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

### IMPROVING VISUAL REHABILITATION FOR STROKE SURVIVORS

Primary Supervisor: Professor Kathryn Rose

Co-Supervisor: Dr Amanda French, Professor Fiona Rowe

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

Discipline of Orthoptics Graduate School of Health University of Technology Sydney October 2022

Shanelle Sorbello

BMedSci | MOrth

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.

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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   |
|--------------------|---|
|                    | 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          |
| Shanelle Sorbello  | (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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|                    | Production Note:  |
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|                    | prior to publication.   |
| 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.

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

#### 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 Deltavariant 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**

<u>Sorbello S</u>, 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

<u>Sorbello S</u>, 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

#### **Conference Presentations**

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

**Sorbello S**, French A, Rose K. (2019) Post-stroke vision care in NSW: what are the care pathways and are they working? *76<sup>th</sup> Orthoptics Australia Annual Scientific Conference*, Sydney, Australia.

**Sorbello S**, French A, Rowe F, Rose K. (2019) Determining the post-stroke vision care pathways in NSW: Feasibility and preliminary outcomes. *29<sup>th</sup> Annual Scientific Meeting of the Stroke Society of Australasia*, Canberra, Australia.

**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.

<u>Sorbello S</u> (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.

**Sorbello S**, French A, Rowe F, Rose K. (2021) Stroke survivor experiences of care for visual impairment after stroke in NSW. 77<sup>th</sup> Orthoptics Australia Annual Scientific Conference, virtual.

**Sorbello S**. (2021) Current post-stroke vision care in NSW: are we doing it right? *Orthoptics Australia Live Journal Club*, virtual.

<u>Sorbello S</u>, French A, Rowe F, Rose K. (2022) The experience of vision impairment among stroke survivors in NSW. *The 14<sup>th</sup> International Orthoptic Association Congress*, virtual.

#### **Awards and Honours**

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Emmie Russel Prize at the 76th Orthoptics Australia Annual Scientific Conference, Sydney, Australia.

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#### 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

L-POST

Leuven Perceptual Organisation Screening Test

TVPS-3

Test Of Visual Perceptual Skills — 3<sup>rd</sup> Edition

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

Al 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.

by movement of the visual field. This is seen when an individual tracks a moving object (slow phase movement), and once the

Prism bar cover test

object moves out of the field of vision, the eyes move back to the point where they first saw the object (fast phase movement). 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. Inflammation of the cornea.

Keratitis

Keratopathy Hemianopia

Loss of sight in one half of the visual field.

Damage or degradation of corneal tissue.

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.

A type of refractive error where the object of fixation Hyperopia

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

Ocular movements where the eyes move in the same direction to movements

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. The head of the optic nerve at the back of the eye, when viewed Optic disc cupping 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'. A visual field defect where the area of visual field loss occurs in Homonymous (visual field defect) the same half of the visual field in both eyes, e.g., loss of the left side of the visual field in both eyes. Used to describe a visual field defect that is identical in both Congruous 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. Inability to bring the eyes into a particular gaze (e.g., inability to Gaze palsy look up or down = vertical gaze palsy). Outward drooping of the eyelid or drooping of the eyelid where **Ectropion** 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 poststroke 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.