals in addition to those related to funding and education included poor communication and poor transfer of patient information between teams, and limited access to vision care appointments [44]. Stroke survivors reported that the impact of post-stroke visual impairment could have been improved by early formal visual assessment, provision of management and advice on adaptive strategies and rehabilitation options [10,11].

Discussion

The main themes identified in the available literature relating to post-stroke vision care pathways and practices are: screening and assessment, management and referral, education and information, barriers and unmet care needs. Within these themes, more specific questions were explored in relation to the timing of each theme, which healthcare professionals are and should be involved, as well as the specificity of care provision. There is very limited evidence pertaining to Australian post-stroke vision care pathways and practices, with a large portion of the existing evidence base originating in the UK and varying in methodology and study population. Thus, at this stage, it is not feasible to perform a systematic review of the evidence on this topic. Without formal investigation, it is difficult to know whether Australian stroke survivors with vision problems are receiving adequate care, if any at all. Barriers to successful post-stroke vision care and existing unmet care needs must be identified to understand the nature of current pitfalls in post-stroke vision care services and enable improvement. Based on the results of one NSW health district, it would appear that inequalities in vision care for stroke survivors do exist within the healthcare system, largely dependent on access to orthoptic services [40].

While the evidence related to the structure and protocols of each service demonstrates large amounts of variability in current practice around the world, similar trends have emerged in relation to their successes and failures. The strongest message to emerge from this evidence is the need for the implementation of a vision care pathway or framework specific to Australian stroke survivors that offers clear guidance on how care should be provided, by whom, and when. In addition to this, a greater focus on stroke-related vision problems is needed within stroke care teams to improve knowledge through the provision of education in this area [34,36]. Nationwide campaigns targeting awareness of stroke-related vision problems among the general Australian

population are also necessary moving forward, so that those suffering a stroke recognise the importance of stroke-related visual symptoms.

Studies concerning vision and ocular health assessment suggest that initial vision screening should be performed in the stroke unit on all stroke patients [3,39,40]. It is evident that this does not happen consistently across Australia and internationally, if at all. Reasons for this may relate to inadequate funding to facilitate appropriate staffing to carry out these assessments [43], as well as a lack of expertise and/or training amongst stroke care teams [33,51]. Differences in the timing of vision assessment between studies may also relate to evolution in services over time and the type of stroke service from which participants were recruited. For example, the VIS study ran from 2006–2010 with recruitment mainly from outpatient services, while the IVIS study ran from 2014–2015 and recruited participants primarily from inpatient services.

Vision screening tools specific to stroke patients appear to be a viable option to address this gap in the initial stages of stroke vision care. Several studies have found that vision screening tools improve the identification of ocular conditions in stroke survivors, even when administered by non-eye care professionals [39,41,53,54]. The efficacy of these tools is proven to be enhanced when appropriate training on the use of the tool is provided [39,41,53,54]. A number of different non-eye care professionals such as occupational therapists, nurses, and physiotherapists are assigned the role of carrying out vision assessment across stroke services. While it is important to acknowledge the value of such professionals being able to identify and manage certain eye conditions, orthoptists appear to be an underutilised resource within stroke care teams. This may, in part, be explained by the difference in the availability of orthoptists and orthoptic training programs between countries. Orthoptics degrees are offered at four universities within the UK, while the USA has a limited number of post-graduate fellowship training positions available, and Denmark does not have any orthoptic training. In Australia there are two universities offering either undergraduate or postgraduate orthoptic degrees. Research has shown orthoptic led assessment to be the gold-standard in stroke vision care and their inclusion in stroke teams may help address gaps in provision of information and vision rehabilitation [3,39,40,55].

The literature reviewed suggests that limited management options for vision problems are provided to stroke patients [10,32,45]. This may be due to: the perceived potential for recovery of some stroke-related vision problems within three to 6 months post-stroke, the visual problems not being detected, or the absence of an available and appropriate care provider. However, when considering the negative impact vision problems can have on rehabilitation [55–57], basic interventions should be provided as early as possible as a minimum. Of the services that reported providing management, the most common strategies used were advice, magnifiers, monocular patching and visual scanning training [32,37,48]. Simple interventions such as these may assist stroke survivors in participation of other rehabilitation activities and ease the burden of vision impairment in the acute stages of recovery, even though they do not cover the entirety of possible beneficial interventions.

Delivery of quality vision care requires appropriately trained staff as well as appropriately targeted provision of information to patients and carers. The provision of clear and targeted information that is specific to the stroke survivor"s visual impairment is seen to be a valuable and empowering form of management [10,11,45,47]. Stroke survivors and their carers should be directed to appropriate long-term care providers and vision support services prior to discharge from the hospital in order to better assist the stroke survivor"s reintegration into the community. Provision of such information is reportedly done to differing levels of success across the different services described.

There is limited evidence pertaining to the provision of vision care for stroke survivors in Australia and internationally. The pooling of data from different countries and, as such, different health services also make it difficult to draw firm conclusions about current practices. In the UK, a stroke-vision care pathway has recently been developed in an attempt to address the known gaps in this area of healthcare [44]. Such a pathway enables stroke sufferers and health professionals alike to be aware of the options and appropriate actions to take in response to stroke-related vision problems. Implementation of stroke clinical pathways has also been shown to improve the coordination of multidisciplinary care, and reduce the length of hospital stays and overall healthcare costs [58].

The lack of evidence and specified guidelines concerning post-stroke vision care within Australia may be an indication that Australian post-stroke vision care has similar pitfalls to those found internationally. As the Australian Clinical Guidelines for Stroke Management [27] are based on and updated according to the publication of relevant systematic reviews and large randomised controlled trials, it is likely that the limited inclusion of vision specific guidelines is related to a lack of high-quality evidence in this area. While we can look to research such as that conducted in the UK as an example, the unique demographic and geographic characteristics of Australia need specific and targeted requirements for a healthcare framework to be successful [59–61]. The development of a stroke-vision care pathway that is appropriate for implementation in Australia may begin to address the unmet care needs across different services and locations of the many Australians who suffer from stroke-related vision problems. Future research should aim to describe and assess potential gaps in the current provision of stroke-vision care within Australia and work towards developing pathways that are appropriate, feasible, and targeted to the needs of stroke survivors and those that care for them. As it stands, current post-stroke vision care pathways and practices in Australia and internationally remain varied and non-standardised. There is evidence of unmet care needs and several gaps in care provision for stroke survivors with vision impairment, particularly in the areas of information provision, referral and long-term management.

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11.22 LICENSES & PERMISSIONS FOR THIRD PARTY MATERIAL

11.22.1 Snell & Lemp (2013)

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