Uses of Self-management for Stroke Rehabilitation

by

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Thesis submitted in fulfilment of the requirements for the degree of

Doctor of Philosophy (Public Health)

under the supervision of

- Professor David Sibbritt
- Distinguished Professor Jon Adams
- Doctor Wenbo Peng

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Certificate of Original Authorship

I, *Md Sazedur Rahman*, declare that this thesis is submitted in fulfilment of the requirements for the award of Doctor of Philosophy (Public Health), in the Faculty 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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Format of This Thesis

This thesis is organised in the Thesis by Compilation format, representing an integrated body of work that incorporates both conventional thesis chapters and published/publishable articles. Consistent with the structure of a Compilation Thesis, this work integrates unabridged content from articles generated by the project, whether published or submitted for publication, into the pertinent chapters of the thesis. In such cases, a chapter preamble and relevant annotations have been included to specify publication details. The subsequent section presents a listing of the articles and authorship contributions.

Published/Publishable Works Incorporated into the Thesis

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3. Rahman MS, Adams J, Peng W, Sibbritt D. The effect of a healthy lifestyle on reducing the utilisation of healthcare professionals and prescription medications among stroke survivors: a longitudinal investigation using linked administrative data. *Disability and Rehabilitation*. 2024. (Under Review).
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Statement of Contributions of Authors

I am the primary author of all the articles incorporated in this thesis. The research papers have been submitted to peer-reviewed journals for publication. I was primarily responsible for determining the research question, analysing the data, interpreting the findings, drafting the manuscripts, and managing the submission procedures. Support in all these areas was provided by my supervisors, Professor David Sibbritt, Distinguished Professor Jon Adams, and Doctor Wenbo Peng.

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List of Abbreviations and Acronyms

TIA	Transient ischemic attack
CDSM	Chronic Disease Self-Management Program
PROSPERO	International Prospective Register of Systematic Reviews
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PRISMA-ScR	Preferred Reporting Items for Systematic Reviews and Meta-Analyses - Extension for Scoping Reviews
PAM	Patient Activation Measures
MNOS	Modified Newcastle-Ottawa Quality Assessment Scale
CASP	Critical Appraisal Skills Programme
HADS	Hospital Anxiety and Depression Scale
SLT	Speech and Language Therapy
mRS	Modified Rankin Scale
PAM	Patient Activation Measures
SSRS	Social Support Rating Scale
ArmA	Adapted Version of the Arm Activity Measures
COPM	Canadian Occupational Performance Measure
SSEQ	Stroke Self-efficacy Questionnaire
DLSES	The Daily Living Self-Efficacy Scale
5Q-5D-3L	The three-level version of the EuroQol five-dimensional questionnaire
CES-D-10	10-item Center for Epidemiologic Studies Depression Scale
MFIS-5	Modified Fatigue Impact Scale-5 item
mRS	Modified Rankin Scale
IADLs	Instrumental activities of daily living
NIHSS	National Institute Health Stroke Scale
PCCQ	Patient Continuity of Care Questionnaire
SD	Standard Deviation
BMI	Body Mass Index
WHO	World Health Organization
NSW	New South Wales
HBM	Health Belief Model

TTM	Transtheoretical Model
CCM	Chronic Care Model
HREC	Human Research Ethics Committee
ANOVA	Analysis of Variance
GEE	Generalised estimating equation
OR	Odds Ratios
AOR	Adjusted Odds Ratio
IRR	Incidence Rate Ratio
AIRR	Adjusted Incidence Rate Ratio
CI	Confidence Interval
MBS	Medicare Benefits Schedule
PBS	Pharmaceutical Benefits Scheme
GP	General Practitioners
ALSWH	Australian Longitudinal Study on Women's Health
PCS	Physical Component Summary
MCS	Mental Component Summary
SF-36	Short Form 36 Health Survey Questionnaire
PF	Physical Function
BP	Bodily Pain
RP	Role Limitations due to Physical Health Problems
GH	General Health
SF	Social Functioning
RE	Role Limitations due to Emotional Problems
MH	Mental Health
MET	Metabolic Equivalent
VIF	Variance Inflation Factors
DAG	Directed Acyclic Graph

Abstract

Background

Self-management has emerged as a promising and integral strategy within the broader scope of long-term rehabilitation after stroke, particularly in the context of ongoing recovery. The adoption of a healthy lifestyle is increasingly recognised as a critical component of the self-management strategy for long-term rehabilitation process. However, research focused on the utilisation of self-management strategies among individuals living with the chronic effects of stroke remains limited and is in its early stages. The primary objective of my thesis was to undertake an in-depth examination of the utilisation of self-management for long-term rehabilitation after stroke.

Methods

My research program included a scoping review and three quantitative longitudinal analyses. For the scoping review, I used a narrative synthesis methodology to investigate the utilisation of self-management strategies and the experiences of individuals with stroke. By utilising data from the 45 and Up Study linked to Medicare Benefits Schedule and Pharmaceutical Benefits Scheme data, two longitudinal studies were conducted to explore the determinants of adopting healthy lifestyle behaviours and the impacts of healthy lifestyle behaviours on healthcare utilisation of individuals with stroke. To examine the impacts of maintaining a healthy lifestyle on physical and mental health outcomes of female survivors of stroke, another longitudinal study was performed using data from the Australian Longitudinal Study on Women's Health (ALSWH). Lifestyle behaviours included physical activity, alcohol consumption status, smoking status, and nutritional supplement use. Longitudinal associations between the dependent variable and independent variables were assessed using Generalised Estimating Equation models.

Results

The scoping review revealed a range of self-management strategies used by survivors of stroke for their rehabilitation, identifying lifestyle modifications or the maintenance of a healthy lifestyle as a prevalent approach. My longitudinal analyses included a total of 1107 survivors of stroke (576 form 45 and Up Study and 531 from ALSWH). Longitudinal analyses identified several significant determinants, such as depression and diabetes, influencing healthy lifestyle behaviours among Australian survivors of stroke. Notably, survivors of stroke maintaining moderate-to-high levels of physical activity were significantly less likely to seek care from a general practitioner (AIRR: 0.85; 95% CI: 0.78, 0.92; $p<0.001$), a nurse (AIRR: 0.77; 95% CI: 0.63, 0.93; $p=0.008$), and an allied health professional (AIRR: 0.73; 95% CI: 0.61, 0.86; $p<0.001$), as well as to use blood-thinning medications (AIRR: 0.86; 95% CI: 0.76, 0.97; $p<0.05$). Smokers among those with stroke exhibited a higher likelihood of receiving care from a specialist doctor (AIRR: 4.50; 95% CI: 1.21, 16.78; $p<0.05$). Furthermore, longitudinal analyses showed that female survivors of stroke who adhered to healthy lifestyle behaviours reported significantly better physical and/or mental health than those who did not.

Conclusions

My thesis provides a comprehensive understanding of the utilisation of self-management strategies for long-term rehabilitation after stroke, with a particular emphasis on the maintenance of a healthy lifestyle. The findings offer evidence-based insights that can guide policymakers and healthcare professionals in enhancing post-stroke care, suggesting that survivors of stroke may benefit from additional support in adopting and/or maintaining a healthy lifestyle as an ongoing component of their long-term management and recovery.

Chapter 1: Introduction

Stroke stands as a prominent contributor to both mortality and disability among adults globally. My thesis undertakes an examination of the utilisation of self-management in long-term rehabilitation after stroke. In my thesis, "long-term rehabilitation after stroke" refers to an extended period of ongoing recovery following initial professional rehabilitation, during which survivors use self-management strategies to prevent additional strokes and enhance their physical and mental health. Chapter 1 introduces several key topics, including an overview of stroke, its types, prevalence, risk factors, and consequences, as well as the concept of long-term rehabilitation after stroke, the role of self-management and a healthy lifestyle in this process. In addition, this chapter highlights the importance of focusing on female survivors of stroke, who often face distinct obstacles in their recovery as a result of biological, social, and health-related factors. Focusing on female survivors of stroke is crucial to reveal gender-specific long-term outcomes of self-management use. Moreover, this chapter includes the current utilisation of health services for stroke rehabilitation in Australia, and it concludes with the formulation of research questions that guide the subsequent analyses.

1.1 Stroke: Definition, Prevalence, and Risk Factors

A stroke is defined as the sudden appearance of symptoms indicative of localised neurological dysfunction, lasting for more than 24 hours or leading to an earlier death[1]. It is caused by an interruption of blood flow to the brain either by artery blockage or rupture[1]. When the brain cells are deprived of oxygen and nutrients due to the lack of blood supply, the brain cells begin to die and stop functioning[2]. The impact of a stroke can vary considerably, with potential outcomes ranging from complete recovery to severe disability or death[3]. Strokes are classified within the broader category of cardiovascular disease[1].

Stroke symptoms include trouble speaking or understanding or experiencing sudden confusion; paralysis or numbness in the face, arm, or leg, especially on one side of the body; difficulties with swallowing; abrupt loss of vision or difficulties seeing in one or both eyes; severe headaches with no apparent reason; sudden nausea or vomiting; and a sudden loss of balance, dizziness, or difficulty walking[4–6].

Strokes are primarily classified into three types: 1) Transient ischemic attack (TIA), 2) Ischaemic stroke, and 3) Haemorrhagic stroke[3,7,8]. A TIA is a short interruption of blood flow to the brain, usually caused by a clot, that normally recovers on its own, and the stroke symptoms resolve, but it is an important warning indicator of future stroke[3,7,8]. An ischemic stroke happens when the blood flow to a portion of the brain is abruptly interrupted or cut off, typically as a result of a blood clot or plaque in the cerebral artery[3,7,8]. Ischaemic stroke is estimated to account for between 62.4% and 91% of all strokes[9,10]. Haemorrhagic stroke occurs when a blood vessel bursts or a blood vessel leaks into the brain[3,7,8]. Haemorrhagic strokes are classified into three types: subarachnoid or subdural haemorrhage (rupture of an artery on the brain's surface), parenchymal or intracerebral haemorrhage (bleeding directly into brain tissue), and intraventricular haemorrhage (bleeding into or around the ventricles)[3,7,8]. Over the last two decades, the global burden of haemorrhagic stroke has increased[10]. Every stroke is different and different strokes may have different degrees of severity and consequences[3,7,8].

While age-standardised stroke prevalence and mortality rates have fallen over the last three decades as a result of improved cardiovascular disease prevention and acute stroke care, the absolute number of stroke incidents and deaths are increasing due to many reasons, including increased average life expectancy, population growth in the majority of countries, advances in acute stroke treatment and increased prevalence of potential risk factors for stroke[10–12]. The absolute number of stroke incidents grew by 70% between 1990 and 2019[10]. In 2020, there were approximately 445,087 Australians who had survived a stroke, with around 27,428 individuals experiencing a first-ever stroke each year, resulting in long-term physical and mental disabilities that place a significant burden on their families, communities, and the country's healthcare systems[13]. By 2050, it is expected that Australians will face 50,600 new strokes each year, and the number of stroke survivors living in the community will reach 819,900, marking a 45.7% increase from 2020[13]. As a new stroke occurs every 19 minutes in Australia, if no action is taken, this frequency is projected to rise to one new stroke every 10 minutes by 2050[13].

There are a variety of non-modifiable and modifiable risk factors for stroke. Age, gender, family history of stroke, hormones, past history of stroke, and race/ethnicity are non-modifiable risk factors, whereas hypertension, diabetes, smoking, obesity, unhealthy diet, high cholesterol, heavy or binge drinking, and physical inactivity are some identified modifiable risk

factors[2,10,14–18]. Some stroke risk factors, such as pregnancy, childbirth, and menopause, can only apply to women[17]. Congenital heart disease, head trauma, anaemia, being male, blood-clotting difficulties, premature birth, maternal drug usage, and maternal medical issues such as infections are risk factors for stroke in children[17].

The risk of stroke is 2-4 times greater in persons with hypertension than in those without hypertension[17]. Furthermore, the likelihood of stroke among people with diabetes is approximately 2.60 times higher than non-diabetic people[19]. However, approximately 90% of all strokes can be attributed to 10 risk factors, including physical inactivity, hypertension, diabetes, smoking, alcohol consumption, diet risk score, waist-to-hip ratio, cardiac causes, depression, and the ratio of apolipoproteins B to A1[14].

1.2 Impacts of Stroke

Stroke is a major cause of disability and mortality in adults worldwide[10]. A stroke has long-term physical, mental, emotional, behaviour, communication, social and financial consequences[10,20–50]. Among acute hospitalisations in neurology departments, stroke is the most common reason for admission[34]. In 2019, there were more than 101 million patients with stroke worldwide[10]. Among the stroke patient population, generally, 30% die within a year, 35% face long-term severe disability, 25% suffer from mild to moderate disabilities, and only 10% achieve complete recovery[35]. Stroke was the second major cause of mortality (11.6% of total deaths) and the third major cause of mortality and disability combined in 2019[10]. Only around 20% of the individuals with stroke survive ten years after the first stroke[23,36].

There are numerous long-term physical and psychological complications associated with stroke, including impaired movement, fatigue, poor concentration, falls, loss of function of the upper limb, problems with swallowing, aphasia, cognitive problems, and depression[10,20–33]. Weakness (paresis) or paralysis (plegia) are the most common results of a stroke, and these can affect just the face, an arm, or a leg, or one entire side of the body and face[17]. Confusion, memory deficits, and problems with thinking/awareness are also common phenomena in stroke survivors[17,26,37]. Visual impairment may affect approximately two-thirds of stroke survivors[27,38]. Stroke survivors (15-49%) usually suffer pain (e.g., shoulder pain, headache, central post-stroke pain), numbness, and abnormal sensations[17,29]. Another detrimental effect of stroke is slurred speech (dysarthria)[21]. More than a quarter of survivors of stroke suffer from

post-stroke anxiety[39]. Post-stroke depression is a major medical condition that frequently impairs rehabilitation and is associated with suicidal thoughts[26,31]. Actually, a large proportion cannot return to work after a stroke[38]. Around 58% of stroke survivors are functionally dependent on others[32]. As the physical and psychological consequences of a stroke are typically complex and long-lasting, people with stroke often require long-term assistance and care[37-47].

Many survivors of stroke require help with basic daily tasks (e.g., showering, clothing, and toileting) from family members[44–47]. Therefore, family members suffer from long-term consequences such as social isolation, physical and psychological problems, financial burden, and a reduction in quality of life[37,48]. For example, among caregivers of people with stroke, more than 40% experience depressive symptoms and 21% experience anxiety symptoms[48]. Moreover, the risk of stroke recurrence is 3.1%, 11.1%, 26.4%, and 39.2% within one month, one year, five years, and ten years, respectively, after the initial stroke, which is responsible for a higher risk of physical and intellectual disability as well as death compared to the primary stroke[49]. Stroke has a detrimental effect on family relationships (5-54%), sexual life (5-76%), leisure activities (15-79%), and can create economic hardships (24-33%). Survivors of stroke have a very poor overall quality of life[24,33,50] . The healthcare costs associated with the treatment and rehabilitation of stroke are becoming increasingly large[13,22]. The annual financial cost of stroke in Australia surpassed $6.2 billion in 2020, in addition to $26.0 billion in lost productivity resulting from both short-term and long-term impairments as well as premature mortality[13].

1.3 Stroke Rehabilitation

Rehabilitation is a process that assists a person with a medical condition in regaining, maintaining, or improving physical, mental, or cognitive abilities affected by a disease or an injury or as a side effect of medical treatment[51]. According to the World Health Organisation (WHO), rehabilitation can be defined as *"a set of interventions designed to optimise functioning and reduce disability in individuals with health conditions in interaction with their environment"*[51]. The realisation of potential, re-enablement, resettlement, role fulfilment, and readjustment are the key purposes of rehabilitation[52]. Rehabilitation can greatly lessen the impact of a wide variety of health issues and can also be used in conjunction with other interventions, such as medical and surgical procedures, to assist in achieving the best possible

outcome[52]. Therefore, it is important to improve health wellbeing, disease prevention, disease management, treatment and long-term care[52-55].

Rehabilitation is an important part of stroke care[51-55]. Stroke rehabilitation is a process that aims to prevent functional disability, restore functional capability, and maximise the independence (e.g., fulfilling personal roles) of people with chronic stroke[53-55]. Stroke rehabilitation is not synonymous with stroke recovery. Stroke recovery can be described as an improvement in a variety of indicators, beginning with biological and neurologic changes detected by performance and activity-based behavioural assessments[52]. Stroke recovery can be partial or fully functional recovery. Stroke rehabilitation is a way of achieving stroke recovery.

Stroke rehabilitation can occur in different settings, including inpatient, outpatient, community-based, or home-based rehabilitation[53-55]. Inpatient rehabilitation typically begins as soon as the patient is medically stable—often within 24 to 48 hours after a stroke—and aims to maximise recovery through intensive, multidisciplinary therapy[53-55]. Outpatient rehabilitation provides structured therapy sessions in a clinical setting[53-55]. Community-based and home-based rehabilitation programs offer ongoing support in less formal environments, helping survivors of stroke regain function, maintain independence, and adopt self-management strategies for long-term recovery[53-55]. However, despite the availability of these options, many survivors of stroke—even in high-income countries—face challenges in accessing or receiving sufficient professional rehabilitation, particularly inpatient and outpatient services[53-55]. A significant proportion of patients with stroke do not receive the recommended amount of rehabilitation due to factors such as limited resources, high costs, and geographic barriers[53-55]. However, incorporating self-management interventions into community-based and home-based rehabilitation programs can empower survivors of stroke to take an active role in their recovery[53-55].

1.3.1 Long-Term Rehabilitation after Stroke

While traditional stroke rehabilitation refers to a time-limited phase of therapeutic interventions provided by health professionals—typically within the first 3–6 months—the recovery process for many survivors of stroke extends far beyond these initial stages[39–43,47,53–55]. As discussed in

Section 1.2, although stroke is a sudden-onset acute cerebrovascular event, it often results in numerous long-term consequences.

Long-term rehabilitation after stroke is a relatively new concept in the field of long-term post-stroke care, focusing on the ongoing recovery process and managing the survivor's health over an extended period, often continuing throughout their lifetime[39–43,47,53–55]. In my thesis, the term 'long-term rehabilitation after stroke' describes this continuous recovery process. This broader conceptualisation acknowledges that survivors of stroke continue to face health challenges throughout their lives, with recovery potentially spanning many years or even lasting until the end of life.

The early phases of stroke rehabilitation primarily focus on regaining lost function through professional therapy. In contrast, long-term rehabilitation emphasises the survivor's sustained efforts to manage symptoms, prevent secondary complications and further strokes, and enhance physical and mental health[39–43,47,50,53–55]. This phase involves both professional care and the survivor's active participation in maintaining their health and improving their quality of life[39–43,47,50,53–55]. Therefore, long-term rehabilitation is an essential component of care for individuals living with chronic stroke. Globally, demand for long-term rehabilitation is anticipated to increase as a result of longer life expectancy, an increase in the number of individuals living with chronic disease and disability and expanding populations[52].

1.3.2 Self-management for Long-term Rehabilitation after Stroke

The terminology "self-management" is frequently used as a technique for managing and improving chronic conditions in the health literature[56]. The Chronic Disease Self-Management Program at Stanford University introduced the concept of self-management for the first time in the 1990s[57]. While terms such as self-care, self-management, self-regulation, and self-monitoring are usually used interchangeably, self-care is the most commonly used as a synonymous terminology for self-management[58]. However, the concept of self-management or self-care is now well-established in modern healthcare practice[57], but still there is no universally accepted definition of self-management or self-care[59]. Barlow et al[58] defined self-management as 'an individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition'. It is a development process by individuals to maintain, monitor, prevent, and manage chronic

conditions through the practice of a healthy lifestyle, behaviors and activities, and medical and pharmacological interventions[60]. It includes medical management, role management, and emotional management of the chronic condition[45,61,62].

Five critical self-management skills have been identified as problem-solving, decision making, resource management, developing a relationship with a health professional, and taking appropriate actions[62]. Self-management is not solely a patient-driven process; it is impacted by a variety of factors, including healthcare providers, family, friends, and society[56]. Successful self-management for long-term conditions requires an integrated approach that includes active participation of patients, family members, and healthcare practitioners[56]. It is a dynamic, everyday process to manage and treat chronic disease's physical and psychological consequences[60]. Self-management is now broadly acknowledged and recommended as a necessary component of chronic disease treatment[56]. It can significantly improve health outcomes, reducing the financial burden and extensive demands on countries' healthcare resources[59].

The concept of self-management in long-term stroke rehabilitation is relatively new. Since the mid-2000s, self-management has received attention in the field of stroke management[57]. For stroke survivors self-management can be focused on three principles: a) optimise secondary stroke prevention, achieve improvements in risk factors control and, reduce the risk of any future stroke through a healthy lifestyle and adherence to medical management, including communication with a physician, use prescribed medicine, self-blood pressure monitoring and improving lifestyle behaviours, b) improve general physical activity level through specific rehabilitative activities and exercises, and c) enhance daily living activities, and participation in social and professional roles[57]. Maintaining a healthy lifestyle, engaging in rehabilitation exercises, participating in self-management programs, increasing knowledge about stroke management, adhering to medical treatment, monitoring signs and symptoms, and setting goals for improvement are some self-management strategies for long-term rehabilitation after stroke[57,63-66]. As advised by a number of international stroke guidelines, self-management is crucial for post-stroke management and long-term recovery[65–69].

1.3.3 Healthy Lifestyle for Long-term Rehabilitation after Stroke

Given the increasing incidence and extreme socioeconomic burden of post-stroke care, there is a pressing need to explore potential cost-effective, safe, and appropriate treatment approaches for people with stroke to improve long-term rehabilitation outcomes and reduce treatment burden[28,50,66,70]. Survivors of stroke are likely to use a number of self-management strategies in addition to prescribed treatments to manage their post-stroke symptoms and challenges[66,70-72]. The most prominent self-management strategy for long-term rehabilitation after stroke is lifestyle modification or the maintenance of healthy lifestyle behaviours[66,71], which includes engaging in physical activity, abstaining from smoking, abstaining or consuming alcohol at low risk levels, and consuming a nutritious diet[65,73–75]. Adopting healthy lifestyle behaviours empowers stroke survivors to take an active role in their long-term rehabilitation[66,88]. A number of international stroke guidelines recommend that post-stroke individuals should adopt a healthy lifestyle for their longer term health promotion[65–69].

Maintaining healthy lifestyle behaviours may be a useful self-management strategy which can improve post-stroke symptoms management, functional ability, neurological recovery, prevention of secondary strokes, cardiovascular outcome, survival rate, and overall rehabilitation outcome[65,73,84,76–100]. For example, physical activity ─ which is defined as any movement of the body that involves the skeletal muscles and expends energy ─ may contribute to lower the risk of hospitalisation, long-term disability, fatigue, falls, pain, venous thromboembolism, cerebrovascular events, subsequent strokes, psychological problems, and mortality following a stroke[77,78,84–93]. Similarly, abstaining from smoking, drinking less alcohol, and taking nutritional supplements are associated with improved functional capacity, brain recovery, and physical and psychological wellbeing, as well as a lowered risk of developing other cardiovascular diseases, nutrition-related diseases, further strokes and adverse outcomes in stroke survivors[73,74,79–82,94–99]. Smoking cessation can significantly reduce mortality among stroke survivors, as two-fifths of deaths from stroke among those under 65 are linked to smoking[100].

1.4 The Importance of Focusing on Female Stroke Survivors

Stroke is a condition that impacts individuals across all demographic groups; however, females experience a higher disease burden in comparison to males[101]. While various aspects of stroke

exhibit similarities between males and females, certain gender differences and unique features exist regarding stroke epidemiology, aetiology (including risk factors and preventive remedies), and consequences[101–104]. Females may have unique risk factors for stroke, such as pregnancy-related conditions, hormonal fluctuations, and the use of oral contraceptives[102]. Besides, as the risk of suffering a stroke increases with age, females exhibit a higher incidence of strokes (due to their longer life expectancy compared to men) and a greater mortality rate resulting from strokes throughout their lifespan[102].

Females also exhibit a higher risk of experiencing severe strokes, stroke-related disability, and mortality in comparison to males[103]. In contrast to male survivors of stroke, female survivors demonstrate lower functional recovery, reduced capacity to participate in everyday activities, and an increased incidence of mental disorders[105,106]. Thromboembolic events are higher in female survivors of stroke than men[103]. Additionally, females are more likely to exhibit "nontraditional" stroke symptoms like pain, discomfort, and headaches[103]. Female survivors of stroke have substantially lower levels of health-related quality of life than male survivors of stroke[105–110].

Currently, the global population with stroke exceeds 101 million, with females comprising approximately 56% of this population[111]. Pre-existing medical conditions are more common in female stroke survivors which may affect the overall stroke rehabilitation process[101–104]. However, several factors, such as age, number of comorbidities, stroke severity, pre-stroke disability, social support, and depression can contribute to the higher rates of post-stroke disability, poorer quality of life, functional impairment, and mortality among female in comparison to male[101–104]. Hence, research that focuses on long-term rehabilitation in female survivors of stroke hold a high priority in the field of health research.

1.5 Current Health Services Use for Stroke Rehabilitation in Australia

Stroke rehabilitation is a dynamic, collaborative, and continuous procedure that aims to enhance the functional abilities, physical and emotional wellbeing, autonomy, social engagement, and secondary stroke prevention for individuals who have experienced a stroke[59,112–114]. Rehabilitation should be rapidly initiated following the stabilisation of stroke survivors, with an emphasis on achieving specific individual goals[112,113]. This should happen

within the first few days (acute phase) of a stroke and may need to be continued throughout their lifetime[113,114]. Notably, recent advancements in stroke management and outcomes have placed greater emphasis on the hyperacute (within the first 24-hour following a stroke)) and acute phases (which typically last between 24 hours and 7 days after the occurrence of a stroke) than on the subacute and post-acute phases (which involve community reintegration)[112–114]. In most Western nations, the average duration of stay in acute hospital care following a stroke is less than 7 days, thus post-stroke individuals who need rehabilitation for more than a week should be moved to an inpatient or outpatient centre or their home[115].

However, after discharge from the hospital, post-stroke treatment mostly focuses on long-term recovery approaches, such as rehabilitation provided by a healthcare practitioner, taking prescribed medications, and adopting a healthy lifestyle[53,59]. Stroke rehabilitation is a multidisciplinary effort that necessitates the collaboration of many different health professionals[53]. In Australia, a general practitioner (GP), specialised physician, nurse, and allied healthcare professional (allied mental health professionals, physiotherapists, occupational therapists, audiologist, dietitians, exercise physiologists, podiatrists, or speech pathologists) are generally included in stroke rehabilitation teams[116]. In general, stroke survivors in Australia are typically prescribed blood-thinning medications (both antiplatelet and anticoagulants), cholesterol-lowering medications, antihypertensive medications, and other necessary treatments for concurrent conditions[117].

1.6 Significance and scope of the thesis

This research is of paramount significance as it directly addresses the global challenge of long-term rehabilitation after stroke, a concern that has gained increasing prominence due to the rising incidence of strokes worldwide. In light of the long-term consequences associated with strokes, there is an escalating demand for long-term rehabilitation strategies that are not only effective but also sustainable and economically viable[28,70]. Traditional approaches, while valuable in immediate care, often fall short of providing the necessary long-term empowerment to stroke survivors[70,118]. The significance of this study lies in its focus on the exploration of self-management utilisation, designed to bridge the existing gaps, and contribute to the evolution of long-term rehabilitation practices for those with stroke. My research focuses on specific self-management strategies, particularly maintaining a healthy lifestyle behaviour such as engaging in physical activity, maintaining nutrition, abstaining from smoking, and reducing

alcohol consumption. Utilising large-scale longitudinal data, my thesis examines the determinants that influence stroke survivors' use of healthy lifestyle behaviours and assessing the long-term impacts of these behaviours on healthcare utilisation and overall wellbeing. By analysing linked health datasets, the study can identify patterns and relationships that provide insights into the effectiveness of self-management strategies over time. This study has the potential to reveal how proactive engagement in self-management can reduce the burden on healthcare services and enhance the quality of life for individuals with stroke.

The scope of this research comprehensively spans various dimensions of long-term recovery and healthcare utilisation after stroke. The research focuses on individuals who have experienced a stroke and are in the long-term recovery phase. The study investigates how engagement in specific self-management strategies influences long-term health outcomes and healthcare utilisation. By analysing linked health datasets, the research examines patterns of healthcare utilisation for secondary conditions, such as anxiety and depression, and assesses the impact of self-management practices on these patterns. The potential applicability of these self-management strategies in diverse environments, including outpatient clinics and home-based care, broadens the scope of my thesis. In addition to its broad reach, my research program aims to make a significant contribution to the existing body of literature by employing a large-scale sample with long-term follow-up.

1.7 Research aim

There is limited evidence regarding the adoption of self-management strategies by post-stroke individuals, and research in this area is relatively new. The aim of this thesis is to conduct a comprehensive investigation into the use of self-management in long-term rehabilitation after stroke. This includes examining perceptions and experiences related to self-management in stroke rehabilitation, identifying factors that influence the adoption of self-management among stroke survivors, and assessing the long-term impacts of self-management behaviours on healthcare utilisation and overall health status.

1.8 Research Questions

Therefore, the primary research questions are as follows:

1) What evidence is available on the use of self-management in stroke rehabilitation?

2) Which self-management strategies are currently being employed and are considered useful for stroke rehabilitation?
3) What proportion of stroke survivors use self-management strategies for their long-term rehabilitation after stroke?
4) Which demographic and health status characteristics influence stroke survivors' use of self-management strategies over time?
5) How does engagement in healthy behaviours at baseline influence the likelihood of maintaining or changing these behaviours over time?
6) Do self-management practices reduce the utilisation of stroke-medications and healthcare professionals for secondary conditions among individuals with stroke?
7) Are self-management strategies useful for improving stroke survivors' physical and mental health status?

Chapter 2: Literature Review

The use of self-management strategies for stroke rehabilitation: a scoping review.

This chapter presents a comprehensive literature review that analyses and synthesises the self-management strategies employed by stroke survivors in stroke rehabilitation, as well as their experiences, based on non-experimental empirical studies published between 2010 and 2021. The chapter addresses Research Questions 1 and 2. Furthermore, it identifies several research gaps and offers directions for future research. The findings have been published in the *Topics in Stroke Rehabilitation***.**

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2.1 Abstract

Introduction: Self-management is generally considered a dynamic and collaborative process by individuals and caregivers to manage a chronic condition. Self-management has recently emerged as a promising strategy for stroke rehabilitation. This scoping review aims to examine and summarise self-management strategies utilised by stroke survivors for stroke rehabilitation.

Methods: PubMed, Scopus, CINAHL (EBSCO), Embase, and ProQuest were searched for articles published between January 2010 and December 2021. Studies were selected if they were published in English in a peer-reviewed journal, utilised a non-experimental research design, and focused on adult stroke survivors. All relevant information from the included

articles was extracted in a systematic way using a pre-developed data extraction form. Two authors performed data extraction and quality evaluation independently. All issues were resolved through discussion among the authors.

Results: We narratively summarised the findings of 15 quantitative, qualitative, and mixed-method studies, including a total of 1,494 stroke survivors. The stroke survivors used a range of self-management strategies for their stroke rehabilitation, including domains related to lifestyle, social support, communication, knowledge and information, and goal-setting. Gender, age, stroke-related disability, fatigue, self-management education, social support, and communication with others were found to be associated with self-management use in stroke rehabilitation.

Conclusions: This scoping review provides an important overview on stroke survivors' use of self-management strategies and their experience. Their use of self-management strategies is complicated and multifaceted, comprising several domains and involving a diverse range of approaches and personal experiences. However, we identified several gaps in the literature and more research is required on the use of self-management strategies for stroke rehabilitation.

2.2 Introduction

In 2019, there were more than 101 million stroke survivors worldwide, with 12.2 million new cases and 6.55 million new deaths[10]. The absolute number of stroke incidence continues to rise for several reasons, including increased average life expectancy, population growth in the majority of countries, and the increased prevalence of potential risk factors for stroke such as obesity, unhealthy diet, and low physical activity[10,72,119,120]. This increase of stroke survivors places a significant burden on healthcare systems[10,72,119,120]. Although stroke is a sudden-onset acute cerebrovascular event, there are numerous long-term physical and mental complications associated with this life-changing event, such as impaired movement[77], fatigue[77,121], poor concentration[77], falls[77], loss of function of upper limb[37], problems with swallowing[37], aphasia[24], seizure[122], anxiety[25,123,124], confusion[123], and depression[25,123,124]. Many stroke survivors require help for basic daily tasks[42–46].

Stroke rehabilitation is a dynamic, progressive, goal-directed process that attempts to maximise stroke survivors' functional capacities, symptom management, cognitive skills, daily activities, communication interactions, and social involvement, as well as to avoid subsequent

strokes[42,66,125–128]. Self-management, which is generally considered a dynamic and collaborative process by individuals and caregivers to manage a chronic condition, is an approach to addressing stroke survivors' long-term needs in stroke rehabilitation[57,62,129,130]. Since the mid-2000s, self-management strategies have gained increased attention among stroke survivors, family members/carers, and healthcare professionals as a means of addressing long-term unmet needs of people in post-stroke life[44,57,72,131–136]. According to several international stroke guidelines, all stroke survivors should undertake self-management strategies for their stroke rehabilitation[65–69].

There is limited documentation on the use of self-management strategies among stroke survivors, and research on this topic is relatively new[57,64,72,132,134]. Previous reviews, mainly based on randomized controlled trials, showed that self-management interventions such as exercise/ physical activity, a nutritious diet, self-management educational training, and social support were effective in stroke rehabilitation[63,72,134,137–140]. Considering the growing burden on stroke survivors and the wider society, research is required to explore not only the efficacy of particular self-management interventions, but also the types of self-management strategies used by stroke survivors and the experiences/perceptions of those stroke survivors around such use. To address this gap, this scoping review aims to examine and summarise the self-management strategies used by survivors after stroke and stroke survivors' experiences of using the self-management strategies.

2.3 Methods

2.3.1 Design

The protocol of this review has been registered with the International Prospective Register of Systematic Reviews (PROSPERO) (number: CRD42021222131). This scoping review was undertaken following the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses - Extension for Scoping Reviews) guidelines (Appendix 1)[141].

2.3.2 Search strategies

We systematically searched peer-reviewed journal articles published between January 2010 and December 2021 on the use of self-management strategies among stroke survivors. The

databases including PubMed, Scopus, CINAHL (EBSCO), Embase, and ProQuest were searched for literature. A similar search strategy was used to search these databases via the following keywords and/or MeSH words ‘stroke’, ‘stroke rehabilitation’, ‘thromboembolism’, ‘brain haemorrhages’, ‘brain ischemia’, ‘ischemic attack’, 'tia', as well as terms regarding self-management including ‘self-care’, ‘self-management’, ‘self-directed’, ‘self-efficacy’, ‘self-administered’, and ‘self-monitored’ (Appendix 2). The searches were restricted to articles published in the English language. Additionally, to guarantee that all relevant literature was included, a manual search of Google Scholar was undertaken using the above keywords.

2.3.3 Selection criteria

The identified articles obtained from the search of each database were imported into EndNote X7. Duplicate items were identified and removed from the results. All observational studies that reported on the use of self-management strategies among adults living with stroke were considered for inclusion. There were no restrictions on the forms of self-management, nor their frequency or duration. However, this review excluded other literature reviews and articles reporting animal studies, clinical trials, conference abstracts, editorials, commentaries, letters to the editor, and case reports.

Two authors (M.S.R. & W.P.) independently retrieved the titles and abstracts to identify the articles that met the inclusion criteria, then critically examined by another author (D.S.). When the title and abstract did not provide enough information, the whole text was examined. Two authors (M.S.R. & W.P.) examined the full texts of potentially eligible articles before final inclusion. In cases of disagreement to include/exclude articles, the other authors (D.S. and J.A.) were consulted.

2.3.4 Search outcomes

Figure 2.1 depicts the study selection process via the PRISMA flowchart. A total of 10,087 items were retrieved via the five electronic databases, and further 35 items were identified during the manual search. After removing duplicates, 7,744 items were screened for titles and abstracts, and 7,670 publications were removed as they were considered irrelevant to the review. The remaining 74 items were assessed on the basis of their full texts, where 59 items were excluded for specific reasons. The common reasons for exclusion were: not the outcomes

of interest, different target population, and not the appropriate research design. Finally, 15 articles from 15 unique studies met the inclusion criteria and were included in this literature review[21,44,146–150,45,46,76,131,142–145].

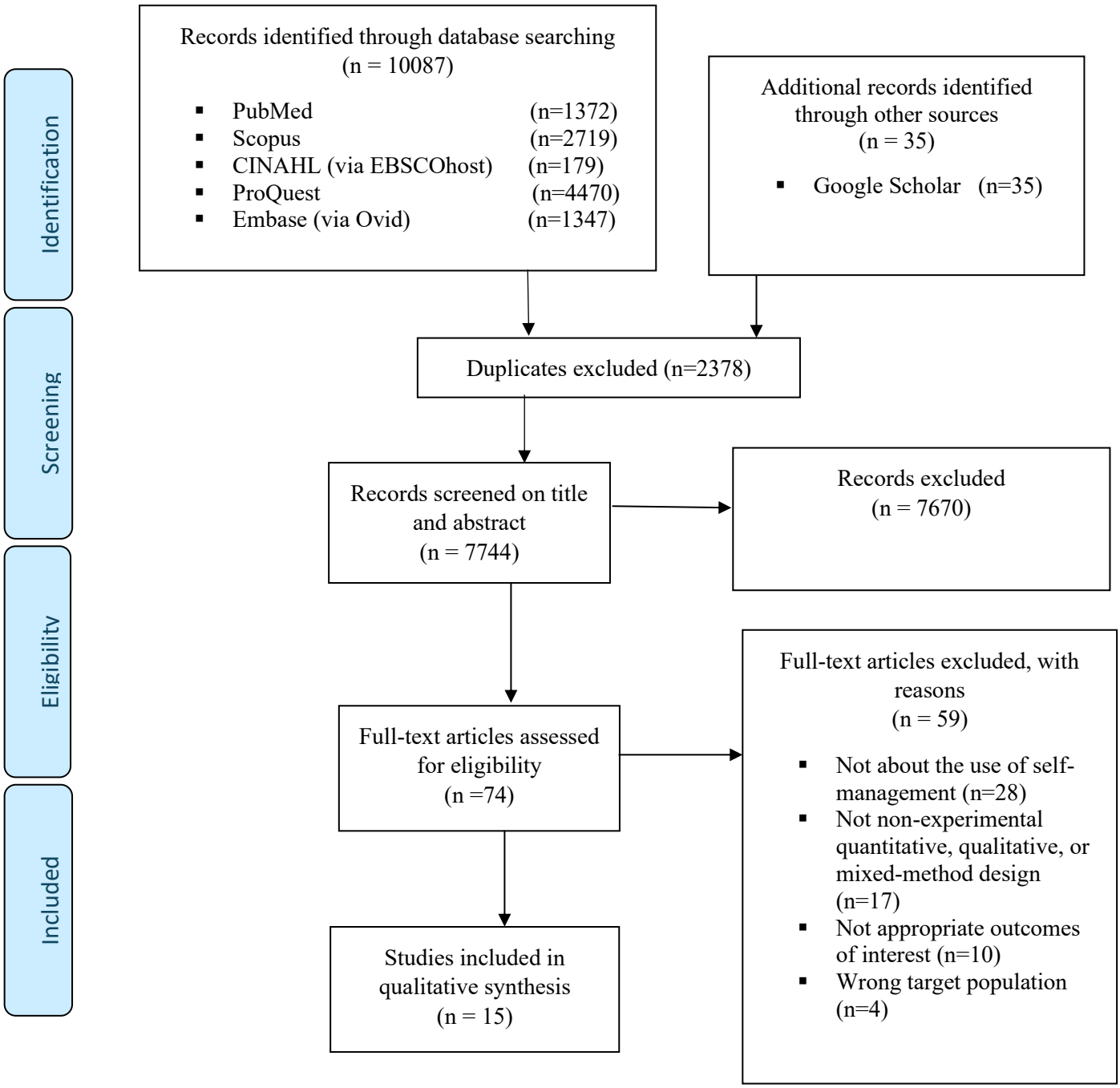

Figure 2.1 Flowchart of literature search and study selection.

2.3.5 Quality appraisal

Using the Modified Newcastle-Ottawa Quality Assessment Scale (Appendix 3), we evaluated the quality of the quantitative observational studies (i.e., cross-sectional questionnaire surveys)[151]. The maximum score for this scale is 10 (1 star = 1 point) while the minimum score is 0, and studies having a quality score of 6 or above are considered to be of high quality[152]. In addition, the quality of the included qualitative studies was appraised using the Critical Appraisal Skills Programme (CASP) qualitative checklist (Appendix 4)[153]. The CASP is the most widely used technique for assessing qualitative research, with a grading system ranging from 0 to 10 based on 10 methodological questions[55,154]. While no scoring rubric has been indicated in the CASP checklist, the following score can be given to each question: 'Yes' (1), 'Can't tell' (0.5), and 'No' (0)[155]. Studies with a quality score of 9-10, 7.5-8.9, or less than 7.5 based on the CASP checklist criteria are categorized as high-quality, moderate-quality, and low-quality, respectively[155]. Two authors (M.S.R. & W.P.) independently conducted the quality assessments and assigned ratings to each study; any differences in the scores were resolved by discussion among all authors.

2.3.6 Data extraction and synthesis

All relevant data of the included articles were extracted in a systematic way using a pre-developed data extraction form that presents the general characteristics of included studies, such as the year of publication, country of the study, inclusion and exclusion criteria of participants, study design, outcome measures, stroke survivors' characteristics, self-management strategies for stroke rehabilitation, perceptions, and experiences of self-management strategies. Two authors (M.S.R. & W.P.) independently completed the extraction form and disagreements about the extracted data were resolved by authors' discussion.

2.4 Results

2.4.1 Characteristics of the study

The characteristics of the included studies are displayed in Table 2.1. Of the 15 articles, seven articles used a qualitative research design[21,44–46,76,142,148], four used a quantitative research design[143,146,149,150], and four used a mixed-method research design[131,144,145,147]. Further, fourteen

articles reported on cross-sectional studies[11–13,19,35–39,41-45] and one article reported on a longitudinal study[142]. Eleven studies solely included stroke survivors[12–13,36–45]; one study focused on survivors of several nervous system disorders including stroke (59% of the total sample)[76]; and three studies involved both stroke survivors and other stakeholders (i.e., nurses, physiotherapists, and carers)[44,131,146]. Only three studies were conducted in low- and middle-income countries (China, India, and Iran), while the others were conducted in high-income countries including the England (n=4), the Netherlands (n=2), Scotland (n=2), Australia (n=2), Canada (n=1), and Taiwan (n=1). The 15 studies including in this review contained a total of 1,494 stroke survivors.

Table 2.1 Characteristics of the included studies.

Author; Country	Inclusion/Exclusion criteria of samples	Study design; setting; sample size	Outcome measures	Stroke survivors' characteristics
Brady et al; Scotland[21].	**Inclusion criteria:** Diagnosis with dysarthria after a stroke during the past three years. **Exclusion Criteria:** Coexistence of dysarthria, aphasia, cognitive disability, and dyspraxia.	In-depth, semi-structured interviews; Community; 24.	**Functional Independence:** Barthel Index; **Cognitive Impairment:** Mini-mental State Questionnaire; **Depression:** Hospital Anxiety and Depression Scale (HADS); **Aphasia:** Sentence Comprehension Test; **Deprivation:** Carstairs Scores; **Dysarthria severity:** Speech and Language Therapy (SLT).	Stroke survivors (n) =24; average age (SD) = 63.5 (±12) years; percentage of female=37.5%; average time since diagnosis with stroke= NR.
Hirsche et al; Canada[76].	**Inclusion criteria:** Diagnosis of stroke; age of 18 years, ability to communicate in English, and physical ability to complete the 6-week chronic disease self-management workshop.	Semi-structured interviews; Community; 22.	-	Stroke survivors (n) =13; average age (SD)=56(±11) years; percentage of female=NR; average time since stroke (SD)=3.2±2 years.
Boger et al; England[46].	**Inclusion criteria:** Living in the community, ≥18 years of age, ≥3 months following stroke, able to	Focus group interviews; Community; 28.	**Functional Independence:** Barthel Index.	Stroke survivors (n)=28; average age=65.67 years; percentage of female=60.71%, average

	understand English, cognitive ability to provide informed consent.			time since stroke (SD)= 57.89 (60.80) months.
Satink et al; the Netherlands[45].	**Inclusion criteria:** Community dwelling stroke survivors.	Focus group interviews; Home; 16.	-	Stroke survivors (n)=16; average age (range)=70.81 (53-84) years; percentage of female=56.25%; median time since most recent stroke= 2 years.
Kidd et al; Scotland[131].	**Inclusion criteria:** Diagnosis with ischaemic or hemorrhagic stroke; released from hospital during the preceding 12 months of the first stroke; residing at home; having a working level of English; and capable of giving written consent.	Mixed method study with qualitative emphasis; Home; 42.	**Disability:** Modified Rankin Scale (mRS); **Patient's knowledge, skill, and confidence for self-management:** Patient Activation Measures (PAM) scores;	**Development phase:** Stroke survivors (n)=20; average age (range)=64 (43-84) years, percentage of female=40%, one or more additional comorbidities=30%; between 1-6 months post-stroke=60% and between 7-12 months post-stroke=40%. **Evaluation phase:** Stroke survivors (n)=6; average age= NR; percentage of female=33.3%; one or more additional comorbidities=83.3%; between 1-6 months post-stroke=83.3% and between 7-12 months post-stroke=16.67%.
Satink et al; the Netherlands[142].	**Inclusion criteria:** Stroke for the first time, living at home, able to talk in Dutch, HADS score <8.	Longitudinal, semi-structured interviews; Home; 10	**Anxiety and Depression:** HADS.	Stroke survivors (n)=10; average age=64.6 years; percentage of female=60%; average time since stroke= NR.
Sadler et al; England[44].	**Inclusion criteria:**	Semi-structured interviews;	-	Stroke survivors (n)= 13; average age (range)=71

	Stroke survivors, participated in rehabilitation services.	Stroke unit and community stroke rehabilitation services; 26.		(53-89) years, percentage of female=38.46%; time since stroke (range)=2-4 months.
Guan et al; China (Mainland)[143].	**Inclusion criteria:** Stroke survivors, stable period, 15 days to 6 months following stroke onset, normal awareness, text or verbal communication, a Barthel Index score >20, no swallowing problem, and willingness to participate. **Exclusion criteria:** Dementia or psychotic disorder, co-morbidity with other medical disorders, and total lack of capacity to do daily activities.	Cross-sectional questionnaire survey; Hospital; 440.	**Functional Independence:** Barthel Index; **Dementia:** Mini-mental Scale Assessment; **Self-management behaviours:** Stroke Self-management Behaviour Scale; **Stroke prevention knowledge:** Social Support Rating Scale (SSRS).	Stroke survivors (n)=440; age ≥60=68.0%; percentage of female=42.7%; average time since stroke =NR.
Kulnik et al; England[144].	**Inclusion criteria:** Stroke survivors, ≥18 years old, severe arm impairment, and ability to provide consent and communicate in English.	Mixed method study with qualitative emphasis; Community; 42.	**Ability to manage daily activities:** ABILHAND Manual Ability Measures; **Arm activity:** Adapted Version of the Arm Activity Measures (ArmA).	Stroke survivors (n)=42; median (range) age group=50-59 (30-39, 70+) years; percentage of female=38.1%; median(range) time since stroke= 39 months (4 months, 46 years).
Nott et al; Australia[145].	**Inclusion criteria**: Diagnosis with ischemic or haemorrhagic stroke, ≥18 years of age at the time of event, enrolled for inpatient post-stroke management, impaired occupational performance, capacity to understand the English-written educational	Mixed-method study; Hospital and community rehabilitation services; 40.	**Performance and satisfaction in self-care, productivity and leisure:** Canadian Occupational Performance Measure (COPM); **Self-efficacy:** Stroke Self-efficacy Questionnaire (SSEQ).	Stroke survivors (n)=40; average age (SD)=69.7 (±15.4) years, percentage of female=40%, average time since stroke= NR.

	materials, available internet access.			
Mahmood et al; India[146].	**Inclusion criteria**: Adult stroke survivors/primary caregivers, having functional communication skills, mobile phone users, and understand either regional (Kannada) or English language. **Exclusion criteria:** Cognitive dysfunction, neuromuscular problems.	Cross-sectional questionnaire survey; Tertiary care university teaching hospital; 102.	-	Stroke survivors (n)= 50; average age (SD)=55.2 (±13.39) years, percentage of female=28%, median time since stroke=0.45 months.
Wang et al; England[147].	**Study 1** **Inclusion criteria:** Diagnosis with stroke, community dwelling, ≥16 years of age. **Exclusion criteria:** NA **Study 2** **Inclusion criteria**: Diagnosis with stroke, community dwelling, ≥18 years of age, sufficient knowledge to communicate in English. **Exclusion criteria:** Any disorders that may impair an individual's ability to provide consent.	Mixed-method study; Community; 51.	**Functional Independence:** Barthel Index; **Self-efficacy:** The Daily Living Self-Efficacy Scale (DLSES), **Anxiety:** HADS.	**Study 1:** Stroke survivors (n)=13; median age (range)=61 (51-76) years; percentage of females=38.5%. average time since stroke=NR. **Study 2:** Stroke survivors (n)=38; median age (IQR)= 67 (57-72.5) years; percentage of female=52.6%; median time since stroke (IQR)=5.5(1.5-10) years.
Azar et al; Iran[148].	**Inclusion criteria:** 3–6 months after stroke diagnosis. **Exclusion criteria:**	In-depth, semi-structured interviews; Hospital.; 15.	-	Stroke survivors (n)=15; average age=51.06 (Range=35-71) year;

	Mental and cognitive problems.			percentage of female=46.6%; average time since stroke =NR.
Sibbritt et al; Australia[149].	**Inclusion criteria:** Diagnosis with stroke.	Cross-sectional questionnaire survey; NR; 576.	**Quality of life:** The three-level version of the EuroQol five-dimensional questionnaire (5Q-5D-3L); **Depression:** 10-item Center for Epidemiologic Studies Depression Scale (CES-D-10), **Fatigue**: Modified Fatigue Impact Scale-5 item (MFIS-5), **Disability:** Modified Rankin Scale (mRS).	Stroke survivors (n)=576; average age (SD)=75.8 (±9.1) years; percentage of female=45.1%; average time since stroke (SD) = 10.4(±8.9) years.
Kuo et al; Taiwan[150].	**Inclusion criteria:** Recently diagnosed with stroke within six months, >20 years of age, and with modified Rankin Scale grades 0 to 3. **Exclusion criteria:** Severe dementia, acute respiratory syndrome, or impaired vision or hearing.	Cross-sectional questionnaire survey; Hospital; 150.	**Self-management:** Self-developed **S**troke Self-Management Scale; **Functional independence:** Barthel Index and Instrumental activities of daily living (IADLs); **Neurological deficits:** National Institute Health Stroke Scale (NIHSS); **Disability:** mRS; **Continuity of care:** Patient Continuity of Care Questionnaire (PCCQ).	Stroke survivors (n)=150; average age (SD)= 65.15 (±13.62) years; percentage of female=28.7%; time since stroke (SD) = 0-6 months.

NR: not reported.

2.4.2 Quality appraisal of the included studies

All included studies in this literature review were found to be of high quality (Table 2.2 and Table 2.3). The average score for overall methodological quality for the quantitative studies was 6.83 out of 10 (range: 7-8) and that for the qualitative studies was 8.78 out of 10 (range:

8-10). The average score for overall methodological quality for the qualitative part of the mixed method studies was 9.62 out of 10 (range: 9.5-10). Two mixed-method studies[131,144] focused on the qualitative analysis and assessment of their quantitative methodological quality was not possible. The average score for overall methodological quality for the quantitative part of the other two mixed method studies[145,147] was 6 out of 10.

Table 2.2 The modified Newcastle-Ottawa scale for assessing the quality of quantitative cross-sectional studies.

Study	Selection				Comparability	Outcome		Total quality score (10)	Classification of quality
	Representativeness of the sample	Sample size	Non-respondents	Ascertainment of the exposure	The subjects in different outcome groups are comparable, based on the study design or analysis. Confounding factors are controlled.	Assessment of the outcome	Statistical test		
Guan et al[143]	*	*	*	*	*	*	*	**7**	**High**
Nott et al[a][145]		*		**	*	*	*	**6**	**High**
Mahmood et al[146]		*	*	**	*	*	*	**7**	**High**
Wang et al[a][147]	*			**	*	*	*	**6**	**High**
Sibbritt et al[149]	*	*	*	**	*	*	*	**8**	**High**
Kuo et al[55]	*	*	*	*	*	*	*	**7**	**High**

*The number of stars (1 star=1 point) assigned to each category was in accordance with the modified Newcastle-Ottawa scale's star-based rating systems[152]. [a]The quality assessment based on the quantitative part. The mixed-method studies of Kidd et al[131] and Kulnik et al[144] were based on qualitative emphasized, and assessment of the quality of the quantitative part were not possible.

Table 2.3 Summary of critical appraisal using the qualitative CASP checklist.

Items	Brady et al[21]	Hirsche et al[76]	Boger et al[46]	Satink et al[45]	Kidd et al[b] [131]	Satink et al[142]	Sadler et al[44]	Kulnik et al[b] [144]	Nott et al[b] [145]	Wang et al[b] [147]	Azar et al[148]
Was there a clear statement of the aims of the research?	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**

Is a qualitative methodology appropriate?	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**
Was the research design appropriate to address the aims of the research?	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**
Was the recruitment strategy appropriate to the aims of the research?	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**No**	**Yes**	**Yes**	**Yes**	**Yes**
Was the data collected in a way that addressed the research issue?	**Yes**	**No**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**
Has the relationship between researcher and participants been adequately considered?	**Yes**	**Yes**	**Cannot tell**	**No**	**Cannot tell**	**Yes**	**No**	**Cannot tell**	**Cannot tell**	**Yes**	**No**
Have ethical issues been taken into consideration?	**No**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**
Is there a clear statement of findings?	**Yes**	**No**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**No**
Was the data analysis sufficiently rigorous?	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**
Is the research valuable?	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**
Total	**9**	**8**	**9.5**	**9**	**9.5**	**10**	**8**	**9.5**	**9.5**	**10**	**8**
Classification of quality	**High**	**High**	**High**	**High**	**High**	**High**	**High**	**High**	**High**	**High**	**High**

[b]The quality assessment based on the qualitative part.

2.4.3 Definition of self-management in stroke survivors

Five articles reported the concept of self-management from the viewpoint of stroke survivors[44–46,131,142]. The word "self-management" was unfamiliar to many stroke survivors, but they understood the concept with further explanation and could provide their own definition[44–46]. The most common definition about self-management among stroke survivors was the process of maintaining “independence and autonomy”, such as doing daily activities independently and

seeking support only when really needed[44–46,131,142]. The other concepts related to self-management included managing post-stroke life (e.g. engaging in social activities)[44–46,131], adopting effective approaches (e.g. healthy lifestyle behaviours) for stroke rehabilitation[76,131,142,149], developing a positive attitude to stroke recovery (e.g. setting goals) [44,131], and participating actively in rehabilitation activities[44–46].

2.4.4 Common self-management strategies used post-stroke

Stroke survivors reported a variety of self-management strategies for stoke rehabilitation (Table 4)[21,44,148–150,45,46,76,131,142,144,145,147]. The majority of stroke survivors described self-management strategies as essential to and beneficial for their stroke rehabilitation, especially for maintaining daily activities and the improvement in emotions such as excitement, pride, motivation, and self-confidence (Table 5)[21,44,148,45,46,76,131,142,144,145,147]. The most commonly used strategies were related to the domains of lifestyle (n=13), followed by social support (n=9), communication (n=8), knowledge and information (n=7), and goal-setting (n=6). Authors of nine studies[21,44–46,76,131,142,144,145] have demonstrates that most of the stroke survivors undertook self-management strategies in several domains simultaneously. In addition, the self-management strategies, such as strategies to maximize the quality of speech, caring out normal tasks, and involving in exercises were caregiver driven[21,44–46].

2.4.5 Lifestyle-related self-management strategies

A diverse range of self-management strategies were found in the lifestyle domain, including the engagement in physical activities or exercises for rehabilitation[21,45,46,131,142,144,145,147,149,150], undertaking normal daily activities[21,44–46,131,142,144,145], coping with stroke-related symptoms[21,44,76,131,142], and changing lifestyle behaviours[21,76,142,149]. Stroke survivors reported that they engaged in physical activities and exercises independently and/or with the assistance of others (e.g., family members, professionals)[21,45,46,131,142,144,145,147,149]. The majority of stroke survivors in two qualitative studies[21,142] and one mixed method study[131] reported that the self-management activities improved their functional abilities and reduced their symptom severity[21,131,142,144]. Some stroke survivors used spiritual, mindfulness, and relaxation techniques to self-manage their post-stroke mental health issues[76,147–149]. Those stroke survivors indicated that these strategies enabled them to cope with social stress and obtain better self-care effect[147,148].

2.4.6 Social support-led self-management strategies

Receiving social support was an important self-management strategy for stroke rehabilitation, including support from family members/friends, peers, and clinicians[21,44–46,76,131,142,144,145]. Family support was perceived as essential for managing stroke survivors' functional limitations, particularly during the early stages post-stroke[21,44–46,142]. However, some stroke survivors reported that increased family assistance could impede their self-management development[44–46,142]. In addition, some stroke survivors indicated that support from health professionals could assist them in identifying effective and appropriate self-management activities[44,46]. Moreover, authors of three qualitative studies reported that peer support is beneficial in the improvement of mental wellbeing, confidence, and self-management knowledge[45,46,76].

2.4.7 Communication related self-management strategies

The involvement in communicative activities with family/friends, carers, health professionals, and other peers was also perceived as a necessary and useful self-management strategy for stroke survivors[21,44–46,131,142,144,145]. For example, authors of two qualitative studies (pooled N=34; average age=66.19 years; female=37.83%) found that communicative interactions were helpful to build confidence, expand self-management information, and improve participants' physical recovery[21,44]. Stroke survivors with speech problems indicated that they used several communication related self-management strategies including speaking slowly, speaking louder, and focusing on the listener to maximise their speech quality[21,45].

2.4.8 Knowledge and information related self-management strategies

Authors of seven studies reported different self-management strategies in the knowledge and information domain[21,45,46,131,142,144,145]. Stroke survivors always recognised their needs and then sought relevant information during the stroke rehabilitation[21,45,46,142]. Stroke survivors from three studies[131,76,145] had participated in self-management programmes to obtain stroke-related knowledge/information. Those stroke survivors in the programmes found that the knowledge and information related self-management strategies could help improve their lifestyle behaviours, social connections, confidence, and the ability to manage post-stroke life[76,131,145]. It is worth noting that several stroke survivors reported the self-management information

learned during their inpatient rehabilitation cannot meet their needs once they have returned home[45,46].

2.4.9 Goals-setting related self-management strategies

Setting realistic and achievable goals (e.g., mobilising independently, losing weight, and fulfilling social duties) was a vital part of the self-management strategy for stroke rehabilitation[76,131,145]. Several stroke survivors indicated that their responsibility, motivation, and self-confidence enabled them to continue with self-management activities, and highlighted the important role of sufficient information for setting an appropriate goal[46,76,131]. Authors of one qualitative study demonstrates that goal setting can help stroke survivors to develop a routine for monitoring their health condition and improving health behaviors[76]. In addition, health practitioners were reported to play an essential role in assisting stroke survivors in establishing and achieving realistic goals[131].

Table 2.4 Summary of the reported self-management strategies.

Main components of self-management	Self-management strategies
Lifestyle-related self-management[21,44,148–150,45,46,76,131,142,144,145,147]	1. Maintaining independence (e.g., doing things for yourself, looking after yourself, try to manage everything individually) 2. Engaging in physical activities/ exercises for rehabilitation 3. Caring out normal tasks and responsibilities as much as possible (e.g., dressing and grooming, eating a meal with knife and fork, cooking a family meal) 4. Cope with the stroke related consequences (e.g., fatigue, pain, frustration) 5. Changing lifestyle behaviours (e.g., smoking cessation, modifying diet, sufficient sleep, maintain personal hygiene, appropriate exercise, being proactive). 6. Doing enjoyable activities (e.g., singing choir, walking the dog) 7. Ongoing monitoring (e.g., the quality of the speech) 8. Using strategies to maximize the quality of speech (e.g., speak slowly, shout louder, focused on listener, breath support, reducing external distraction, word substitution)

	9. Increasing mobility 10. Involving the affected arm in every possible activity 11. Creating the environment at home for conducting rehabilitation (i.e., embedding rehabilitation into everyday life) 12. Using self-care products (e.g., multivitamins/minerals, vitamins, fish oil/omega 3, hypericum, CoQ10, herbal medicines, homeopathic remedies, folic acid, garlic and ginkgo) 13. Using necessary devices (e.g., electric stimulation devices, braces, and splints) 14. Using strategies to manage psychological and emotional effects of stroke like stress or anxiety reduce anxiety (e.g., uses of self-help relaxation, mindfulness and spiritual self-care techniques) 15. Using strategies to manage memory problem and loss of concentration (e.g., writing a note)
Social support-led self-management[21,44–46,76,131,142,144,145]	1. Seeking support from family members, friends, their pre-stroke community, and healthcare professionals during post-stroke rehabilitation 2. Peer support 3. Developing co-management with partner to enact self-management 4. Maintaining a good relationship with health professionals
Communication related self-management[21,44–46,131,142,144,145]	1. Good communication with formal/informal caregivers and health professionals 2. Involvement in communicative interaction activities (e.g., practice with family members, friends, or healthcare staff, meet with other people) 3. Enhancing social engagement 4. Creating community with other stroke survivors
Knowledge and information related self-management[21,45,46,131,142,144,145]	1. Participating in self-management educational programmes 2. Learn from experiment and error in everyday life as well as from shared experiences of other stroke survivors 3.Seeking appropriate information about stroke rehabilitation 4. Expanding professional driven rehabilitation activities (e.g., through modifying, adapting, adding new meaningful self-management strategies, and shared strategies of other stroke survivors) 6. Identifying the limitations and strength (e.g., energy level) 7. Identifying the most helpful professionals for specific issue 8. Discovering new strategies to self-manage (e.g., recording the speech to identify problematic words and then practice the problematic words)

	12. Identifying needs, local support, and stroke related services 14. Identifying important self-management strategies that help to improve
Goal-setting related self-management[21,46,76,131,142,145]	1. Setting realistic and achievable goals (e.g., mobilizing independently, achieving an ability to resume everyday activities prior to stroke, losing weight, cessation of smoking, maximize the quality of speech, and improving brain and memory function) 2. Action plan

Table 2.5 Stroke survivors' views and experience of self-management strategies.

Study	Stroke survivors' use of self-management strategies
Brady et al[21]	1. Various strategies (e.g., breath support and the development of an action plan) were used, aiming to improve the speech production and communicative interactions. 2. Almost all participants engaged in speech rehabilitation activities regularly. 3. Most perceived their responsibility, motivation, self-confidence, self-discovery, and determination enabled them to continue self-management activities. 4. Family members, friends, and healthcare professionals played a crucial role in improving their stroke recovery. 5. Some perceived implementing professional-directed strategies were beneficial for stroke management.
Hirsche et al[76]	1. The respondents participated in the chronic disease self-management (CDSM) programme. 2. Goal-setting, coping with the situations and action planning were identified as the most important self-management strategies to improve. 3. Several participants reported that their lifestyle behaviours had improved (e.g., smoking cessation, modifying diet, improving exercise habits) through participation in the CDSM programmes. 4. Several stroke survivors acknowledged that peer support benefitted them considerably in gaining knowledge. Peer support enhanced their mental wellbeing, confidence, communication ability, and social participation.
Boger et al[46]	1. The word 'self-management' was unfamiliar to the participants; but they understood the concept after additional explanation. 2. While the majority of participants believed that self-management was a helpful strategy, not everyone agreed. 3. In the face of functional limitations caused by a stroke, the majority of participants indicated that receiving or asking support from family, friends, formal/informal carers, and health professionals was essential for self-management and stroke rehabilitation.

	4. Some stroke patients thought that enhancing their communication skills would assist them in self-management activities. 5. Self-confidence, professionals support, peer-support, determination, appropriate decision-making, and supportive environment helped some participants in developing self-management skills. 6. Stroke survivors gained self-confidence and psychological satisfaction in peers who appeared to be dealing with more challenging conditions, although peer comparison did not always result in an increase in confidence. 7. The availability of peer support inspired individuals to experiment with various self-management techniques, and it also allowed participants to make healthcare and self-management decisions. 8. According to the participants, stroke clubs were an excellent source of peer support. They claimed that being in a group setting with their peers contributed in the development of their self-management skills. 9. While some stroke patients struggled to continue exercising without assistance of others, some patients remained committed despite obstacles. 10. Many respondents believed that without sufficient information, appropriate decision making was impossible. They perceived that seeking relevant information was a key part of the overall self-management. 11. Stroke patients reported getting a great deal of information regarding self-management during their inpatient rehabilitation, but the information was not useful after discharge as they were not prepared to accept it in the early period of stroke. 12. Many participants expressed a lack of professional support (e.g., insufficient emotional support, lack of qualified specialists).
Satink et al[45]	1. Although most participants were unfamiliar with the word 'self-management,' they understood the concept of it without further explanation. 2. Participants demonstrated self-management as a multidimensional, long-term, individual learning process. 3. Accepting the stroke consequences and current situation was recognized as important for self-management. 4. Some respondents commented that engaging in enjoyable activities (e.g., choir singing, dog walking) led them to feel that they could also maintain their daily lives. 5. Participants perceived that their ability to identify limitations and strengths (e.g., energy level) facilitated their adjustment capability and post-stroke life management. 6. Many participants stated that family support was essential during their rehabilitation process and that without it, they might not have been able to maintain self-management strategies and return to their normal routines and activities.

	7. Some participants indicated that while family support can help in self-management, taking on so many tasks prevent stroke survivors from practicing and improving self-management skills. 8. Some stroke patients emphasized the importance of peer support in self-management process as the fellow sufferers truly understood one another and did not hesitate to seek assistance. 9. Several participants expressed concern about the insufficiency of professional care following discharge. Another concern expressed by some patients was a lack of emotional support from healthcare professionals. 10. Some stroke survivors recommended that having a coach visit their home on a regular basis would let them learn about increasing their ability to manage their strokes through the development of self-management skills.
Kidd et al[131]	1.The participants engaged in nurse-led 4-week 'tailored self-management action plan' programmes for their stroke rehabilitation. 2. Most of the respondents (85%) actively engaged in self-management activities and they were also able to self-manage during illness, stress, and/or anxiety. 3. Stroke patients (n=3, 15%) who did not participate actively in nurse-led rehabilitation activities had lack of knowledge to self-manage, lack of confidence, fatigue and moderate/severe disability 4. Participants, with the assistance of their nurses, set a variety of goals (e.g., self-mobility, weight reduction, quitting smoking, returning to a normal life, improving memory function, and fulfilling social duties) and goal-setting was described as a beneficial strategy for stroke rehabilitation. 5. Nearly all stroke patients (25/26) acknowledged that they received appropriate, practical, and timely self-management guidance and advice during the programme, and this programme increased their knowledge, confidence, and skills to manage their post-stroke life.
Satink et al [142]	1. Over time, the concept of self-management had changed from managing daily activities to taking on a full role to maintaining a meaningful and valuable life after a stroke. 2. Participants developed self-management skills gradually through participation in daily activities, which enabled them to manage disabilities and personal roles. 3. During the participants' everyday activities, several self-management processes were simultaneously happening, including interacting with other people, seeking support, learning from their experiences, and coping with their own difficulties. 4. Participants considered keeping a positive outlook was an important self-management strategy. 5. Receiving support was considered as a crucial component of self-management by majority of the participants. Developing co-management with partner was also perceived as beneficial to self-manage. 6. Few participants felt that increased family assistance could impede their ability to develop self-management skills.

	7. According to some participants, identifying limitations and learning to handle them was a part of self-management process. Some understood their inability to perform certain tasks due to their stroke, and avoiding them was regarded as a part of the self-management techniques. 8. Several stroke survivors experienced invisible problems such as concentration loss or hypersensitivity and they learned to manage them through trial and error of everyday life (e.g., using shopping list). 9. Several expressed that enhancing their communication skills (specially to obtain information and get support) was an important self-management technique. 10. Many stroke survivors narrated that action plan helped them to perform activities. 11. Increased mobility enabled participants to expand their social circles and took control of when and where they went. It was connected with their physical recovery, resource utilisation, and transportation arrangements. 12. During their final visit, the authors found that most participants had achieved the ability to maintain themselves and their everyday lives through active participation in daily activities. 13. Although most of the participants gradually learnt to self-manage their daily activities, there were some situations where some were unable to manage their own lives.
Sadler et al[44]	1. Over half of participants emphasized the important role of maintaining a good relationship and communication with therapists, mentioning it as a significant component of early recovery. 2. Several stroke survivors stated that their good relationships with therapists enabled them in acquiring the necessary knowledge and expertise. 3. More than half of stroke survivors reported that they relied on family members for both practical and emotional support after their stroke.
Guan et al[143]	1. The mean self-management behaviour score was 151.95±23.58 out of a maximum 250. 2. Education level, social support level, stroke knowledge level were significantly associated with stroke patients' self-management behaviours in recovery.
Kulnik et al[144]	1. The patient followed professional advice to manage their affected arm, particularly in the first few weeks and months following the stroke. 2. Participants emphasized that arm rehabilitation is a challenging and long-term process (may be years), and that there are no shortcuts to recovery. 3. According to the participants, maintaining a positive outlook and hope enabled them to continue with rehabilitation activities and manage their severely impaired arm. 4. Several stroke patients said that rehabilitation professionals projected their arm would never recover, which had a profound negative effect on them, and they advised that health personnel should refrain from making such detrimental statements. 5. Self-management skills were expanded through modifying, self-discovery, adding new meaningful self-management strategies.

	6. Stroke survivors expressed anger, frustration, concern, and grief on losing an arm or failing to improve, but demonstrated positive feelings such as enthusiasm, pleasure, pride, and self-confidence upon making progress.
Nott et al[145]	1. The stroke patients engaged in a 12-week self-management programme led by occupational therapists. The programme included a number of activities, such as assisting participants in setting realistic and achievable goals (e.g., self-care, resuming daily activities, community engagement) and learning strategies for accomplishing them. 2. According to several patients, occupational therapy coaching provided them with current information, increased their sense of self-efficacy, and improved their skills. 3. Participants who experienced both in-patient rehabilitation and self-management programmes at home acknowledged the advantages of rehabilitation at home. They stated that their home setting offered them with more opportunity to participate in recovery activities and work toward their goals than in-patient rehabilitation. 4. The perceived self-efficacy by stroke survivors was found to be a key mediator of improvements in occupational performance and work satisfaction. 5. Self-efficacy was found to increase with family, friend, and community support and decrease in the lack of support. 6. The support received during the programme helped stroke survivors to “get back to normal”. 7. Health professionals often used timetable to accomplish goals, which benefited some individuals but it did not useful to everyone. 8.Other stroke survivors' shared experiences (e.g., how they are progressing with self-management) motivated them to engage in self-management activities and boosted their sense of self-efficacy. 9. Participants found encouragement and psychological satisfaction in peers who appeared to be dealing with similar or more challenging conditions.
Mahmood et al[146]	1. Almost 90% of the patients and 92% of the caregivers demonstrated a willingness to engage in mobile-based self-management approaches. 2. Around 72% patients and 82.7% caregivers consented to pay a nominal fee for these kinds of services. 3. Over 80% of the patients and caregivers agreed that a mobile-based home exercise programme could benefit stroke rehabilitation, increase stroke awareness, reduce the time and cost associated with utilising stroke care services, improve follow-up access, and make it easier to obtain necessary information.
Wang et al[147]	1. Thinking of a pleasant place, breathing watch, positive thoughts, and body relaxation were the most preferred self-help mindfulness and relaxation techniques.

	2. Participants mentioned that practicing self-help mindfulness and relaxation techniques assisted them in calming down, relaxing their body (e.g., falling asleep more quickly), and turning their attention away from feelings of fear and worry. 3. Some reported that the techniques helped them preparing for specific stressful activities, such as communicating with other people.
Azar et al[148]	1. Participants used spiritual self-care, which includes supplication and religious beliefs to deal with their mental consequences of stroke. 2. Most of the participants reported that spiritual self-care facilitated them in reducing psychological problems associated with stroke, developing a positive outlook, coping with stroke consequences, making appropriate decisions, fulfilling their personal role, increasing their social inclusion, and practicing better self-care. 3. Participants found encouragement and psychological satisfaction in people/peers who appeared to be dealing with more challenging conditions.
Sibbritt et al [149]	1. Approximately 35.5% and 18.6% participants, respectively, used at least one self-care product and practice (e.g., physical activities/exercises, meditation, mindfulness, yoga, tai-chi), with vitamin D supplements (15.3 %) and omega (14.6 %) being the most frequently used self-care products and physical activities/exercises (14.6%) being the most frequently used self-care practice for stroke rehabilitation. 2. Females and younger people were more likely to utilise self-care products and practices. 3. Individuals with slight or moderate disabilities, and those reported high levels of fatigue were more likely to use self-care products.
Kuo et al[150]	1. The average score for self-management was 110.5 ± 15.12 out of a maximum 150. 2. Higher levels of education, exercising one to two times per week as compared to never exercising, having a stroke within two to six months as compared to 0-1 month, and continuity of care were factors influencing the overall self-management of newly diagnosed stroke survivors.

NR: not reported.

2.4.10 Characteristics of stroke survivors who used self-management strategies

Authors of one study[76] did not report the gender of the respondents; in the remaining 1481 stroke survivors, 625 (42.2%) were female. Another study[131] did not report the age of the stroke survivors who participated in their evaluation phase, while the rest of the studies did, however, the modes are different. In terms of the stroke survivors' conditions, Brady et al., 2011[21] focused on stroke survivors with dysarthria and Kulnik et al., 2020[144] focused on stroke survivors with a severely impaired arm, while the remaining studies employed stroke survivors with different conditions (Table 2.1).

A study conducted in Australia found that female patients, younger people, individuals with slight or moderate disabilities, and those who reported high fatigue levels (measured using MFIS-5) were more likely to utilise self-management[149]. Another quantitative study among Chinese population found that the education level, social support level, and stroke knowledge level were significantly associated with stroke survivors' self-management behaviours during their recovery stages[143]. Moreover, a quantitative study conducted in Taiwan revealed that higher levels of education, exercising one to two times per week as compared to never exercising, having a stroke within two to six months as compared to 0-1 month, and continuity of care were factors influencing the overall self-management of newly diagnosed stroke survivors (Table 2.5)[150].

2.5 Discussion

This article provides the first literature that focused on the use of self-management strategies for stroke rehabilitation and stroke survivors' experience in using those self-management strategies. Although self-management approaches have been strongly recommended by several clinical guidelines for stroke rehabilitation[65–69] we only found 15 non-experimental empirical studies published between 2010 and 2021 on this issue. Most of the included studies were conducted in the high-income countries. Therefore, more studies focusing on the self-management strategies for stroke survivors are required in low- and middle-income countries. Although the studies included in this review were all evaluated as being of a high quality, only one article in this review contains sample size over 500[149], more studies examining large and/or nationally representative samples are thus required. Also, most included studies were cross-sectional with a short period. Large-scale longitudinal studies are needed to examine the effect of self-management strategies used throughout different stages of the stroke survivors' life and treatment journey.

According to some clinical guidelines[65–69], successful self-management strategies after stroke require an integrated approach that includes an active participation of stroke survivor, family member/carer, and healthcare professions, as well as strong collaboration among them. Our review found that stroke survivors used a range of self-management strategies for their stroke management and rehabilitation, including lifestyle, social support, communication, knowledge and information, and goal-setting strategies. Interestingly, all those five self-management

domains identified in this review are currently recommended by clinical guidelines for stroke rehabilitation[65–69]. In this review, most stroke survivors were found to use different self-management domains simultaneously, and within each of these domains, stroke survivors used a diverse range of strategies for stroke rehabilitation.

Notably, most of the stroke survivors included in this review reported self-management strategies as effective for improving their functional recovery, communication abilities, stroke management, daily living activities, social participation, and mental wellbeing, as well as for reducing symptom severity. However, it is important to note that these measures of effectiveness are self-reported. Besides, the demographic and healthcare characteristics of those stroke survivors remain unclear. There is a need for further studies in the field of stroke rehabilitation to identify the profile of stroke survivors who use self-management strategies. Moreover, only one study reported the prevalence of the used self-management strategies for stroke rehabilitation and found stroke survivors with higher fatigue were more likely to use self-care products (rather than self-care practices)[149]. However, the authors did not examine the association between fatigue level and each self-care product included in the study. In fact, systematic reviews/Cochrane review also indicated insufficient evidence in the effectiveness of self-management interventions for the treatment of post-stroke fatigue, including fatigue self-management led by allied health practitioners[121,156,157]. Further studies thus are warranted to determine the prevalence of use of those common self-management strategies among stroke survivors and their associations with post-stroke fatigue.

This scoping review found that goal setting is utilised as a self-management strategy by stroke survivors of all ages and comorbid conditions[76,131]. Goal setting has been described as a critical strategy for overall stroke rehabilitation and outcome[72,158,159]. It is worth noting that some clinical guidelines strongly recommended that goals should be developed in coordination with the stroke survivor, health professionals, and their family/caregivers, and the goals should be clear, challenging but achievable, and regularly monitored and updated[65–69]. Stroke survivors of two studies included in this review reported that goal setting helped them in changing health-related behaviours, and engaging in self-management activities[76,131]. Therefore, future studies should be designed to explore the effectiveness of the common goals set for stroke survivors over time.

2.5.1 Limitations of the study

This scoping review has several limitations. We only included studies written in the English language. Future study that includes articles conducted in languages other than English can be recommended to provide more detailed results about diverse cultural perspectives on self-management strategies for stroke rehabilitation. Moreover, our review also excluded literature reporting studies conducted in children (<18 years of age) due to stroke in children being relatively rare (1.3-13 in 100,000 children)[160]. In addition, there was a lack of information on study participants (e.g., stroke severity, gender, and age).

2.5.2 Future directions

Given the importance of self-management in stroke rehabilitation, research is required to determine how to promote self-management among stroke survivors. Considering the importance of formal and informal caregivers, future research should focus on including them in self-management implementation and advance existing self-management strategies based their experiences and opinions. Also, to determine the effectiveness of varied self-management strategies in improving stroke survivors' functional capacity, mental health, and everyday activities, large-scale studies examining the stroke survivors' quality of life and health services use are needed.

2.6 Conclusions

This scoping review provides an important overview on stroke survivors' use of self-management strategies and their experience. Their use of self-management strategies is complicated and multifaceted, comprising several domains and involving a diverse range of approaches and personal experiences. However, there is no available rigorous evidence regarding the prevalence rates of commonly used self-management strategies post stroke, the profile of such users, as well as the long-term effects of those strategies over the course of a stroke survivor's life and treatment journey. Therefore, more research is required on the use of self-management strategies for stroke rehabilitation.

Chapter 3: Methods

This chapter begins with an overview of the theoretical framework that acts as a foundation of this research. Following this, an overview of the research methodology is presented, encompassing data sources, sample design, variables employed in this research, statistical analyses utilised, and the ethical considerations relevant to this research project is discussed. Note that subsequent results chapters provide additional methodology that addresses each of the research questions.

3.1 Theoretical Framework

My thesis thoroughly examines the use of self-management strategies in long-term stroke rehabilitation, uncovering the perceptions, experiences, determinants, and long-term impacts of such strategies among those with post-stroke. In order to comprehensively examine the different aspects of self-management practises employed by individuals following a stroke event, the theoretical framework incorporates four well-established health behaviour models: the Health Belief Model (HBM)[161], Transtheoretical Model (TTM)[162], Chronic Care Model (CCM)[163], and Wilson and Cleary Model of Health-Related Quality of Life[164].

My research examines how stroke survivors' evolving health beliefs and perceptions influence their adherence to self-management strategies within the framework of the Health Belief Model[161]. Social psychologists Hochbaum, Rosenstock, and Kegels developed the Health Belief Model in the 1950s to explain why individuals might not take preventive health measures, such as adopting healthy behaviours, despite the availability of information and services[161]. The model suggests that people's health-related behaviours are influenced by their perceptions of a health threat's severity, susceptibility, benefits, and barriers[161]. The inclusion of the temporal dimension permits an analysis of the process in which these beliefs develop and influence health-related self-management behaviour throughout the course of rehabilitation . The HBM, which has conventionally been employed to understand and promote health-related behaviours, can be extended to examine the impacts of those behaviours, such as self-management, on broader health outcomes, including healthcare utilisation and health status among those with stroke[165–167].

The implementation of the Transtheoretical Model provides a framework for comprehending the progressive phases of behaviour modification[162,168,169]. The Transtheoretical Model, also known as the Stages of Change model, was developed during the late 1970s and early 1980s by James O. Prochaska and Carlo C. DiClemente. Although the initial purpose of the model was to examine the cessation of smoking among smokers[162], it has since been implemented in the context of numerous health-related behaviours[168,169]. Prochaska and DiClemente recognised that behaviour modification is an ongoing procedure comprising several stages[162]. By employing this temporal framework, it becomes possible to identify the determinants that influence individuals' adherence to behaviour modification during the longitudinal phase of stroke rehabilitation[168,169].

The Chronic Care Model demonstrates particular importance in the context of chronic conditions such as stroke[163,170–172]. In the 1990s, Dr. Edward H. Wagner and colleagues developed the Chronic Care Model with the aim of addressing the challenges associated with the efficient management of chronic conditions[163]. It focuses on the improvement of care for individuals with long-term conditions through various components, including self-management practices[163,170–172]. In the context of stroke rehabilitation, CCM can provide valuable insights regarding the impacts of self-management interventions on healthcare utilisation as well as physical and mental health[171,172].

The Wilson and Cleary Model was developed by Ira B. Wilson and Paul D. Cleary in 1995 to provide a comprehensive framework for understanding and evaluating the impacts of health and illness on individuals' overall quality of life[164]. The model incorporates several kinds of health outcomes across multiple levels, encompassing physiological and biological aspects, symptoms, functioning, perceptions of general health, and subjective wellbeing[164]. The model offers a valuable framework for the development, implementation, and assessment of self-management interventions by encompassing a wide range of outcomes and placing significant focus on the patient's subjective perception of health and wellbeing[164,173]. By incorporating components from the Wilson and Cleary Model, this research investigates the impact of self-management on the self-reported health status of stroke survivors[173]. This dimension encompasses both the physical and mental aspects of health, offering a comprehensive understanding of the holistic impacts of self-management over a period of time[173].

The integration of these four established health behaviour frameworks provides a comprehensive understanding of the perceptions regarding the utilisation of self-management in stroke rehabilitation, the factors that influence the adoption of self-management among stroke survivors, and the impacts of self-management behaviours on healthcare utilisation and health status over time.

3.2 Methodological Overview

My thesis addresses several key research questions to guide the investigation of self-management strategies in long-term rehabilitation after stroke (as outlined in Section 1.8). These questions focus on identifying the self-management strategies employed by survivors of stroke, understanding the demographic and health characteristics that significantly influence these behaviours, and assessing the impact of self-management approaches on long-term healthcare use and health outcomes. The longitudinal studies included in my thesis adhere to the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines for cohort studies[174]. The following section explains the data sources used to answer these research questions and their relevance to my thesis objectives.

3.2.1 Data Sources

For this research, I used two distinct sources of data: The Sax Institute's 45 and Up Study[175] and the Australian Longitudinal Study on Women's Health (ALSWH)[176]. Both longitudinal studies recruited individuals with diverse chronic illnesses into their respective cohorts. The participants of the 45 and Up Study[175] and ALSWH[176] provided consent for long-term follow-up and that participants' survey responses to be linked to routinely collected health administrative data and health registry sources, including the Medicare Benefits Schedule (MBS)[177] and the Pharmaceutical Benefits Scheme (PBS)[178] data, among others. The MBS dataset includes information on claims for all medical and diagnostic services, whereas the PBS dataset consists of information on reimbursed prescription medications.

The 45 and Up Study is the largest ongoing study of ageing in the Southern Hemisphere focusing on people aged 45 years and older living in New South Wales (NSW)[175]. The principal objective of the 45 and Up Study is to provide researchers and policy makers with current and accurate data concerning a wide range of public health-related exposures and outcomes

associated with the ageing population[179]. The Study places emphasis on examining the social and economic determinants that influence healthy ageing; the health consequences of obesity and physical activity; the influence of environmental factors on healthy ageing; the determinants and management of mental health issues, cancer, cardiovascular disease; the utilisation of health services during the ageing process; and health concerns among individuals aged 80 and above[179] The research presented in this thesis utilised data from the baseline survey (2005-2009) and a sub-study survey (2017) of the 45 and Up Study, which was linked to the MBS and PBS datasets.

The Australian Longitudinal Study on Women's Health (ALSWH) is the largest and longest-running study on women's health in Australia, which was established in 1995[176]. The primary aims of ALSWH are to track changes in women's health over time, identify associated factors that may influence their health outcomes across their life course, and evaluate the effects of changes in policy and practise[180]. The factors influencing the health and wellbeing of more than 57,000 Australian women across four cohorts are investigated in this population-based survey[180]. The data of ALSWH surveys offers important insights into the long-term health of women[180]. The ALSWH is funded by the Department of Health and Aged Care of the Australian Government and is administered jointly by the University of Queensland and the University of Newcastle[176].

3.2.2 Sample Design and Surveys Questionnaires

3.2.2.1 45 and Up Study

The baseline data collected information from people aged 45 years and older, who resided in (the State of) NSW, Australia[179]. To ensure coverage of almost the whole population, a random sample of participants was taken from the Services Australia (formerly Department of Human Services and Medicare Australia) enrolment database[179]. Oversampling was undertaken among individuals aged 80 years and older as well as those who resided in rural and remote regions[179]. The baseline survey collected data from 267,357 individuals between 2005 and 2009, with an approximate 19% response rate, representing nearly 11% of the population of New South Wales aged 45 and older[179]. Participants enrolled in the study by responding to a baseline postal questionnaire and providing informed consent for follow-up and the linkage of their information to routine health databases including MBS and PBS records[179]. A sub-study of the

45 and Up Study was carried out between April and October of 2017, and a questionnaire was sent to 1,300 respondents who reported having had a stroke in the baseline survey[149]. The response rate for the sub-study questionnaire was 44.3%, with 576 stroke survivors completing and returning it[149]. The data from these 576 stroke survivors were analysed and reported in this research. The average age of those 576 stroke survivors was 66.5 (SD=9.1) years at baseline and 75.8 (SD=9.1) years at the time of the sub-study survey.

The longitudinal data of the 45 and Up Study provides a comprehensive insight into various dimensions of health and social factors[175,181]. These include lifestyle behaviours, household and demographic characteristics, personal experiences, social roles, changes in relationships, chronic diseases, medical interventions, and the overall quality of life reported by the participants[20]. Both the baseline and sub-study data included information on social and demographic characteristics (e.g., age, height, weight, education, marital status); health behaviours (e.g., physical activity, smoking, supplement use, alcohol consumption); general health (e.g., disease and surgical history)[181] (see Appendix 7,8, and 9). The stroke survivors' baseline and sub-study information was linked to the MBS and PBS data[182], and the linkage was conducted by the Sax Institute using a unique identifier that was provided by the Services Australia[182].

3.2.2.2 The Australian Longitudinal Study on Women's Health

The ALSWH commenced data collection in 1996, focusing on three distinct age groups of women: young (18–23 years; born 1973-1978), mid-age (45–50 years; born 1946-1951) and old (70–75 years; born 1921-1926). From the database of the Health Insurance Commission (currently known as Medicare Australia), the participants of the baseline surveys of the ALSWH study were selected using a random sampling method within each of the age groups (except for women residing in rural and remote areas, who were oversampled at a double rate than urban women)[180]. The participants are broadly representative of the nationwide female population within the specified age groups[180].

The research presented in my thesis utilised the dataset of the ALSWH mid-age cohort, of which 13,714 women participated in the baseline survey in 1996[176]. The data from this cohort of participants was collected through mailed surveys at intervals of approximately three years[176]. At the approval of this research project, datasets from nine surveys were available for

this cohort, with participant ages ranging from 45-50 years in the first survey in 1996 to 68-73 years in the ninth survey in 2019[183]. However, due to the availability and consistency of the variables associated with a healthy lifestyle, only data from surveys 5 through to 9 were used in analyses. The questionnaire item *"In the Past 3 years, have you been diagnosed with or treated for stroke"* was utilised across all surveys to identify stroke patients. A total of 531 stroke survivors were identified in different surveys. Among them, 456 stroke survivors participated in survey 5 (2007); 433 stroke survivors participated in survey 6 (2010); 402 in survey 7 (2013); 360 in survey 8 (2016); and 333 in survey 9 (2019). Note that the decline in the number of participants is a frequent phenomenon observed in longitudinal surveys, mostly attributed to causes such as attrition and loss to follow-up[184]. The average age of these 531 female stroke survivors was 58.1 (SD=1.4) years in survey 5 and 70.5 (SD=1.5) years in survey 9.

3.2.3 Variables

The dependent (i.e. outcome) variables for study were physical activity, alcohol consumption status, smoking status, supplement use, number of times participants received care from health professionals, the number of dispensed stroke-related medications and the self-reported physical and mental health status. The independent variables were gender, age, education, marital status, body mass index (BMI), comorbidities, and survey periods.

3.2.3.1 Measures

For both cohorts, physical activity was calculated using questionnaires from the Active Australia Survey[185], whose reliability and validity have been demonstrated to be acceptable as a self-reported measure of physical activity[186]. Participants reported their weekly frequency and time (hours and minutes) engaged in: (i) continuous walking for at least 10 minutes; (ii) moderate physical activities (such as social tennis, gentle swimming, gardening/housework); and (iii) vigorous physical activities that caused them to breathe more heavily or puff and pant (such as jogging, cycling, aerobics, competitive tennis). According to the physical activity recommendations in adults, participants were categorised as inactive/sedentary if they engaged in physical activity for <150 minutes/week, and moderately/highly active if they engaged in physical activity for ≥150 minutes/week[187]. The participants were asked to report the number of standard alcoholic drinks they usually consumed daily. For both cohorts, the risk of alcohol

consumption was classified as "no/low risk" if the participant consumed ≤14 drinks/week, and as "moderate/high risk" if they consumed >14 drinks/week, in accordance with Australian alcohol guidelines designed to reduce the risk of long-term harm[188]. Similarly, for both cohorts, the smoking status was determined by asking participants how often they currently smoke cigarettes or any tobacco products. In the 45 and Up study cohort, a participant who consumed multivitamins, minerals, omega-3, or fish oil was classified as a supplement user. Meanwhile, in the ALWHS cohort, a participant who consumed multivitamins and/or minerals was classified as a supplement user.

The number of times participants received care from general practitioners (GP), nurse practitioners, allied health professionals or specialist doctors was used to calculate the number of times they received care from health professionals. Allied health professionals included allied mental health professionals, physiotherapists, occupational therapists, audiologist, dietitians, exercise physiologists, podiatrists, and speech pathologists. Specialist doctors involved psychiatrist and neurosurgery specialist. Number of dispensed stroke-related medications was calculated from the number of dispensed blood thinning medications, cholesterol lowering medication, or blood pressure medication. Blood thinning medications included antiplatelet medications and anticoagulant medications (see Appendix 5 and 6 for the MBS and PBS items). Number of comorbidities was calculated from the diseases: hypertension, heart disease, diabetes, depression, anxiety, asthma, arthritis, cancer, bronchitis, low iron level, and osteoporosis.

The self-reported physical and mental health status was determined using the Physical Component Summary (PCS) scores and Mental Component Summary (MCS) scores obtained from the Short Form 36 Health Survey Questionnaire (SF-36)[189–192]. The SF-36 questionnaire comprises eight distinct multi-item scales, consisting of a total of 36 items[189–192]. These scales evaluate various aspects of an individual's health, including physical function (PF), bodily pain (BP), role limitations due to physical health problems (RP), general health (GH), vitality (V), social functioning (SF), role limitations due to emotional problems (RE), and mental health (MH)[189–192]. Two summary measures of health status, namely PCS scores and MCS scores, are calculated using standard scoring algorithms based on the eight scales[189–192] . The PCS score is comprised of PF, BP, RP, and GH, whereas the MCS score is comprised of V, SF, RE, and MH[190–192]. PCS and MCS scores range from 0 to 100 (mean = 50, standard deviation=10), with

higher scores indicating better health[189–192]. The SF-36 is commonly used to measure self-reported physical and mental health status in various populations including stroke survivors[189–192]. The SF-36 has been shown to have high reliability and validity for use with stroke survivors[192,193].

3.2.4 Statistical Analyses

In this thesis research, the chi-square test was employed to evaluate the bivariate association between a dependent variable and an independent variable in the cross-sectional analysis. Besides, to examine the mean differences between a dependent variable and an independent variable, a two-sample t-test was utilised for groups with two categories, while an Analysis of Variance (ANOVA) test was employed for groups with more than two categories.

Longitudinal studies are commonly utilised in health research to assess the health trajectories, the progression of diseases, the development or decline of health, and the effectiveness of interventions over time[194–196]. Multiple approaches are used in the analysis of longitudinal data, including paired t-tests, repeated measures analysis of variance (ANOVA), Generalised Estimating Equation (GEE), and mixed-effect models[196–200]. A limitation associated with employing the paired t-tests and repeated measures ANOVA is their inability to control for covariates[196–198]. To overcome such limitations, two statistical approaches, namely GEE and mixed-effects models, are commonly used in longitudinal analysis[196–200]. It is noteworthy that the model fitting tendencies of these two approaches vary depending on the objectives of the study[196–200]. As opposed to the mixed-effect model, which employs random effects to capture the correlation between individual observations of the same subject, GEE utilises a quasi-likelihood function to provide population-averaged estimates of the parameters[198-200]. It is widely acknowledged that GEE possesses several unique characteristics[194–198]. In GEE, the variance-covariance matrix of responses is considered as nuisance parameters, which simplifies the process of estimating this model in comparison to mixed-effect models[198-200]. GEE is given preference, specifically when the primary focus is on the overall treatment effect[194–198].

Therefore, in my research, generalised estimating equation (GEE) models were employed to assess the longitudinal association between a dependent variable and independent variables. Backwards stepwise regression model process was used to determine the most parsimonious model for each dependent variable[201]. Multicollinearity across variables was assessed using Variance Inflation Factors (VIF)[203]. Sensitivity analyses were performed by examining alternative model specifications and adjusting for potential confounding factors to ensure the robustness of the findings[202]. The statistical software Stata 14.0 was utilised throughout all the analysis processes. The level of statistical significance for each test was set at $p<0.05$.

3.3 Ethical Considerations

The 45 and Up Study was granted ethical approval by the Human Research Ethics Committee (HREC) of the University of New South Wales. The Human Research Ethics Committees at the University of Newcastle and the University of Queensland, Australia, granted ethics approval for ALSWH. The participants provided clear written consent to participate and long-term follow-up in the 45 and Up study and ALSWH. In addition, the HREC at the University of Technology Sydney permitted the use of the linked datasets of the 45 and Up Study for this research. In addition, approval was received from the ALSWH Data Access Committee to use the de-identified ALSWH Core dataset for this research.

Chapter 4: A longitudinal investigation of the determinants of stroke survivors' utilisation of a healthy lifestyle for stroke rehabilitation in Australia.

This chapter explores Research Questions 3, 4, and 5, focusing on the prevalence and determinants of healthy lifestyle behaviours among post-stroke individuals in Australia. The study utilises longitudinal data obtained from the baseline survey conducted between 2005 and 2009 and a sub-study survey conducted in 2017 of the 45 and Up Study. Within this investigation, the chapter uncovers several noteworthy and significant findings. The findings have been published in the journal *Scientific Reports* (2024).

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4.1 Abstract

The aim of this study was to determine the longitudinal predictors of lifestyle behaviours among stroke survivors in Australia. For this longitudinal study we used data from the baseline survey (2005-2009) and a sub-study survey (2017) of the 45 and Up Study. Physical activity, alcohol consumption, smoking status, and supplement use were included as dependent variables. Generalised estimating equation models were employed to assess the longitudinal association between the dependent variable and demographic and health status measures. The average age of the participants (n=576) was 67 (SD=9) years at baseline and 76 (SD=9) years at the sub-study survey time, with 54.9% being male. The longitudinal analysis revealed that

the likelihood of moderate/high physical activity significantly declined over time and was lower among participants with diabetes, but was higher among those with university education. The likelihood of smoking was significantly higher in females, moderate/high-risk alcohol consumers, and those with depression, but was lower among supplement users. The likelihood of moderate/high-risk alcohol consumption significantly declined with time, and was lower among females, but higher among smokers. The likelihood of supplement use significantly declined over time, but was higher among females and/or those with asthma. Our findings help illustrate that many stroke survivors may benefit from further support in adopting and maintaining a healthy lifestyle as part of their stroke management and long-term rehabilitation, which is crucial to optimising their quality of life and successful secondary stroke prevention.

4.2 Introduction

Stroke is a sudden onset of symptoms of localised neurological dysfunction caused by an interruption in blood flow to the brain[1-2]. It is a leading cause of adult disability and mortality, and the number of people having a stroke event continues to rise and is predicted to increase significantly in future decades[10,34]. For example, the number of stroke incident cases grew by 70% between 1990 and 2019 worldwide, and by 2050, the number of stroke survivors is expected to nearly double (200 million) compared to 2019 (101 million)[10]. From the perspectives of both healthcare and research, it is essential to address the long-term demands of post-stroke individuals[77].

In 2018, there were approximately 387,000 Australians aged ≥15 years (1.3% of the population) who had survived a stroke, with around 39,500 individuals experiencing a stroke each year[204]. This results in long-term physical and mental disabilities that place a significant burden on their families, communities, and country's healthcare systems[204]. Common consequences of a stroke include permanent disability, restrictions in motor function, fatigue, pain, falls, dysarthria, aphasia, memory deficits, cognitive impairments, visual problems, social isolation, anxiety, depression, and dependency, among others[205,206]. Moreover, almost 43% of first-ever in a lifetime survivors of stroke are at risk of a second stroke within ten years[207]. The death rate among recurrent stroke survivors is around 41% within the first month after the first recurrent event, which is significantly higher than first-ever stroke survivors (22%)[207]; therefore, preventing stroke recurrence is an important way to reduce the mortality rate from

stroke. Consequently, several international clinical guidelines strongly recommend that stroke survivors adopt self-management strategies, including a healthy lifestyle, as part of their long-term rehabilitation after a stroke[65–69].

Self-management is a widely accepted strategy for reducing the chronic disease burden and supporting people in managing their long-term conditions more efficiently[60]. The term "self-management" is defined as a development process where individuals maintain, monitor, manage, and prevent chronic conditions through the practice of a healthy lifestyle, behaviours and activities, and medical interventions[60]. Self-management has emerged as a potentially useful strategy for long-term rehabilitation after stroke in recent years since it enables stroke survivors with long-term management and provides a pathway to maximise stroke recovery[71,76,140,149]. For example, it has been empirically established that lifestyle modification or maintaining a healthy lifestyle is the most common self-management strategy for long-term rehabilitation after stroke[66,71,76,140,149].

Unhealthy behaviours, such as physical inactivity, inadequate nutrition, excessive alcohol intake, and smoking are major primary and secondary stroke risk factors[94,208]. Stroke survivors are more likely to have low levels of physical activity, most likely due to their disability, fatigue, functional limitations, inaccessible surroundings, lack of motivation, depression, and lack of social support[77,209]. For successful self-management, these stroke-related challenges need to be overcome[77]. Moderate to vigorous physical activity (≥150 minutes/week) is important in stroke rehabilitation, where such activity can improve functional capacity (such as muscle strength, upper limb motor movement, and balance), cardiovascular health, confidence, and quality of life in stroke survivors, as well as reduce their risk of subsequent stroke[73,77,78,88,94]. Similarly, nutritional supplements, quitting smoking, and consuming less alcohol are also associated with improved health status, mental wellbeing, physical performance, the prevention of further strokes, brain recovery, and lower nutrition-related diseases and mortality rates among stroke survivors[73,79–82,94,99,210].

Despite the recent and emerging research on post-stroke self-management, little is known about the adoption and maintenance of healthy lifestyle behaviours among stroke survivors. No large-scale longitudinal study has been undertaken to evaluate the related determinants of a healthy lifestyle among stroke survivors in Australia. To directly address this gap, this study investigated the longitudinal determinants of lifestyle behaviours among Australian stroke

survivors. We hypothesised that baseline engagement in healthy lifestyle behaviours would influence their long-term maintenance of such behaviours among stroke survivors. Additionally, the presence of comorbid conditions at baseline was hypothesised to be associated with a lower likelihood of engaging in healthy lifestyle behaviours over time. Furthermore, it was anticipated that survivors of stroke with higher educational attainment would be more likely to maintain healthy lifestyle behaviours over time compared to those with lower educational attainment.

4.3 Methods

4.3.1 Sample

The data retrieved from the baseline survey and a sub-study survey of the Sax Institute's 45 and Up Study conducted in Australia. The baseline survey collected data from ≥45 years of age male and female residents of New South Wales, Australia. The 45 and Up Study details are provided elsewhere[211]. In brief, participants were selected at random from the Services Australia Medicare enrolment database to assure coverage of almost the whole population. To ensure statistical power, ≥80 years old people as well as remote and rural inhabitants were oversampled due to their smaller populations. Participants were enrolled in the study between 2005 and 2009 by answering a baseline postal questionnaire and providing informed consent to participate and long-term follow-up. The baseline survey collected data from 267,357 individuals, with an approximate 19% response rate, representing nearly 11% of the population of New South Wales aged 45 and older. Between April and October 2017, a sub-study survey of respondents from this cohort was conducted[149]. The sub-study questionnaire was sent to 1,300 participants who stated they had been diagnosed with a stroke on the baseline 45 and Up study survey. Both the baseline and sub-study data included information on social and demographic characteristics; health behaviours (e.g., physical activity, smoking, supplement use, alcohol consumption); general health; and health service utilisation[181]. A total of 576 stroke survivors completed and returned the sub-study questionnaire, with a response rate of 44.3%. The data from these 576 stroke survivors were analysed and reported in this study[149].

4.3.2 Outcome variables

The outcome variables for this study were physical activity, alcohol consumption status, smoking status, and supplement use. The measures of outcome variables were as follows:

In the baseline and sub-study questionnaires, physical activity was calculated using questionnaires from the Active Australia Survey[185], whereby the reliability and validity have been demonstrated to be acceptable as a self-reported measure of physical activity[186]. Participants reported their weekly frequency and time (hours and minutes) engaged in: (i) continuous walking (W) for at least 10 minutes; (ii) moderate physical activities (M) (such as social tennis, gentle swimming, gardening/housework); and (iii) vigorous physical activities (V) that caused them to breathe more heavily or puff and pant (such as jogging, cycling, aerobics, competitive tennis). According to the Active Australia Survey, the value of time spent in vigorous physical activity was double that of time spent in lower-intensity physical activity[185]. Therefore, the time of physical activity during the previous week was computed as W+M+2V, where W, M, and V denote the total amount of time spent on walking, moderate physical activity, and vigorous physical activity, respectively[187,212]. According to the physical activity recommendations in adults, participants were categorised as inactive/sedentary if they engaged in physical activity for <150 minutes/week, and moderately/highly active if they engaged in physical activity for ≥150 minutes/week[187].

The total number of alcoholic drinks was calculated from the item “how many alcoholic drinks do you have each week?” (one drink equals a small glass of wine, middy of beer or nip of spirits). The risk of alcohol consumption was classified as "no/low risk" if the participant consumed ≤14 drinks/week, and as "moderate/high risk" if they consumed >14 drinks/week, in accordance with Australian alcohol guidelines designed to reduce the risk of long-term harm[188].

Current smokers were identified in the baseline survey using the question “are you a regular smoker now?” In contrast, current smokers during the sub-study period were identified using the question, “how often do you currently smoke cigarettes or any tobacco products?”.

For both the baseline and sub-study periods, supplement usage was identified if any of the following items were used within the previous month: multivitamins, minerals, omega-3, or fish oil.

4.3.3 Covariates

Covariates included sex (male, female), education (no formal school/school only, trade/apprentice/diploma, university), marital status (never married, married/living with a partner, widowed/divorced/separated), body mass index (BMI), hypertension, heart disease, diabetes, depression, anxiety, and asthma.

At baseline and sub-study, self-reported height (m) and weight (kg) were used to determine the BMI (kg/m^2). According to World Health Organization classifications, BMI was categorised as follows: underweight or normal (<25.0 kg/m^2), overweight (25.0-29.9 kg/m^2), and obese (BMI ≥30.0 kg/m^2)[213]. The presence of hypertension, heart disease, diabetes, depression, anxiety, and asthma were determined from the questions "has a doctor ever told that you have …" [any of these particular conditions] in the baseline questionnaire and "in the past 12 months, have you been diagnosed or treated by a doctor for any of the following disease", in the sub-study questionnaire.

4.3.4 Statistical Analysis

Bivariate association between a dependent variable and an independent variable was assessed using chi-square tests. While the data were cross-sectional at each time point (baseline and follow-up), the longitudinal approach allowed us to examine associations between initial behaviours and their continuity or change over time. Generalised estimating equation (GEE) models, specifying the binomial family with logit link function and robust standard errors, were employed to assess the longitudinal association between a dependent variable and independent variables. GEE was chosen for its capacity to address within-subject correlations in a repeated measures framework and for delivering robust estimates, making it suitable for our emphasis on population-averaged effects[194,195,198,199]. All variables that returned a $p<0.25$ in bivariate analysis were entered into a GEE model and adjusted odds ratios (AORs) were calculated. This threshold was chosen based on the recommendation that variables with p-values up to 0.25 in the univariate analysis should be included in multivariate models to account for potential confounders[201]. Backwards stepwise regression was employed to systematically exclude non-significant variables, producing a more parsimonious model, which was especially useful due to the exploratory character of the study and a large number of covariates[201]. We assessed multicollinearity across variables utilising variance inflation factors (VIF)[202], and no significant

multicollinearity was identified (VIF<10). Sensitivity analyses were performed by examining alternative model specifications and adjusting for potential confounding factors. The primary findings remained consistent across various iterations of the model[203]. The statistical software Stata 14.0 was utilised throughout all of the analysis processes. The level of statistical significance for each test was set at $p<0.05$.

4.3.5 Ethical Approval

The 45 and Up Study was granted ethical approval by the Human Research Ethics Committee (HREC) of the University of New South Wales. HREC at the University of Technology Sydney permitted the use of the baseline and sub-study datasets from the 45 and Up Study in this study (approval number: ETH19-3442). The participants provided clear written consent to participate and long-term follow-up in the 45 and Up study. All methods were performed in accordance with the relevant guidelines and regulations.

4.4 Results

This study included a total of 576 stroke survivors who had participated in both the baseline and sub-study surveys. Table 4.1 displays the demographic and health status characteristics of the participants. The majority of the sample was male (54.9%). The average age of the participants was 66.5 (SD=9.1) years at baseline and 75.8 (SD=9.1) years at the time of the sub-study survey.

Table 4.1 Demographic and health status characteristics of the participants.

Characteristics	Baseline (2005-2009)		Sub-study (2017)	
	Frequency	Percentage	Frequency	Percentage
Sex				
Male	316	54.9	316	54.9
Female	260	45.1	260	45.1
Education				
No formal school/School only	264	46.4	276	48.3
Trade/Apprentice/Diploma	194	34.1	187	32.8
University	111	19.5	108	18.9
Marital Status				
Never Married	44	07.7	51	9.0
Married/Living with partner	402	70.3	359	63.3
Widowed/Divorced/Separated	126	22.0	157	27.7

Smoking				
No	536	93.1	490	89.6
Yes	40	6.9	57	10.4
Alcohol consumption risk				
None/Low	468	83.0	487	87.4
Moderate/High	96	17.0	70	12.6
BMI (kg/m^2)				
Underweight or Normal (<25.0)	185	34.8	180	35.4
Overweight (25.0-29.9)	223	42.0	195	38.4
Obese (≥30.0)	123	23.2	133	26.2
Physical activity				
Inactive/Sedentary (<150 min)	131	23.6	199	37.3
Moderate/High (≥150 min)	425	76.4	335	62.7
Hypertension				
No	324	56.3	374	64.9
Yes	252	43.7	202	35.1
Heart disease				
No	460	79.9	438	76.0
Yes	116	20.1	138	24.0
Diabetes				
No	498	86.5	474	82.3
Yes	78	13.5	102	17.7
Depression				
No	431	86.4	519	90.1
Yes	68	13.6	57	9.9
Anxiety				
No	451	90.4	524	91.0
Yes	48	9.6	52	9.0
Asthma				
No	437	87.6	521	90.5
Yes	62	12.4	55	9.5
Supplements use				
No	327	56.8	472	81.9
Yes	249	43.2	104	18.1

As shown in Figure 4.1, there were some changes over time, where the percentage of smokers increased from baseline (6.9%) to sub-study (10.4%), but the percentage of moderate/high-risk alcohol consumers declined from baseline (17.0%) to sub-study (12.6%). Similarly, moderate/high physical activity (76.4% at baseline and 62.7% in sub-study) and supplements use (43.2% at baseline and 18.1% in sub-study) decreased over time.

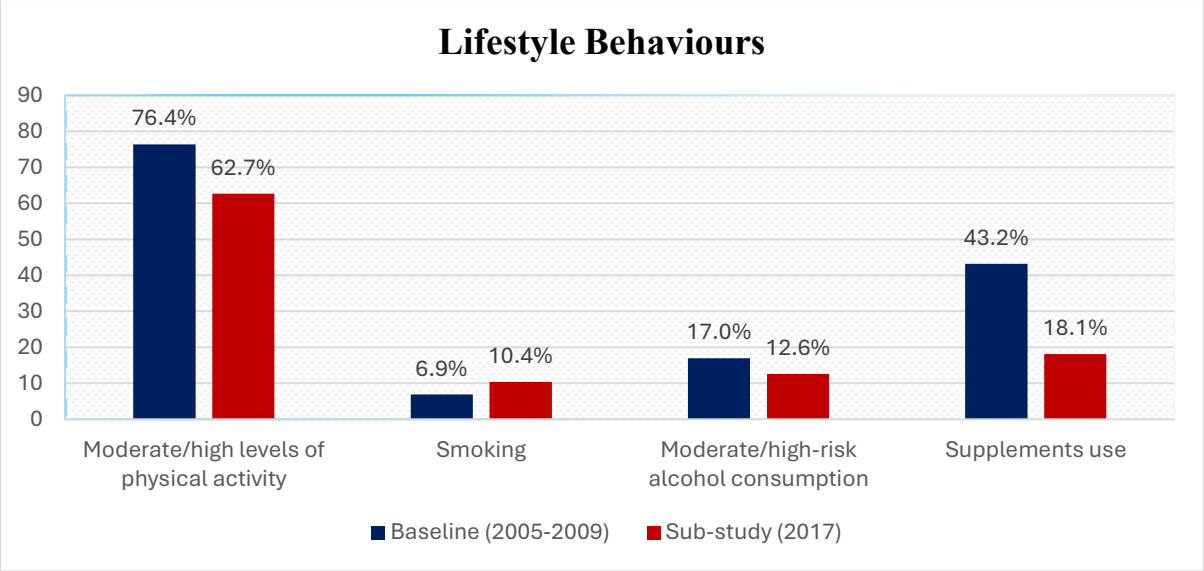

Figure 4.1: Lifestyle behaviours of the participants.

Table 4.2 presents the cross-sectional association between physical activity and demographic and health status characteristics. Statistically significant associations were identified between physical activity and six characteristics at baseline and/or the sub-study. At baseline, a greater percentage of participants who undertook a moderate or high level of physical activity were smokers (p=0.025), moderate/high-risk alcohol consumers (p=0.035), had underweight or normal BMI (p=0.019), and/or did not have asthma (p=0.029). Similarly, in the sub-study, a greater percentage of participants who undertook a moderate or high level of physical activity were those who did not have diabetes (p=0.015), had an overweight BMI (p=0.025), and had university-level education (p=0.011).

Table 4.2 Association between physical activity and demographic and health status characteristics.

Characteristics	Physical Activity					
	Baseline (2005-2009)			Sub-study (2017)		
	Inactive/ Sedentary	Moderate/high	*p*-value	Inactive/ Sedentary	Moderate/high	*p*-value
	n (%)	n (%)		n (%)	n (%)	
Sex			0.503			0.883
Male	69 (22.5)	238 (77.5)		108 (37.0)	184 (63.0)	
Female	62 (24.9)	187 (75.1)		91 (37.6)	151 (62.4)	
Education			0.727			0.011
No formal school/School only	60 (23.8)	192 (76.2)		106 (43.6)	137 (56.4)	

Trade/Apprentice/Diploma	48 (25.4)	141 (74.6)		63 (35.0)	117 (65.0)	
University	23 (21.3)	85 (78.7)		29 (27.4)	77 (72.6)	
Marital Status			0.760			0.814
Never Married	08 (19.0)	34 (81.0)		20 (40.8)	29 (59.2)	
Married/Living with partner	93 (23.7)	299 (76.3)		121 (36.4)	211 (63.6)	
Widowed/Divorced/Separated	29 (24.6)	89 (75.4)		55 (38.2)	89 (61.8)	
Smoking			0.025 [F]			0.490
No	128 (24.7)	391 (75.3)		172 (36.7)	297 (63.3)	
Yes	*	>32 (> 86.5) [A]		22 (41.5)	31 (58.5)	
Alcohol consumption risk			0.035			0.415
None/Low	114 (25.2)	338 (74.8)		170 (37.5)	283 (62.5)	
Moderate/high	14 (15.0)	79 (85.0)		21 (32.3)	44 (67.7)	
BMI (kg/m^2)			0.019			0.025
Underweight or Normal	28 (15.7)	150 (84.3)		65 (38.0)	106 (62.0)	
Overweight	56 (25.7)	162 (74.3)		55 (29.7)	130 (70.3)	
Obese	33 (28.0)	85 (72.0)		55 (44.7)	68 (55.3)	
Hypertension			0.801			0.599
No	75 (24.0)	238 (76.0)		122 (36.4)	213 (63.6)	
Yes	56 (23.0)	187 (77.0)		77 (38.7)	122 (61.3)	
Heart disease			0.823			0.296
No	103 (23.4)	338 (76.7)		144 (36.0)	256 (64.0)	
Yes	28 (24.3)	87 (75.7)		55 (41.0)	79 (57.0)	
Diabetes			0.076			0.015
No	107 (22.3)	373 (77.7)		152 (34.9)	284 (65.1)	
Yes	24 (31.6)	52 (68.4)		47 (48.0)	51 (52.0)	
Depression			0.889			0.203
No	94 (22.6)	321 (77.4)		175 (36.4)	306 (63.6)	
Yes	15 (23.4)	49 (76.6)		24 (45.3)	29 (54.7)	
Anxiety			0.535			0.075
No	100 (23.1)	332 (76.9)		175 (36.1)	310 (63.9)	
Yes	09 (19.1)	38 (80.9)		24 (49.0)	25 (51.0)	
Asthma			0.029			0.410
No	89 (21.2)	331 (78.8)		182 (37.8)	299 (62.2)	
Yes	20 (33.9)	39 (66.1)		17 (32.1)	36 (68.0)	
Supplements use			0.446			0.998
No	78 (24.8)	237 (75.2)		161 (37.3)	271 (62.7)	
Yes	53 (22.0)	188 (78.0)		38 (37.2)	64 (62.8)	

Note: *p*-value is obtained using chi-square test, unless indicated by [F] in which case the *p*-value is obtained using Fisher Exact test. *Indicates n < 5 (disclosure of such small numbers in publications presents a potential risk to confidentiality and is prohibited by The Sax Institute's 45 and Up Study). [A]The exact number and percentage are not mentioned in order to prevent the identification of small numbers (<5) within the corresponding data cell.

A longitudinal GEE model was used to determine the most important factors for predicting moderate to high levels of physical activity over time (Table 4.3). Participants were 47% less

likely to be moderately/highly physically active at the time of the sub-study (AOR=0.53; 95% CI: 0.42, 0.68; p<0.001) than the baseline period. Similarly, moderate/high physical activity was 37% lower among participants with diabetes (AOR: 0.63; 95% CI: 0.43, 0.91; p=0.015) than the non-diabetic participants. Conversely, moderate/high physical activity was 1.60 times higher among participants with university education (AOR=1.60; 95% CI: 1.07, 2.39; p=0.022) than the participants with no formal school/school education.

Table 4.3 Output of a Generalised Estimating Equation (GEE) model predicting physical activity across baseline and sub-study periods.

	Moderate/high Physical activity *	
Variables	**AOR (95% CI)**	***p*-value**
Time		
Baseline	1.00	
Sub-study	0.53 (0.42, 0.68)	<0.001
Education		
No formal school/School only	1.00	
Trade/Apprentice/Diploma	1.19 (0.87, 1.61)	0.271
University	1.60 (1.07, 2.39)	0.022
Diabetes		
No	1.00	
Yes	0.63 (0.43, 0.91)	0.015

* Reference category: Inactive/Sedentary.
AOR: Adjusted odds ratio.

Table 4.4 shows the cross-sectional association between smoking status and the selected demographic and health status characteristics. Statistically significant associations were identified between smoking status and seven characteristics at baseline and/or the sub-study. At baseline, a greater percentage of participants who were smokers were female (p=0.022), consumed alcohol at moderate or high-risk levels (p=0.001), undertook moderate to high levels of physical activity (p=0.025), and/or did not have hypertension (p=0.002). At both the baseline and sub-study periods, a greater percentage of participants who were smokers were single (p<0.05), had depression (p<0.05) and/or had anxiety (p<0.05).

Table 4.4 Association between smoking and demographic and health status characteristics.

Characteristics	Smoking					
	Baseline (2005-2009)			Sub-study (2017)		
	No	Yes	*p*-value	No	Yes	*p*-value
	n (%)	n (%)		n (%)	n (%)	
Gender			0.022			0.069
Male	301 (95.2)	15 (4.7)		277 (91.7)	25 (8.3)	
Female	235 (90.4)	25 (9.6)		213 (86.9)	32 (13.1)	
Education			0.818			0.173
No formal school/School only	245 (92.8)	19 (7.2)		224 (87.8)	31 (12.2)	
Trade/Apprentice/Diploma	181 (93.3)	13 (6.7)		161 (89.4)	19 (10.6)	
University	105 (94.6)	06 (5.4)		101 (94.4)	06 (5.6)	
Marital Status			<0.001			<0.001
Never Married	36 (81.8)	08 (18.2)		34 (70.8)	14 (29.2)	
Married/Living with partner	385 (95.8)	17 (4.2)		324 (94.2)	20 (5.8)	
Widowed/Divorced/Separated	111 (88.1)	15 (11.9)		126 (86.3)	20 (13.7)	
Alcohol consumption risk			0.001			0.056
None/Low	443 (94.7)	25 (5.3)		421 (91.3)	40 (8.7)	
Moderate/High	82 (85.4)	14 (14.6)		58 (84.1)	11 (15.9)	
BMI (kg/m^2)			0.139			0.862
Underweight/Normal	167 (90.3)	18 (9.7)		152 (89.9)	17 (10.1)	
Overweight	211 (94.6)	12 (5.4)		174 (91.6)	16 (8.4)	
Obese	117 (95.1)	06 (4.9)		114 (90.5)	12 (9.5)	
Physical activity			0.025 [F]			0.490
Inactive/Sedentary	-	*		172 (88.7)	22 (11.3)	
Moderate/High	-	-		297 (90.6)	31 (9.4)	
Hypertension			0.002			0.915
No	292 (90.1)	32 (9.1)		313 (89.7)	36 (10.3)	
Yes	244 (96.8)	08 (3.2)		177 (89.4)	21 (10.6)	
Heart disease			0.212			0.335
No	425 (92.4)	35 (7.6)		367 (88.9)	46 (11.1)	
Yes	111 (95.7)	05 (4.3)		123 (91.8)	11 (8.2)	
Diabetes			0.636 [F]			0.908
No	-	-		401 (89.5)	47 (10.5)	
Yes	-	*		89 (89.9)	10 (10.1)	
Depression			0.024			0.047
No	406 (94.2)	25 (5.8)		445 (90.5)	47 (9.5)	
Yes	59 (86.8)	09 (13.2)		45 (81.8)	10 (18.2)	
Anxiety			0.025			0.020
No	424 (94.0)	27 (6.0)		450 (90.5)	47 (9.5)	
Yes	41 (85.4)	07 (14.6)		40 (80.0)	10 (20.0)	
Asthma			0.999 [F]			0.451
No	-	-		445 (89.9)	50 (10.1)	
Yes	-	*		45 (86.5)	07 (13.5)	
Supplements use			0.080			0.850

No	299 (91.4)	28 (8.6)	399 (89.5)	47 (10.5)
Yes	237 (95.2)	12 (4.8)	91 (90.1)	10 (9.9)

Note: *p*-value is obtained using chi-square test, unless indicated by [F] in which case the *p*-value is obtained using Fisher Exact test. *Indicates n < 5 (disclosure of such small numbers in publications presents a potential risk to confidentiality and is prohibited by The Sax Institute's 45 and Up Study). - The numbers and percentages are not mentioned in order to prevent the identification of small numbers (<5) within the corresponding data cell.

A longitudinal GEE model was used to determine the most important factors for predicting smoking status over time (Table 4.5). The model indicates that: female participants were 2.28 times more likely to smoke (AOR=2.28; 95% CI: 1.23, 4.21; p=0.009) than male participants; moderate/high-risk alcohol consumers were 2.61 times more likely to smoke (AOR: 2.61; 95% CI: 1.43, 4.76; p=0.002), than the none/low risky alcohol consumers; and participants with depression were 2.72 times (AOR: 2.72; 95% CI: 1.61, 4.58; p<0.001) more likely to smoke than the non-depressed participants. Conversely, the odds of smoking was 81% lower among participants who were married/living with a partner (AOR=0.19; 95% CI: 0.09, 0.40; p<0.001) compared to the single participants; the odds of smoking was 49% lower among participants with hypertension (AOR: 0.51; 95% CI: 0.33, 0.79; p=0.003) than the non-hypertensive participants; and the odd of smoking was 40% lower among supplements users (AOR: 0.60; 95% CI: 0.39, 0.92; p=0.020) than who did not use supplements.

Table 4.5 Output of a Generalised Estimating Equation (GEE) model predicting smoking status across baseline and sub-study periods.

	Smoking status [*]	
Characteristics	**AOR (95% CI)**	***p*-value**
Sex		
Male	1.00	
Female	2.28 (1.23, 4.21)	0.009
Marital Status		
Never Married	1.00	
Married/Living with partner	0.19 (0.09, 0.40)	<0.001
Widowed/Divorced/Separated	0.49 (0.23, 1.04)	0.065
Alcohol consumption risk		
None/Low	1.00	
Moderate/High	2.61 (1.43, 4.76)	0.002
Hypertension		
No	1.00	
Yes	0.51 (0.33, 0.79)	0.003

Depression		
No	1.00	
Yes	2.72 (1.61, 4.58)	<0.001
Supplements		
No	1.00	
Yes	0.60 (0.39, 0.92)	0.020

* Reference category: No Smoking.
AOR: Adjusted odds ratio.

Table 4.6 provides the cross-sectional association between the risk of alcohol consumption and the demographic and health status characteristics. Statistically significant associations were identified between alcohol consumption status and only five characteristics at baseline and/or the sub-study. At baseline, a greater percentage of participants who consumed alcohol at moderate or high-risk levels were smokers (p=0.001), moderately/highly physically active (p=0.035); had hypertension (p=0.025), and/or did not have asthma (p=0.006). At both the baseline and sub-study periods, a greater percentage of participants who consumed alcohol at moderate or high-risk levels were male (p<0.001).

Table 4.6 Association between alcohol consumption and demographic and health status characteristics.

Characteristics	**Risk of alcohol consumption**					
	Baseline (2005-2009)			**Sub-study (2017)**		
	None/low	**Moderate/ high**	***p*-value**	**None/low**	**Moderate /high**	***p*-value**
	n (%)	**n (%)**		**n (%)**	**n (%)**	
Sex			<0.001			<0.001
Male	231 (74.5)	79 (25.5)		249 (81.4)	57 (18.6)	
Female	237 (93.3)	17 (6.7)		238 (94.8)	13 (5.2)	
Education			0.517			0.715
No formal school/School only	221 (84.7)	40 (15.3)		234 (87.6)	33 (12.4)	
Trade/Apprentice/Diploma	158 (83.6)	31 (16.4)		158 (88.3)	21 (11.7)	
University	87 (79.8)	22 (20.2)		91 (85.1)	16 (14.9)	
Marital Status			0.270			0.335
Never Married	32 (74.4)	11 (25.6)		39 (81.2)	09 (18.8)	
Married/Living with partner	332 (84.1)	63 (15.9)		311 (88.6)	40 (11.4)	
Widowed/Divorced/Separated	100 (82.0)	22 (18.0)		130 (86.7)	20 (13.3)	
Smoking			0.001			0.056
No	443 (84.4)	82 (15.6)		421 (87.9)	58 (12.1)	
Yes	25 (64.1)	14 (35.9)		40 (78.4)	11 (21.6)	
BMI (kg/m^2)			0.746			0.478

Underweight or Normal	152 (84.0)	29 (16.0)		155 (89.1)	19 (10.9)	
Overweight	177 (81.2)	41 (18.8)		161 (85.2)	28 (14.8)	
Obese	100 (83.3)	20 (16.7)		117 (88.6)	15 (11.4)	
Physical activity			0.035			0.415
Inactive/Sedentary	114 (89.1)	14 (10.9)		170 (89.0)	21 (11.0)	
Moderate/High	338 (81.1)	79 (18.9)		283 (86.5)	44 (13.5)	
Hypertension			0.025			0.866
No	273 (86.1)	44 (13.9)		315 (87.3)	46 (12.7)	
Yes	195 (79.0)	52 (21.0)		172 (87.8)	24 (12.2)	
Heart disease			0.801			0.168
No	375 (82.8)	78 (17.2)		367 (86.4)	58 (13.6)	
Yes	93 (83.8)	18 (16.2)		120 (90.9)	12 (9.1)	
Diabetes			0.311			0.138
No	401 (82.3)	86 (17.7)		396 (86.5)	62 (13.5)	
Yes	67 (87.0)	10 (13.0)		91 (91.9)	08 (8.1)	
Depression			0.437			0.683
No	349 (82.5)	74 (17.5)		439 (87.6)	62 (12.4)	
Yes	57 (86.4)	09 (13.6)		48 (85.7)	08 (14.3)	
Anxiety			0.739			0.749
No	367 (82.8)	76 (17.2)		444 (87.6)	63 (12.4)	
Yes	39 (84.8)	07 (15.2)		43 (86.0)	07 (14.0)	
Asthma			0.006 [F]			0.926
No	-	-		440 (87.5)	63 (12.5)	
Yes	-	*		47 (87.1)	07 (12.9)	
Supplements use			0.089			0.726
No	258 (80.6)	62 (19.4)		395 (87.2)	58 (12.8)	
Yes	210 (86.1)	34 (13.9)		92 (88.5)	12 (11.5)	

Note: *p*-value is obtained using chi-square test, unless indicated by [F] in which case the *p*-value is obtained using Fisher Exact test. *Indicates n < 5 (disclosure of such small numbers in publications presents a potential risk to confidentiality and is prohibited by The Sax Institute's 45 and Up Study). -The numbers and exact percentages are not mentioned in order to prevent the identification of small numbers (<5) within the corresponding data cell.

A longitudinal GEE model was used to determine the most important factors for predicting alcohol consumption status over time (Table 4.7). The model shows that participants were 31% less likely to engage in moderate/high-risk alcohol consumption during the sub-study period (AOR=0.69; 95% CI: 0.54, 0.87; p=0.002) compared to the baseline period. Additionally, female participants were 80% less likely than male individuals to engage in moderate/high risk alcohol intake (AOR=0.20; 95% CI: 0.12, 0.32; p<0.001). Conversely, moderate/high-risk alcohol consumption was 2.93 times higher among smokers than among non-smokers (AOR: 2.93; CI: 1.78, 4.85; p<0.001).

Table 4.7 Output of a Generalised Estimating Equation (GEE) model predicting alcohol consumption risk across baseline and sub-study periods.

Characteristics	Moderate/high risk alcohol consumption * AOR (95% CI)	*p*-value
Time		
Baseline	1.00	
Sub-study	0.69 (0.54, 0.87)	0.002
Sex		
Male	1.00	
Female	0.20 (0.12, 0.32)	<0.001
Smoking		
No	1.00	
Yes	2.93 (1.78, 4.85)	<0.001

* Reference category: None/low risk.
AOR: Adjusted odds ratio.

Table 4.8 shows the unadjusted cross-sectional association between supplement use and the demographic and health status characteristics. Statistically significant associations were identified between supplements use and only three characteristics at baseline and/or the sub-study. At baseline, a greater percentage of participants who consumed supplements did not have hypertension (p=0.043) and who had asthma (p=0.012). At both the baseline and sub-study periods, a greater percentage of participants who consumed supplements were female (p<0.05).

Table 4.8 Association between supplements use and demographic and health status characteristics.

	Supplements use					
	Baseline (2005-2009)			Sub-study (2017)		
Characteristics	No	Yes	*p*-value	No	Yes	*p*-value
	n (%)	n (%)		n (%)	n (%)	
Sex			<0.001			0.004
Male	203 (64.2)	113 (35.8)		272 (86.1)	44 (13.9)	
Female	124 (47.7)	136 (52.3)		200 (76.9)	60 (23.1)	
Education			0.685			0.990
No formal school/School only	150 (56.8)	114 (43.2)		227 (82.3)	49 (17.7)	
Trade/Apprentice/Diploma	113 (58.3)	81 (41.7)		153 (81.8)	34 (18.2)	
University	59 (53.2)	52 (46.8)		89 (82.4)	19 (17.6)	
Marital status			0.515			0.914

Never Married	25 (56.8)	19 (43.2)		41 (80.4)	10 (19.6)	
Married/Living with partner	234 (58.2)	168 (41.8)		297 (82.7)	62 (17.3)	
Widowed/Divorced/Separated	66 (52.4)	60 (47.6)		130 (82.8)	27 (17.2)	
Smoking			0.080			0.850
No	299 (55.8)	237 (44.2)		399 (81.4)	91 (18.6)	
Yes	28 (70.0)	12 (30.0)		47 (82.5)	10 (17.5)	
Alcohol consumption risk			0.089			0.726
None/Low	258 (55.1)	210 (44.9)		395 (81.1)	92 (18.9)	
Moderate/High	62 (64.6)	34 (35.4)		58 (82.9)	12 (17.1)	
BMI (kg/m^2)			0.926			0.442
Underweight or Normal (<25.0)	108 (58.4)	77 (41.6)		151 (83.9)	29 (16.1)	
Overweight (25.0-29.9)	126 (56.5)	97 (43.5)		154 (79.0)	41 (21.0)	
Obese (≥30.0)	70 (56.9)	53 (43.1)		106 (79.7)	27 (20.3)	
Physical activity			0.446			0.998
Inactive/Sedentary	78 (59.5)	53 (40.5)		161 (80.9)	38 (19.1)	
Moderate/High	237 (55.8)	188 (44.2)		271 (80.9)	64 (19.1)	
Hypertension			0.043			0.138
No	172 (53.1)	152 (46.9)		313 (83.7)	61 (16.3)	
Yes	155 (61.5)	97 (38.5)		159 (78.7)	43 (21.3)	
Heart disease			0.385			0.627
No	257 (55.9)	203 (44.1)		357 (81.5)	81 (18.5)	
Yes	70 (60.3)	46 (39.7)		115 (83.3)	23 (16.7)	
Diabetes			0.246			0.309
No	278 (55.8)	220 (44.2)		392 (82.7)	82 (17.3)	
Yes	49 (62.8)	29 (37.2)		80 (78.4)	22 (21.6)	
Depression			0.151			0.326
No	243 (56.4)	188 (43.6)		428 (82.5)	91 (17.5)	
Yes	32 (47.1)	36 (52.9)		44 (77.2)	13 (22.8)	
Anxiety			0.292			0.543
No	252 (55.9)	199 (44.1)		431 (82.3)	93 (17.7)	
Yes	23 (47.9)	25 (52.1)		41 (78.9)	11 (21.1)	
Asthma			0.012			0.062
No	250 (57.2)	187 (42.8)		432 (82.9)	89 (17.1)	
Yes	25 (40.3)	37 (59.7)		40 (72.7)	15 (27.3)	

Note: *p*-value is obtained using chi-square test.

A longitudinal GEE model was used to determine the most important factors for predicting supplement consumption over time (Table 4.9). The model shows that participants were 74% less likely to use supplements during the sub-study period (AOR=0.26; 95% CI: 0.21, 0.34; p<0.001) compared to the baseline period. Conversely, female participants were 1.83 times more likely than their male counterparts to use supplements (AOR=1.83; 95% CI: 1.34, 2.49; p<0.001), while supplements use was 1.71 times higher among participants with asthma (AOR: 1.71; 95% CI: 1.11, 2.62; p=0.014) compared to those without asthma.

Table 4.9 Output of a Generalised Estimating Equation (GEE) model predicting supplements use across baseline and sub-study periods.

Characteristics	Supplements use * AOR (95% CI)	*p*-value
Time		
Baseline	1.00	
Sub-study	0.26 (0.21, 0.34)	<0.001
Sex		
Male	1.00	
Female	1.83 (1.34, 2.49)	<0.001
Asthma		
No	1.00	
Yes	1.71 (1.11, 2.62)	0.014

* Reference category: No supplements use.
AOR: Adjusted odds ratio.

4.5 Discussion

This is the first large-scale longitudinal analysis focusing upon the determinants of healthy lifestyle behaviours among stroke survivors in Australia. The study identified a number of interesting and important findings.

Our analysis revealed that moderate/high levels of physical activity were significantly less prevalent during the sub-study period than during the baseline period. These declines in the prevalence of moderate to vigorous physical activity over time may be related to the increased age of stroke survivors, considering that physical fitness and physical function both decline with age, and a number of medical conditions become more prevalent with increasing age[214,215]. Stroke recurrence may also contribute to a decline in physical activity over time, as an estimated 43% of stroke survivors are at risk of having another stroke within ten years of the first stroke[207], which is associated with a higher risk of physical and mental disability than that associated with the initial stroke[207,216]. Physical inactivity and a sedentary lifestyle can have numerous adverse consequences on the health and wellbeing of stroke survivors, including an increased risk of disability, physical and cognitive functional decline, the development of comorbid conditions, falls, the onset of mental disorders, and recurrent vascular events[78]. Our finding that the recommended amount of physical activity (≥150 min/week) decreases over time is concerning for successful long-term management after a stroke, and it highlights the importance of developing appropriate and effective programmes to promote the recommended

amounts of physical activity for all post-stroke individuals throughout their survivorship. Moreover, future research is needed to explore potential strategies for sustaining adherence to the recommended amount of physical activity, with a special focus on elderly stroke survivors.

Another finding from our analysis was that post-stroke individuals who also reported having diabetes were significantly less likely to engage in the recommended amount of physical activity, which is consistent with a longitudinal study conducted in the general population in Germany that showed diabetes patients had lower physical activity levels than those without diabetes[217]. Diabetes patients commonly experience a variety of complications and challenges, including but not limited to depression, coronary heart disease, peripheral vascular disease, chronic kidney disease, liver disease, infection, falls, vision loss, hearing loss, urinary incontinence, cognitive impairment and dementia, frailty, functional disability, and functional limitations[218,219]. These complications may lead to increased levels of disability in stroke survivors who also have diabetes, thereby providing greater challenges for their participation in recommended levels of physical activity. Diabetes is not only a major risk factor for primary and secondary stroke[220] and a range of complications[218,219], it is also associated with poor post-stroke recovery[220,221]; and hence, effective diabetes management is crucial in stroke rehabilitation[78,220–222]. Moderate to high levels of physical activity may help stroke survivors with diabetes in reducing their risk of diabetes-related complications and recurrent strokes, as well as enhancing their functional recovery[222].

The findings of our study also demonstrate a significant association between having a university education and engaging in moderate to high levels of physical activity amongst those living post-stroke. This finding supports previous research among stroke survivors[223], which demonstrate the importance of high level of education in positively influencing engagement with adequate physical activity. In light of this specific finding from our study, further investigation and reflection upon implementing relevant community-based educational programs may provide a pathway to increasing adherence to the recommended levels of physical activity among those living post-stroke. In particular, stroke survivors with lower educational attainment may benefit from targeted education and support to facilitate this adherence.

Our study shows that the prevalence of smoking increased from baseline to the sub-study. The longitudinal analysis reveals that females, moderate/high-risk alcohol consumers, and participants with depression were more likely to smoke over time. A limitation of our study is the absence of data on participants' past (i.e., pre-stroke) smoking status. This information could have helped assess changes in smoking behaviour before and after the stroke. However, smoking and alcohol consumption are two leading avoidable causes of premature death and illness[224]. Following a stroke event, modifying health behaviours such as smoking and alcohol consumption is crucial to reduce the risk of developing a variety of illnesses, experiencing worse symptoms, poor functional outcomes, potential drug interactions, and a recurrence of stroke[65]. Several clinical stroke rehabilitation guidelines strongly recommend quitting smoking and reducing alcohol consumption (≤14 drinks/week)[65–69]. However, consistent with earlier findings[225], our study identified that depression was an important predictor for smoking amongst post-stroke individuals. Depression following a stroke is prevalent and can impede the overall process of rehabilitation[30,226]. As depression and smoking are independently associated with stroke recurrence and poor functional outcome among stroke survivors[30,226–230], the significant contribution of depression to smoking in our longitudinal study is noteworthy; and our results suggest that effective and appropriate targeted interventions focused upon helping reduce depression following a stroke may be a useful contribution in attempts to reduce smoking prevalence amongst stroke survivors and promote secondary stroke prevention.

Our analyses found that moderate/high-risk alcohol consumption (>14 drinks/week) among stroke survivors significantly decreased over time. Moderate/high levels of alcohol consumption have several detrimental effects in post-stroke individuals, including a greater risk of developing different medical conditions, having a stroke recurrence, worsening of stroke-related symptoms, interference with certain stroke medications, and poor functional outcomes[231]. Healthcare professionals, friends and family members, community support groups, self-management programmes, and online resources can contribute to the dissemination of information regarding the adverse effects associated with risky alcohol consumption among stroke survivors and serve as sources of motivation to reduce their moderate/high-risk alcohol intake[71,76,140,149]. However, further research is required to identify the key influencers—whether individuals, community groups, or healthcare providers—and

the evidence-based strategies that can educate people living with stroke about the risks associated with alcohol consumption and how to reduce those risks.

Our study also demonstrated, as expected, a bi-directional relationship between smoking and moderate-high-risk alcohol consumption amongst stroke survivors. The positive relationship between smoking and alcohol consumption is already well-established[232–234]. This association may be due to inter-personal behaviour (i.e., alcohol consumers may also smoke and vice-versa), environmental factors (i.e., users of both substances may use them simultaneously in the same situations), or the fact that alcohol consumption encourages smoking (and vice-versa)[232–234]. As the combined effects of smoking and moderate/high-risk alcohol consumption may have more dangerous health outcomes in post-stroke individuals[65], the significant link between these behaviours found in our stroke cohort is notable and highlights the importance of potentially ceasing both behaviours to achieve optimal long-term post-stroke health management. Our findings add weight to the need for further investigation of the drivers, enablers and barriers to such behaviours. Additionally, community-based self-management programs and ongoing social support—focused on reducing risk factors associated with unhealthy lifestyles—may play a substantial role in assisting stroke survivors to quit smoking and reduce risky alcohol consumption[76,131].

Our study also identified a significant decline in reported supplement use among stroke survivors over time. However, there is no study in Australia or any other country that is directly comparable to this finding. Possible reasons for the decline in supplement use over time may include the completion of the recommended dosage of the supplements, meeting the desired needs of the users, increased medication burden, potential interaction of supplements with stroke/other medications, and/or failing to experience the expected outcomes from supplement use over time[80,81,235]. Given the potential benefits of dietary supplements for aspects of stroke rehabilitation[80,81,99,210], further research is warranted to investigate various core aspects of supplement use amongst stroke survivors and specifically explore the causes of supplement use decline among stroke survivors with time.

Our study has several notable strengths, including a large sample size, long-term follow-up and the inclusion of a wide range of demographic and health-related characteristics. An additional

salient feature of our study is its capacity to effectively control for multiple demographic and health-related factors inside the model, hence enhancing the strength of the analyses.

Despite these strengths, our study has several limitations. First, the findings of this study, which were confined to residents of a particular state, may not be applicable to the entire adult population of stroke survivors in Australia. Second, the measures included in this study have been widely used and validated in comparable large population samples; nevertheless, they are based on self-report questions that are subject to recall bias. Third, survivor bias may have influenced our results, as only participants who survived until the follow-up were included. This bias may overestimate certain health outcomes, as individuals who have survived a stroke for a longer period might possess characteristics that are not representative of all post-stroke individuals. Fourth, participation bias is another concern, as the analysis was limited to individuals who responded to the Sub-study questionnaire. Non-respondents may differ in significant ways, such as having poorer health status, potentially affecting the generalisability of our findings. However, the robustness of the findings was confirmed by sensitivity analyses, suggesting that potential biases had a minimal impact on our study's outcomes.

Moreover, we were unable to compare the baseline characteristics of individuals who had a stroke and died before follow-up, those who survived but did not respond to the follow-up questionnaire, and those who survived and responded. Additionally, the study did not account for participants who developed stroke between baseline and follow-up, which limits our understanding of how lifestyle behaviours evolve in those experiencing a new stroke during the study period. Future research could address these limitations by performing such comparisons to provide more comprehensive insights.

Furthermore, diagnostic information to determine whether participants experienced a stroke, the type of stroke, or time since the stroke event was unavailable. Finally, as our study focused on assessing the independent determinants of each lifestyle behaviour, we did not analyse the combined impact of having multiple risky behaviours (e.g., individuals with two or more risky behaviours compared to those with one or none). Future research could explore such analyses to better understand how the presence of multiple risk factors influences health outcomes, providing insights for targeted health promotion and self-management strategies.

4.6 Conclusions

This study provides the first specific insights into longitudinal determinants of healthy lifestyle behaviours among stroke survivors in Australia using a large-scale sample with long-term follow-up. The improved understanding about the determinants that significantly contribute to or impede a healthy lifestyle amongst those living post-stroke may help the development of strategies to promote the adoption and maintenance of a healthy lifestyle in stroke survivors as part of their stroke management and rehabilitation, which is crucial to optimising their quality of life and successful secondary stroke prevention. The study suggests some specific groups of post-stroke individuals, such as older adults, individuals with low levels of education, and those diagnosed with diabetes and/or depression, should be the focus of further attention by researchers, policymakers, healthcare professionals, and stroke support groups in order to promote healthy behaviours amongst stroke survivors.

4.7 Acknowledgements

This research was completed using data collected through the 45 and Up Study (www.saxinstitute.org.au). The 45 and Up Study is managed by the Sax Institute in collaboration with major partner Cancer Council NSW and partners the Heart Foundation and the NSW Ministry of Health. We thank the many thousands of people participating in the 45 and Up Study. Additionally, we would like to thank the participants in the substudy. We also acknowledge the Sax Institute's Secure Unified Research Environment (SURE) for the provision of secure data access.

Chapter 5: The effect of a healthy lifestyle on reducing the utilisation of healthcare professionals and prescription medications among stroke survivors: a longitudinal investigation using linked administrative data.

This chapter investigates Research Question 6, examining whether a healthy lifestyle is associated with a reduced utilisation of healthcare professionals and/or prescription medications for stroke survivors. The study utilised data obtained from the Sax Institute' 45 and Up Study, linked to the Medicare Benefits Schedule and Pharmaceutical Benefits Scheme datasets. This is the first longitudinal study on this topic and reveals several important findings with relation to the effect of maintaining a healthy lifestyle on stroke survivors' healthcare utilisation. The findings have been submitted to the journal *Disability and Rehabilitation***.**

Rahman MS, Adams J, Peng W, Sibbritt D. A longitudinal investigation of the determinants of stroke survivors' utilisation of a healthy lifestyle for stroke rehabilitation in Australia. *Disability and Rehabilitation.* (Under review October, 2024).

Author's contributions for this chapter: Md Sazedur Rahman: Conceptualisation of the study, study design, formal analysis, writing the manuscript, corresponding author. **Jon Adams**: Conceptualisation of the study, review & editing of the manuscript. **Wenbo Peng**: Assisted with formal analysis, review & editing of manuscript. **David Sibbritt***:* Conceptualisation of the study, study design, assisted with analysis, review & editing of the manuscript.

5.1 Abstract

Introduction: Lifestyle modification is becoming more common in stroke rehabilitation. This study aimed to examine whether a healthy lifestyle was associated with reduced utilisation of healthcare professionals and/or prescription medications for stroke survivors.

Methods: The study utilised data obtained from the 45 and Up Study, specifically the baseline survey (2005-2009) and a sub-study survey (2017), both of which were linked to the Medicare Benefits Schedule and Pharmaceutical Benefits Scheme data. The information of 576 stroke

survivors was used for this study. The dependent variables were the number of times a person received care from a range of healthcare professions and the number of different prescription medications used by participants. The independent variables measuring healthy lifestyle were smoking, alcohol consumption risk, physical activity, and supplement use. Generalised Estimating Equation models were employed to assess the longitudinal association between a dependent variable and independent variables.

Results: The average age of the participants (n=576) was 67 (SD=9) years at baseline and 76 (SD=9) years at the sub-study survey time, with 54.9% being male. Stroke survivors who engaged in moderate-to-high levels of physical activity were significantly less likely to receive care from a general practitioner (AIRR: 0.85; 95% CI: 0.78, 0.92; p<0.001), a nurse (AIRR: 0.77; 95% CI: 0.63, 0.93; p=0.008), and an allied health professional (AIRR: 0.73; 95% CI: 0.61, 0.86; p<0.001), as well as to take blood-thinning medications (AIRR: 0.86; 95% CI: 0.76, 0.97; p<0.05). Stroke survivors who smoked were more likely to receive care from a specialist doctor (AIRR: 4.50; 95% CI: 1.21, 16.78; p<0.05). Moreover, stroke survivors who consumed supplements were more likely to receive care from an allied health professional (AIRR: 1.24; 95% CI: 1.03, 1.50; p<0.05).

Conclusion: This is the first longitudinal study to investigate the effects of healthy lifestyle behaviours on the utilisation of healthcare professionals and prescription medications. The findings carry substantial implications for long-term stroke recovery and secondary prevention, highlighting the positive effects of moderate-to-high physical activity and the associated risks of smoking.

5.2 Introduction

Stroke is a major cause of disability and mortality in adults throughout the world[10], and the healthcare costs associated with the treatment and rehabilitation of stroke are becoming increasingly burdensome[6]. As the physical and psychological consequences of a stroke are typically complex and long-lasting, stroke survivors often require long-term assistance and care[37].

Recent research reveals that more than one-third of those experiencing a stroke survive for a minimum of ten years following the stroke incidence[236], with the majority experiencing some degree of stroke-related disability and challenges[237]. The common long-term consequences of

stroke include paralysis, muscle weakness, swallowing problems, fatigue, pain, speech problems, visual problems, problems with balance and mobility, memory deficits, difficulties with attention and concentration, reduced analytical ability, and mental disorders[77,238,239]. Notably, current developments in stroke management and outcomes have prioritised emergency and acute care, with comparatively less emphasis on the post-acute phase[70,118]. With limited resources, it is also a significant challenge for healthcare systems to provide comprehensive professional support for stroke survivors throughout their survivorship journey.

Stroke survivors are commonly prescribed blood-thinning medication (antiplatelet and anticoagulant), cholesterol-lowering medication, antihypertensive medication, and other medications required for the treatment of concomitant conditions[240]. Polypharmacy, defined as the use of five or more medications, is common among post-stroke individuals due to the high prevalence of multimorbidity in this population[241]. Such polypharmacy has the potential to cause detrimental drug effects, drug interactions, increased expenses, reduced adherence to therapies, worsen functional outcomes, lead to greater health complications, diminished activities of daily living as well as impede the rehabilitation of post-stroke individuals[241–244].

Given the increasing incidence and extreme socioeconomic burden of post-stroke care, there is a pressing need to explore potential cost-effective, safe, and appropriate long-term treatment approaches for stroke survivors to improve rehabilitation outcomes and reduce treatment burden.[28] As advised by a number of international stroke guidelines, self-management is crucial for post-stroke management and rehabilitation[65–69]. Stroke survivors are likely to use a number of self-management strategies in addition to prescribed treatments to manage their post-stroke symptoms and challenges[71]. The most prominent self-management strategy for long-term management and secondary stroke prevention is lifestyle modification or the maintenance of healthy lifestyle behaviours, which includes engaging in physical activity, abstaining from smoking, abstaining or consuming alcohol at low-risk levels, and consuming a nutritious diet[65,73–75]. Despite the extensive documentation of the favourable health outcomes associated with a healthy lifestyle in individuals after stroke, there is a high prevalence of unhealthy behaviour amongst stroke survivors[73,78,245,246]. These behaviours have detrimental impact on their ability to do normal daily activities and increasing their the risk of experiencing further strokes as well as other chronic diseases[73,78,245,246].

Maintaining healthy lifestyle behaviours may be a useful self-management strategy for post-stroke management, physical and mental wellbeing, and secondary stroke prevention. Consequently, this could lower the use of post-stroke healthcare (e.g., physician consultations, and medication use)[247]. For example, physical activity ─ which is defined as any movement of the body that involves the skeletal muscles and expends energy ─ may contribute to a lower risk of various outcomes, including hospitalisation, long-term disability, fatigue, falls, pain, venous thromboembolism, cerebrovascular events, subsequent strokes, psychological problems, and mortality following a stroke[77,78,92,93,84–91]. Abstaining from smoking, drinking less alcohol (≤14 drinks/week), and taking nutritional supplements are all associated with improved functional capacity, brain recovery, and physical and psychological wellbeing, as well as a lowered risk of developing other cardiovascular diseases, nutrition-related diseases, further strokes and adverse outcomes in stroke survivors[73,74,98,99,79–82,94–97]. However, the effect of healthy lifestyle behaviours on utilisation of healthcare among those with stroke remains relatively unknown globally. To directly address this gap, we hypothesised that a healthy lifestyle would be associated with reduced utilisation of healthcare professionals and prescription medications amongst stroke survivors. This research has the potential to deepen our understanding of the impacts of healthy lifestyle behaviours on overall long-term recovery after stroke.

5.3 Methods

5.3.1 Data sources

The study utilised data from a baseline survey and a sub-study survey of the Sax Institute's 45 and Up Study conducted in Australia. These survey datasets were linked to the Medicare Benefits Schedule (MBS)[248] and Pharmaceutical Benefits Scheme (PBS)[249] data. Information regarding the 45 and Up Study can be found elsewhere[179]. But briefly, the baseline data collected information from people aged 45 years and older who resided in (the State of) New South Wales (NSW), Australia. To ensure coverage of almost the whole population, a random sample of participants was taken from the Services Australia Medicare enrolment database. Oversampling was undertaken among individuals aged 80 years and older as well as those who resided in rural and remote regions. The baseline survey collected data from 267,357 individuals between 2005 and 2009, with an approximate 19% response rate, representing nearly 11% of the population of NSW aged 45 and older. Participants enrolled in the study by

responding to a baseline postal questionnaire[149] and providing informed consent for follow-up and the linkage of their information to routine health databases, including MBS and PBS data. The MBS data includes claims for all medical and diagnostic services, whereas the PBS dataset consists of reimbursed prescription medications supplied. A sub-study of the 45 and Up Study was carried out between April and October of 2017, and a questionnaire was sent to 1,300 respondents who reported having a stroke in the baseline survey[182]. The response rate for the sub-study questionnaire was 44.3%, with 576 stroke survivors completing and returning it. These stroke survivors' baseline and sub-study information were linked to the MBS (2006-2017) and PBS (2006-2017) data. Services Australia provided the MBS and PBS data, and the linkage of these datasets was done by the Sax Institute using a unique identifier[182].

5.3.2 Dependent variables

The dependent variables included the number of times participants received care from general practitioners (GP), nurse practitioners, allied health professionals, and specialist doctors and any of these health professionals[250]. Allied health professionals included allied mental health professionals, physiotherapists, occupational therapists, audiologists, dietitians, exercise physiologists, podiatrists, and speech pathologists. Specialist doctors involved psychiatrist and neurosurgery specialist. Additional dependent variables included the number of dispensed blood-thinning medications, cholesterol-lowering medications, blood pressure medications, and any of these medications[188]. Blood thinning medications included antiplatelet medication and anticoagulant medication. Healthcare providers were identified using MBS item numbers, while medications were identified using PBS item codes (see Appendix 5 and Appendix 6 for detailed lists of MBS and PBS items, respectively). For medication use, we assumed adherence if the prescriptions were filled, as actual medication consumption data were not available. Utilisation of healthcare providers was coded based on the relevant MBS item numbers.

5.3.3 Independent variables

The independent variables for this study were smoking (no, yes), alcohol consumption risk (none/low-risk, moderate/high-risk), physical activity (inactive/sedentary, moderate/high), and supplement use (no, yes).

Following the Australian alcohol guidelines, the risk associated with alcohol intake was categorised as "no/low-risk" if the participant consumed ≤14 drinks/week and as

"moderate/high-risk" if they consumed more than 14 drinks/week[188]. In order to determine physical activity levels, the Active Australia Survey's questionnaires were utilised[185]. The total amount of time spent engaging in physical activity over the preceding week was calculated as W+M+2V, where W, M, and V refer to the total amount of time engaged in walking, moderate physical activity, and vigorous physical activity, respectively[187]. Participants were categorised as inactive/sedentary if their physical activity was <150 minutes/week and moderately/highly active if it was ≥150 minutes/week[187]. A participant was considered to have used supplements if they used multivitamins, minerals, omega-3, or fish oil within the month before completing the survey questionnaire[149].

5.3.4 Confounding variables

The confounding variables included in the regression models included sex (male, female), level of education (no formal school/school only, trade/apprentice/diploma, university), marital status (never married, married/living with partner, widowed/divorced/separated), body mass index (BMI) (underweight/normal (<25.0 kg/m^2), overweight (25.0-30.0 kg/m^2), obese (≥30.0 kg/m^2)[213], and number of comorbidities (0, 1, ≥2). Number of comorbidities was calculated from the diseases: hypertension, heart disease, diabetes, depression, anxiety, and asthma.

5.3.5 Statistical Analysis

To test the mean differences between a dependent variable and an independent variable, the two-sample t-test was employed if the group consisted of only two categories. The analysis of variance (ANOVA) test was used if the group contained more than two categories. Generalised Estimating Equation (GEE) models, specifying the Poisson family and log link function with robust standard error, were employed to assess the longitudinal association between a dependent variable and independent and confounding variables. Variables were included in the multivariable GEE models if their corresponding crude incidence rate ratio (IRR) had an associated $p<0.25$; then, a backward stepwise regression model process was used to determine the most parsimonious model for each dependent variable. After the model-building process, the final model provides the estimates for the adjusted IRR (AIRR). The analysis spans 12 years of claims data, with total claims per year used as a measure of healthcare utilisation. The ‘year’ variable was included in the models to account for temporal trends and evaluate changes in healthcare utilisation over time. Claims were aggregated by year, and the models assess

longitudinal patterns rather than annual averages per person. A value of $p<0.05$ was considered as the statistically significant level for each test. Throughout the analysis processes, the statistical software Stata 14.0 was utilised.

5.3.6 Ethical Approval

The Human Research Ethics Committee (HREC) of the University of New South Wales provided approval for the 45 and Up Study. Our study received ethical approval from the HREC at the University of Technology Sydney (approval number: ETH19-3442).

5.4 Results

This study included a total of 576 stroke survivors who answered both the baseline (2005-2009) and sub-study (2017) questionnaires. Over half of the participants (54.9%) were male. The participants' average age was 66.5 (SD=9.1) years at baseline and 75.8 (SD=9.1) years during the sub-study survey. As a result of the sub-study and MBS data linkage process, information on healthcare provider use for 576 participants was identified from 2006 to 2017.

Table 5.1 Distribution of the stroke survivors receiving care from different healthcare providers from 2006 to 2017.

Year	GP		Nurse		Allied health professionals		Specialist doctor		Any of these healthcare providers	
	No n (%)	Yes n (%)	No n (%)	Yes n (%)	No n (%)	Yes n (%)	No n (%)	Yes n (%)	No n (%)	Yes n (%)
2006	12 (2.1)	545 (97.9)	434 (77.9)	123 (22.1)	532 (95.5)	25 (4.5)	548 (98.4)	09 (1.6)	12 (2.1)	545 (97.9)
2007	18 (3.2)	547 (96.8)	429 (75.9)	136 (24.1)	527 (93.3)	38 (6.7)	553 (97.9)	12 (2.1)	17 (3.0)	548 (97.0)
2008	15 (2.6)	551 (97.4)	386 (68.2)	180 (31.8)	502 (88.7)	64 (11.3)	547 (96.6)	19 (3.4)	15 (2.6)	551 (97.4)
2009	11 (1.9)	555 (98.1)	336 (59.4)	230 (40.6)	478 (84.5)	88 (15.5)	546 (96.5)	20 (3.5)	11 (1.9)	555 (98.1)
2010	13 (2.3)	558 (97.7)	342 (59.9)	229 (40.1)	471 (82.5)	100 (17.5)	553 (96.9)	18 (3.1)	12 (2.1)	559 (97.9)
2011	13 (2.3)	555 (97.7)	332 (58.5)	236 (41.5)	449 (79.1)	119 (20.9)	550 (96.8)	18 (3.2)	12 (2.1)	556 (97.9)
2012	14 (2.5)	556 (97.5)	510 (89.5)	60 (10.5)	414 (72.6)	156 (27.4)	550 (96.5)	20 (3.5)	14 (2.5)	556 (97.5)
2013	12 (2.1)	557 (97.9)	502 (88.2)	67 (11.8)	396 (69.6)	173 (30.4)	550 (96.7)	19 (3.3)	11 (1.9)	558 (98.1)
2014	13 (2.3)	556 (97.7)	478 (84.0)	91 (16.0)	377 (66.3)	192 (33.7)	549 (96.5)	20 (3.5)	13 (2.3)	556 (97.7)

2015	11 (1.9)	555 (98.1)	463 (81.8)	103 (18.2)	345 (61.0)	221 (39.0)	545 (96.3)	21 (3.7)	11 (1.9)	555 (98.1)
2016	11 (1.9)	556 (98.1)	442 (78.0)	125 (22.0)	353 (62.3)	214 (37.7)	545 (96.1)	22 (3.9)	11 (1.9)	556 (98.1)
2017	12 (2.1)	554 (97.9)	431 (76.2)	135 (23.8)	328 (58.0)	238 (42.0)	548 (96.8)	18 (3.2)	07 (1.2)	559 (98.8)
Total	05 (0.9)	571 (99.1)	174 (30.2)	402 (69.8)	204 (35.4)	372 (64.6)	476 (82.6)	100 (17.4)	05 (0.9)	571 (99.1)

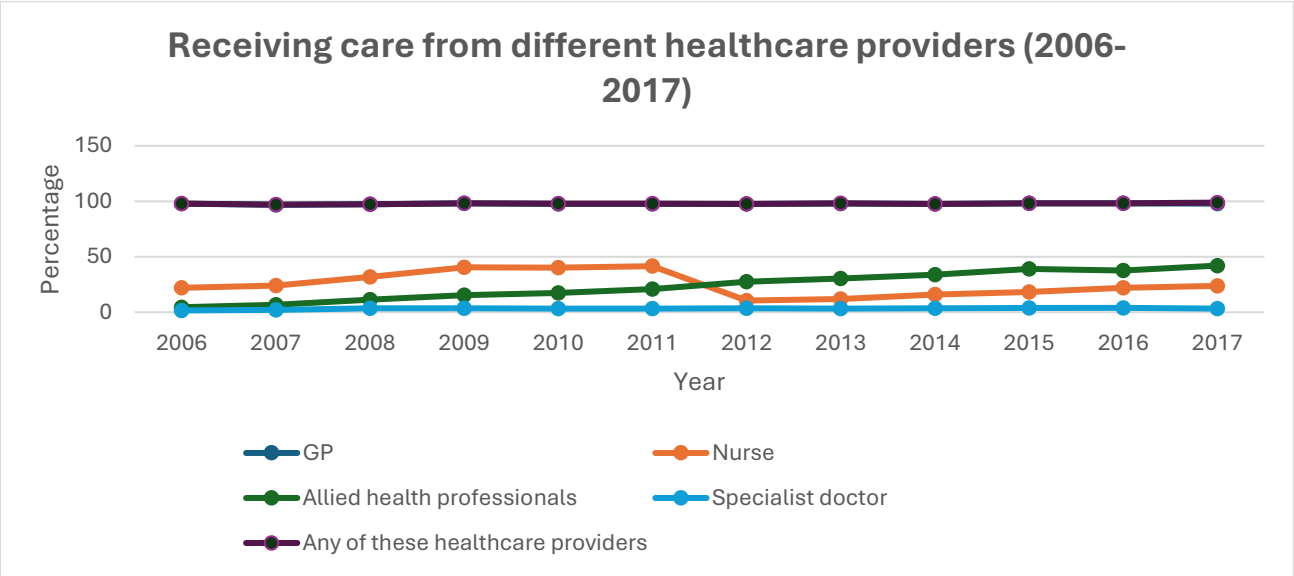

Figure 5.1: Percentage of the stroke survivors receiving care from different healthcare providers from 2006 to 2017.

5.4.1 Consultation with healthcare providers

Table 5.1 displays the distribution of stroke survivors receiving care from various healthcare providers between 2006 and 2017. Additionally, Figure 5.1 illustrates the percentage of participants accessing different providers between 2006 and 2017, highlighting trends over time. Between 2006 and 2017, more than 99% of participating stroke survivors consulted with a general practitioner (GP), and almost 70% visited a nurse. Nearly 65% of the participants received care from an allied health professional, and more than 17% received care from a specialist doctor.

Table 5.2 presents the average number of visits to healthcare providers from 2006 to 2017, according to the selected characteristics of participants using sub-study data linked to MBS data. The average visit to the GP was significantly greater among participants with ≥2 comorbidities ($p<0.001$) and/or those who were physically inactive or sedentary ($p<0.001$). Similarly, the average visit to the nurse was significantly greater among participants who were

physically inactive or sedentary (p<0.001). The average visit to the allied health professionals was significantly greater among participants who were widowed/divorced/separated (p=0.001), obese (p=0.006), those with ≥2 comorbidities (p<0.001), and/or those who were physically inactive or sedentary (p<0.001). Additionally, the average visit to the specialist doctor was significantly greater among participants who had ≥2 comorbidities (p<0.001), who were smokers, and/or who used supplements (p=0.011). Further, the average visits to any of these healthcare providers was significantly higher among participants with ≥2 comorbidities (p<0.001); and who were physically inactive or sedentary (p<0.001).

Table 5.2 Average number of visits to the different healthcare providers (MBS data merged with substudy).

Characteristics	Average number of visits (2006-2017)				
	GP	**Nurse**	**Allied health professionals**	**Specialist doctor**	**Any of these healthcare providers**
Sex					
Male	123.3	5.6	10.2	2.9	142.0
Female	122.7	5.3	12.0	2.7	142.8
p-value	*0.932*	*0.689*	*0.138*	*0.926*	*0.921*
Education					
No formal school/School only	127.1	5.9	12.5	1.9	147.5
Trade/Apprentice/Diploma	123.0	5.3	10.3	5.3	143.9
University	111.9	4.7	8.8	0.8	126.2
p-value	*0.227*	*0.334*	*0.053*	*0.336*	*0.133*
Marital Status					
Never Married	124.1	4.9	9.9	5.6	144.6
Married/Living with partner	117.8	5.2	9.6	3.5	136.1
Widowed/Divorced/Separated	133.7	6.3	14.7	0.4	155.1
p-value	*0.102*	*0.279*	*0.001*	*0.397*	*0.111*
BMI category					
Underweight or Normal	126.5	5.1	8.8	3.3	143.8
Overweight	115.0	5.9	10.6	1.3	132.9
Obese	123.4	5.4	14.0	3.4	146.2
p-value	*0.321*	*0.614*	*0.006*	*0.745*	*0.356*
Number of comorbidities *					
0	111.1	4.9	8.2	0.6	124.8
1	119.0	5.1	9.5	0.4	134.0
≥2	143.8	6.6	16.6	8.2	175.2
p-value	*<0.001*	*0.058*	*<0.001*	*0.013*	*<0.001*
Smoking					
No	121.3	5.4	11.0	2.0	139.7
Yes	127.4	6.5	8.5	10.7	153.1
p-value	*0.572*	*0.280*	*0.212*	*0.034*	*0.308*
Alcohol consumption risk					
None/Low	123.8	5.5	11.3	2.8	143.4
Moderate/High	111.2	4.9	9.8	3.7	129.7
p-value	*0.207*	*0.568*	*0.424*	*0.805*	*0.258*
Physical activity					
Inactive/Sedentary	137.8	7.1	13.9	3.2	162.0

Moderate/High	111.7	4.5	8.5	2.1	126.9
p-value	*<0.001*	*<0.001*	*<0.001*	*0.650*	*<0.001*
Supplements use					
No	121.6	5.5	10.9	1.4	139.4
Yes	129.5	5.2	11.8	9.2	155.8
p-value	*0.346*	*0.692*	*0.541*	*0.011*	*0.108*

[*] *Comorbidities included: hypertension, heart disease, diabetes, depression, anxiety, and asthma.*

Table 5.3 presents the final adjusted GEE Poisson regression models of receiving care from different healthcare providers, produced from backward, stepwise model building. The receipt of care from a GP was significantly lower among participants who were moderately or highly physically active (AIRR: 0.85; 95% CI: 0.78, 0.92; p< 0.001), compared to the inactive/sedentary participants. Similarly, the receiving care from a nurse was significantly lower among moderately or highly physically active participants (AIRR: 0.77; 95% CI: 0.63, 0.93; p=0.008), compared to the inactive/sedentary participants.

The receiving care from an allied health professional was significantly greater among participants who were supplements users (AIRR: 1.24; 95% CI: 1.03, 1.50; p=0.025), compared to non-users of supplements. Conversely, the receipt of care from an allied health professional was significantly lower among participants who were moderately or highly physically active (AIRR: 0.73; 95% CI: 0.61, 0.86; p<0.001), compared to the inactive/sedentary participants. The receipt of care from a specialist doctor was significantly greater among participants who were smokers (AIRR: 4.50; 95% CI: 1.21, 16.78; p=0.025), compared to non-smokers.

The receipt of care from at least one of the selected healthcare providers was significantly lower among participants who were moderately or highly physically active (AIRR: 0.83; 95% CI: 0.76, 0.91; p<0.001), compared to inactive/sedentary participants.

Table 5.3 GEE Poisson regression model for calculating adjusted incidence rate ratios for receiving care from different healthcare providers.

Characteristics	**GP** **AIRR*** (95% CI); p-value	**Nurse** **AIRR***	**Allied** **AIRR*** (95% CI); p-value	**Specialists** **AIRR*** (95% CI); p-value	**Any of these healthcare providers** **AIRR***

		(95% CI); p-value			(95% CI); p-value
Smoking					
No	-	-	-	1.00	-
Yes	-	-	-	4.50 (1.21, 16.78); 0.025	-
Physical activity					
Inactive/Sedentary	1.00	1.00	1.00	-	1.00
Moderate/High	0.85 (0.78, 0.92); <0.001	0.77 (0.63, 0.93); 0.008	0.73 (0.62, 0.86); <0.001	-	0.83 (0.76, 0.91); <0.001
Supplements use					
No	-	-	1.00	-	-
Yes	-	-	1.24 (1.03, 1.50); 0.025	-	-

Note: Alcohol consumption was not significantly associated with any of the dependent variables.
AIRR: Adjusted Incidence Rate Ratio
** Adjusted for gender, education, marital status, BMI, number of comorbidities, and years.*

5.4.2 Use of Prescription medications

As a result of the sub-study and PBS data linkage process, 570 participants' information related to using selected prescription medication. Table 5.4 displays the distribution of different selected medication used by these participants from 2006 to 2017. Additionally, Figure 5.2 illustrates the percentage of participants using different medications between 2006 and 2017, highlighting trends over time. It can be seen that across 2006 to 2017 showing that almost 84% of these stroke survivors used blood thinning medication, more than 85% used cholesterol lowering medications and almost 40% used blood pressure medication. In addition, greater than 95% of participants used at least one of these selected prescription medicines from 2006 to 2017.

Table 5.4 The percentages of stroke survivors who used different medications.

Year	Blood thinning medication		Cholesterol lowering medication		Blood pressure medication		Any of these medications	
	No n (%)	Yes n (%)	No n (%)	Yes n (%)	No n (%)	Yes n (%)	No n (%)	Yes n (%)
2006	294 (61.9)	181 (38.1)	223 (46.9)	252 (53.1)	403 (84.8)	72 (15.2)	148 (31.2)	327 (68.8)
2007	283 (58.2)	203 (41.8)	199 (40.9)	287 (59.1)	416 (85.6)	70 (14.4)	132 (27.2)	354 (72.8)
2008	265 (53.2)	233 (46.8)	189 (37.9)	309 (62.1)	415 (83.3)	83 (16.7)	119 (23.9)	379 (76.1)
2009	259 (51.0)	249 (49.0)	181 (35.6)	327 (64.4)	413 (81.3)	95 (18.7)	108 (21.3)	400 (78.7)
2010	250 (47.7)	274 (52.3)	184 (35.1)	340 (64.9)	411 (78.4)	113 (21.6)	102 (19.5)	422 (80.5)

2011	235 (44.5)	293 (55.5)	161 (30.5)	367 (69.5)	399 (75.6)	129 (24.4)	84 (15.9)	444 (84.1)
2012	235 (42.9)	313 (57.1)	166 (30.3)	382 (69.7)	406 (74.1)	142 (25.9)	93 (17.0)	455 (83.0)
2013	213 (38.3)	343 (61.7)	171 (30.8)	385 (69.2)	413 (74.3)	143 (25.7)	82 (14.7)	474 (85.3)
2014	197 (35.6)	357 (64.4)	160 (28.9)	394 (71.1)	411 (74.2)	143 (25.8)	71 (12.8)	483 (87.2)
2015	199 (36.0)	354 (64.0)	146 (26.4)	407 (73.6)	419 (75.8)	134 (24.2)	65 (11.7)	488 (88.3)
2016	220 (39.9)	331 (60.1)	148 (26.9)	403 (73.1)	420 (76.2)	131 (23.8)	64 (11.6)	487 (88.4)
2017	215 (39.1)	335 (60.9)	157 (28.5)	393 (71.5)	422 (76.7)	128 (23.3)	63 (11.4)	487 (88.6)
Total	92 (16.1)	478 (83.9)	83 (14.6)	487 (85.4)	339 (59.5)	231 (40.5)	25 (4.4)	545 (95.6)

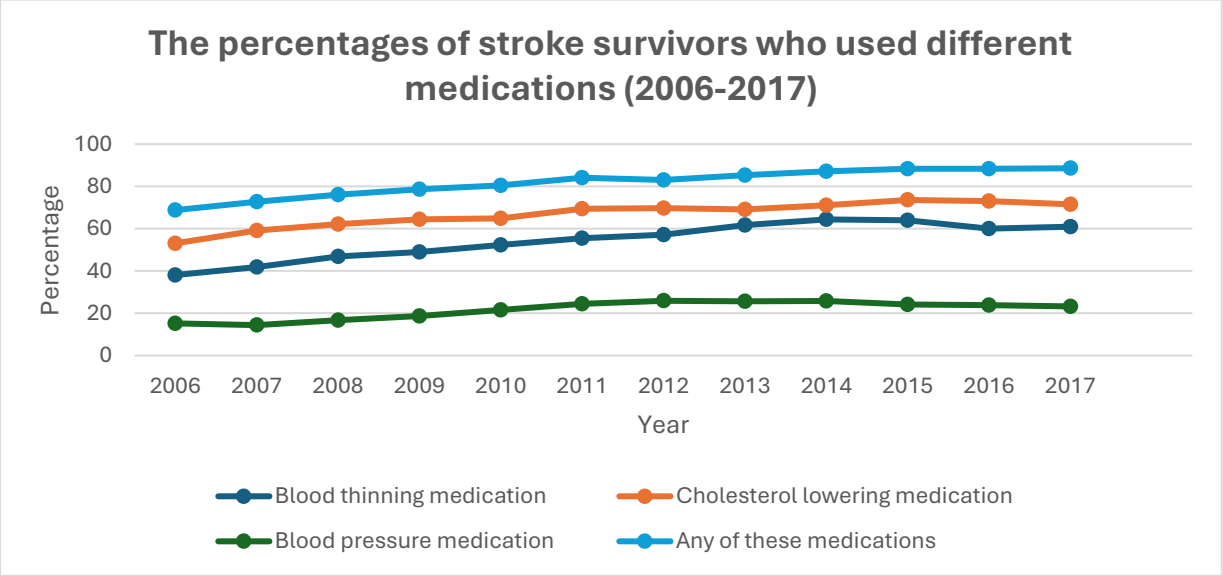

Figure 5.2: The percentages of stroke survivors who used different medications from 2006 to 2017.

Table 5.5 presents the average number of different medications dispensed between 2006 and 2017 according to the characteristics of the participants using sub-study dataset linked with PBS dataset. The average number of blood thinning medication dispensed was significantly greater among those who were physically inactive or sedentary (p=0.020). For the cholesterol lowering medications or blood pressure medications, there were no statistically significant associations with any of the healthy behaviour measures.

Table 5.5 Average number of different medications dispensed according to the characteristics of stroke survivors (PBS dataset merged with sub-study).

Characteristics	Blood thinning medications	Cholesterol lowering medication	Blood pressure medication	Any of these medications
Sex				
Male	66.4	85.9	25.3	177.6
Female	52.6	74.2	23.3	150.2
p-value	*0.005*	*0.019*	*0.578*	*0.003*
Education				
No formal school/School only	60.2	80.6	26.5	167.2
Trade/Apprentice/Diploma	60.1	78.8	19.5	158.5
University	61.1	83.3	28.2	172.6
p-value	*0.988*	*0.827*	*0.144*	*0.540*
Marital Status				
Never married	60.3	65.2	26.1	151.7
Married/Living with partner	59.5	78.7	23.7	161.9
Widowed/Divorced/Separated	63.6	91.8	25.7	181.1
p-value	*0.766*	*0.010*	*0.853*	*0.126*
BMI (kg/m^2)				
Underweight or Normal	61.2	75.2	18.0	154.4
Overweight	60.1	77.3	25.1	162.5
Obese	58.2	89.6	32.7	179.9
p-value	*0.903*	*0.091*	*0.016*	*0.138*
Number of comorbidities *				
0	54.2	69.8	14.6	138.6
1	64.3	78.3	22.3	164.9
≥2	64.6	98.2	40.2	202.9
p-value	*0.118*	*<0.001*	*<0.001*	*<0.001*
Smoking				
No	61.2	81.9	24.4	167.6
Yes	59.3	73.4	26.9	159.6
p-value	*0.816*	*0.311*	*0.687*	*0.613*
Alcohol consumption risk				
None/Low	59.8	79.9	25.5	165.2
Moderate/High	61.8	82.8	19.3	163.9
p-value	*0.791*	*0.699*	*0.260*	*0.929*
Physical activity				
Inactive/Sedentary	67.4	77.8	25.7	170.9
Moderate/High	55.3	82.0	24.3	161.6
p-value	*0.020*	*0.429*	*0.694*	*0.344*
Supplements use				
No	60.2	81.0	24.9	166.1
Yes	60.2	79.0	22.0	161.2
p-value	*0.996*	*0.757*	*0.524*	*0.684*

* *Comorbidities included: hypertension, heart disease, diabetes, depression, anxiety, and asthma.*

Table 5.6 presents the final adjusted GEE Poisson regression models of use of different prescription medications, produced from backward, stepwise model building. The blood thinning medications use was significantly lower among those who were moderately or highly physically active (AIRR: 0.86; 95% CI: 0.76, 0.97; p=0.015), compared to the

inactive/sedentary participants. Note that for the cholesterol lowering medications or blood pressure medications, there were no statistically significant associations with any of the healthy behaviour measures.

Table 5.6 GEE Poisson regression model for calculating adjusted incidence rate ratios for different medications dispensed.

Characteristics	Blood thinning medications AIRR* (95% CI); p-value	Cholesterol lowering medication AIRR* (95% CI); p-value	Blood pressure medication AIRR* (95% CI); p-value	Any of these medications AIRR* (95% CI); p-value
Physical activity				
Inactive/Sedentary	1.00	-	-	-
Moderate/High	0.86 (0.76, 0.97); p=0.015	-	-	-

Note: Alcohol consumption, smoking status, and supplements use were not significantly associated with any of the dependent variables.
AIRR: Adjusted Incidence Rate Ratio
** Adjusted for gender, education, marital status, BMI, number of comorbidities, and years.*

Figure 5.3 presents a Directed Acyclic Graph (DAG) illustrating the impacts of health behaviours (smoking, physical activity, and supplement use) on healthcare utilisation (care from various health professionals and the use of blood-thinning medications) while accounting for confounding factors (age, gender, education, marital status, number of comorbidities, and years) among stroke survivors. The DAG visualises that moderate-to-high levels of physical activity reduce the likelihood of receiving care from general practitioners, nurses, allied health professionals, and the use of blood-thinning medications. In contrast, smoking increases the likelihood of receiving care from specialist doctors. Similarly, supplement use increases the likelihood of receiving care from allied health professionals. Arrows in the DAG represent the directional impact of health behaviours on healthcare utilisation and the role of confounders in these relationships.

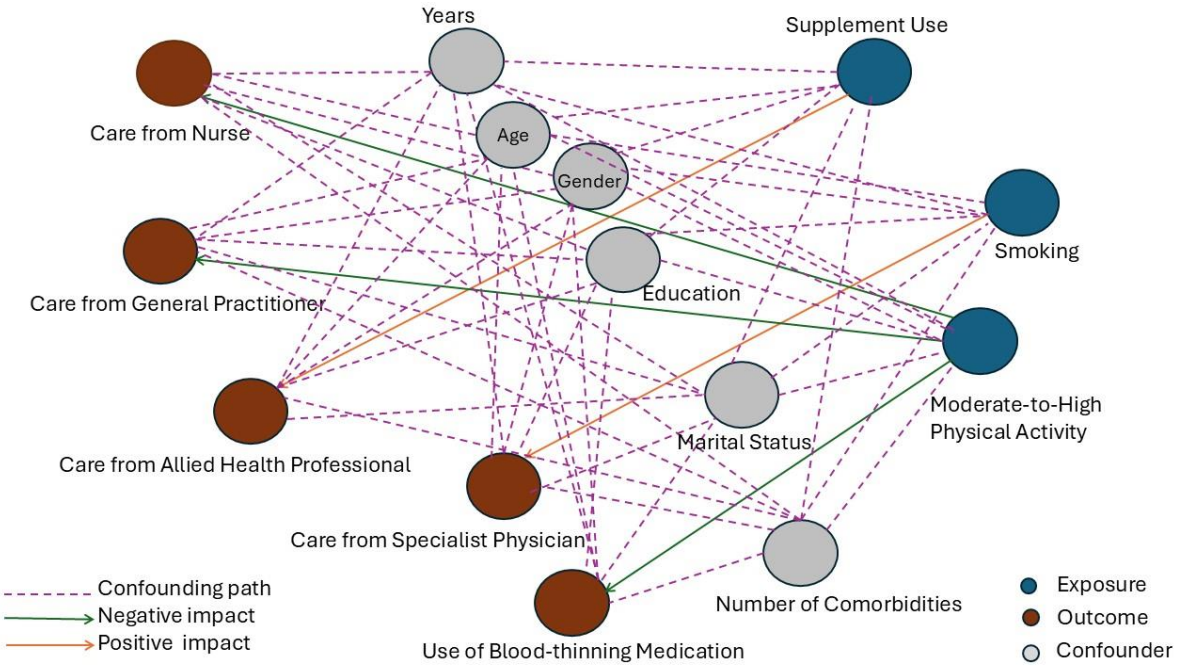

Figure 5.3: Relationships between health behaviours, confounders, and healthcare utilisation among survivors of stroke.

5.5 Discussion

This is the first longitudinal study employing linked health administrative data with a longitudinal cohort study to examine the effects of a healthy lifestyle on the use of healthcare amongst stroke survivors. The study reveals evidence with relation to the effect of maintaining a healthy lifestyle on one's utilisation of medical professionals and the use of prescription medications.

This study revealed that almost 97%-99% of stroke survivors sought consultation with at least one healthcare professional (a general practitioner, nurse, allied health professional, or specialist physician) each year. This finding is not too surprising as most post-stroke individuals may suffer from a wide range of long-term physical and mental disability as a result of the stroke and may also have other pre-existing or post-stroke clinical conditions.

Although the number of comorbidities showed a strong association with healthcare utilisation outcomes in the univariate analysis, its effect was not reported in the outcomes of the fully adjusted GEE models. This decision was made to maintain focus on the impact of healthy

lifestyle behaviours on healthcare utilisation, as the number of comorbidities was treated as a confounding variable.

This study also found that moderately/highly physically active stroke survivors were significantly less likely to receive care from the selected healthcare providers (except specialists). The health benefits of physical activity for individuals with post-stroke are extensively documented[77,78,92,84–91]. It is evident from previous studies that engaging in physical activity may improve stroke survivor's physical fitness, physical function, muscle strength, motor recovery, cardiovascular health outcome, gait, mobility, balance, self-care ability, cognitive function, and mental wellbeing[77,78,92,84–91]. Additionally, it may also reduce the risk of hospitalisation, stroke-related disability, stroke recurrence, fatigue, falls, visual problems, and other health outcomes[77,78,92,84–91]. These beneficial outcomes of physical activity may explain why post-stroke individuals in our study who engaged in moderate-to-high physical activity utilised lower healthcare services. The growing population of stroke survivors poses significant challenges for healthcare professionals in meeting their extensive needs for treatment, rehabilitation, and care throughout recovery. However, our research offers encouraging findings that adhering to the recommended level of physical activity among post-stroke individuals could potentially alleviate the burden on some types of healthcare professionals and reduce the treatment demands faced by stroke survivors.

Our study also revealed that moderately/highly physically active post-stroke individuals were significantly less likely to take blood-thinning medications. This may be owing to the fact that moderate-to-high physical activity reduces the risk of developing venous thromboembolism (deep vein thrombosis and pulmonary embolism) and improves oxygen supply to cells, blood fluidity, coronary arteries' ability to transport blood, blood flow, and plays a role in the formation and dissolution of blood clots[251–256]. Physical activity works as medication for those living with the consequences of a stroke[78]. A network meta-analysis showed that exercise intervention was more effective than blood thinning medication (antiplatelet and anticoagulant medications) on mortality outcomes in post-stroke individuals[87]. However, the combined effects of pharmacological interventions and active healthy behaviours may yield more favourable outcomes in post-stroke symptoms management and secondary stroke prevention[67,257], which could eventually reduce healthcare utilisation of stroke survivors. For example, the confluence of stroke medication and healthy lifestyles can reduce the risk of

recurrent vascular incidents in stroke survivors by up to 80%[67,257]. However, as polypharmacy has potential adverse effects in stroke rehabilitation and physical activity may reduce the number of medication use, future investigations are required to determine appropriate medications and dosages for stroke survivors who adhere to a healthy lifestyle.

Our findings provide further support to international stroke guidelines that advise stroke survivors to engage in recommended levels of physical activity (≥150 minutes/week) as an integral component of their effective long-term stroke management and secondary prevention[65–69].

Our data shows that those stroke survivors who smoked were more likely to receive care from a specialised physician in comparison to their non-smoking counterparts. This may be owing to the fact that smoking is positively associated with psychiatric disorders, an increased risk of subsequent strokes, and adverse cardiovascular outcomes in those with stroke[230,258,259], all of which may require consultation with a specialist physician (psychiatrist and neurosurgery specialist). The results of our study indicate that abstaining from smoking may have positive effects in terms of health service use over the longer term for prevention management and avoiding other chronic illnesses. Thus, it may be beneficial to consider ways in which to implement appropriate and targeted interventions through community-based self-management educational programs, for example, to reduce the prevalence of smoking among stroke survivors[260].

In addition, stroke survivors who used supplements in our study were more likely to receive treatment from an allied health professional. This finding may be due to the possibility that stroke survivors who consumed supplements may have had certain nutrition-related conditions such as malnutrition, dysphagia, bone loss, and weakness; and, as a result, they may have necessitated increased utilisation of healthcare services provided by allied health professionals to address these health issues[261–263]. Another potential reason may be the proactive role of these allied health professionals like dietitian in introducing or recommending such supplements as a complementary approach to support stroke survivors' wellbeing and recovery[97]. It is also plausible that those who used supplements in our study had a greater tendency towards adopting a healthy lifestyle, therefore potentially receiving increased advice from allied healthcare professionals related to exercise, nutrition, and other facets of health. However,

further research is necessary to examine the underlying factors contributing to the increased utilisation of allied health professionals among stroke survivors who consume dietary supplements.

The major strength of our study is that it is based on large administrative data sets linked to the long-established 45 and Up study with long-term follow-up. An additional salient feature of our study is its capacity to effectively control for multiple demographic and health-related factors inside the model, hence enhancing the strength of the particular analysis. Despite the 45 and Up Study's modest baseline response rate of approximately 19%, the importance of representativeness in cohort studies is not critical, and the observed relationships between cross-sectional exposure and outcomes were comparable to those seen in state-based surveillance systems with more excellent response rates[179,264].

Nevertheless, this study has a number of limitations. Firstly, the findings of this study, which were confined to residents of a particular state, may not apply to the entire adult population of Australia. Secondly, the measures of physical activity, alcohol intake risk, smoking status, supplement use, and the number of comorbidities were derived from self-report questions susceptible to recall bias. Thirdly, survivor bias may have influenced our results, as only participants who survived until the follow-up were included. This bias may overestimate certain health outcomes, as individuals who have survived a stroke for a longer period might possess characteristics that are not representative of all post-stroke individuals. Fourthly, participation bias is another concern, as the analysis was limited to individuals who responded to the Sub-study questionnaire. Non-respondents may differ in significant ways, such as having poorer health status, potentially affecting the generalisability of our findings. However, the robustness of the findings was confirmed by sensitivity analyses, suggesting that potential biases had a minimal impact on our study’s outcomes.

Fifthly, the absence of information on private prescriptions and over-the-counter medications (e.g., aspirin), which are not captured in the PBS dataset, represents a limitation that may lead to an underestimation of medication use. Sixthly, this study did not include some relevant specialists, such as neurologists, cardiologists, and endocrinologists, who play a critical role in long-term rehabilitation and ongoing care for stroke survivors. Including these specialists could provide additional insights into post-stroke healthcare utilisation. Another limitation is the lack

of specificity regarding which types of allied healthcare professionals and specialist physicians were involved in care, limiting our ability to analyse their specific roles in post-stroke care. Furthermore, the absence of pre-stroke healthcare utilisation data is another limitation. This limitation may affect the interpretation of changes in post-stroke healthcare utilisation.

5.6 Conclusion

This groundbreaking longitudinal study highlights the paramount importance of adopting a healthy lifestyle for post-stroke individuals, demonstrating its potential to reduce reliance on healthcare professionals and prescription medications. The findings carry substantial implications for stroke rehabilitation and secondary prevention, highlighting the positive effects of moderate-to-high physical activity and the associated risks of smoking. Our findings suggest that stroke survivors may benefit from additional assistance in adopting and maintaining a healthy lifestyle as an integral aspect of their long-term stroke care. Further research is needed to thoroughly assess the impact of nutritional supplement intake and risky alcohol consumption on healthcare utilisation among those with stroke, contributing to a more comprehensive understanding and informing targeted interventions for optimal patient care.

5.7 Acknowledgements

This research was completed using data collected through the 45 and Up Study (www.saxinstitute.org.au). The 45 and Up Study is managed by the Sax Institute in collaboration with major partner Cancer Council NSW and partners the Heart Foundation and the NSW Ministry of Health. We thank the many thousands of people participating in the 45 and Up Study. Besides, we would like to thank the participants in the substudy. In addition, we thank Services Australia for their supply of Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS) data. We also acknowledge the Secure Unified Research Environment (SURE) for the provision of secure data access. We extend our sincere thanks to the Australian Research Council for funding Distinguished Professor JA via an ARC Professorial Future Fellowship (FT140100195) while working on this project and manuscript. MSR acknowledges the scholarship support of the University of Technology Sydney (UTS).

Chapter 6: The impacts of a healthy lifestyle on the physical and mental health status of female stroke survivors in Australia.

This chapter investigates Research Question 6, which aims to explore the impacts of adopting a healthy lifestyle on self-reported physical and mental health outcomes among Australian females who are living with stroke. The research employed data obtained from the 1946-51 cohort of the Australian Longitudinal Study on Women's Health[176]. The analyses revealed some important findings that have been published in the journal *Topics in Stroke Rehabilitation***.**

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Author's contributions for this chapter: Md Sazedur Rahman: Conceptualisation of the study, study design, formal analysis, writing the manuscript, corresponding author. **Jon Adams**: Conceptualisation of the study, review & editing of the manuscript. **Wenbo Peng**: Assisted with formal analysis, review & editing of manuscript. **David Sibbritt***:* Conceptualisation of the study, study design, assisted with analysis, review & editing of the manuscript.

6.1 Abstract

Introduction: Despite emerging research on post-stroke self-management, little is known about the adoption and long-term maintenance of healthy lifestyle behaviours among female stroke survivors. This longitudinal study aimed to explore the impacts of adopting a healthy lifestyle on self-reported physical and mental health outcomes among Australian females who are living with stroke.

Methods: The study utilised data retrieved from the Australian Longitudinal Study on Women's Health's 1946-51 cohort (from survey 5 conducted in 2007 to survey 9 conducted in 2019), focusing on 531 female survivors of stroke identified across different surveys. The dependent variables for this study were self-reported physical and mental health status, whereas the independent variables were lifestyle behaviours including physical activity, smoking,

alcohol consumption, and supplement use. Generalised Estimating Equation models were used to assess the longitudinal associations between a dependent variable and independent variables.

Results: The average age of the participants was 58.1 (SD=1.4) years in survey 5 and 70.5 years in survey 9. The longitudinal analyses revealed that stroke survivors who engaged in moderate/high levels of physical activity had significantly better physical and mental health status than their inactive or sedentary counterparts. Besides, current smokers had significantly poorer physical and mental health status than non-smokers. In addition, risky/high-risk alcohol consumers had significantly poorer mental health status compared to no/low-risk alcohol consumers.

Conclusions: Our findings suggest that post-stroke individuals can improve their physical and mental health by maintaining a healthy lifestyle. Specifically, targeted and appropriate programmes and strategies are needed to promote physical activity and reduce smoking and alcohol consumption in female stroke survivors in order to optimise their overall health and health-related quality of life.

6.2 Introduction

As a leading cause of long-term neurological and functional disability as well as adult mortality, stroke has become a significant global public health concern[10,266]. More than half of stroke survivors were unable to regain their functional independence, and even those who attained functional independence continued to experience considerable physical and emotional difficulties[267]. Health status, including both physical and mental health status, is significantly lower in stroke survivors compared to the age-matched general people[268–271]. The number of individuals living with stroke is increasing due to the ageing population and advancements in acute stroke treatment[34]. Currently, the global population of stroke survivors exceeds 101 million, with females comprising approximately 56% of this population[111].

Previous studies have shown that various factors, such as age, gender, body mass index (BMI), functional status, stroke severity, comorbidities, degree of dependency, and social support were associated with the self-reported physical and mental health status of post-stroke individuals[33,105–108,110,272–275]. Also, female stroke survivors were found to have lower levels of physical and/or mental health than male stroke survivors[105–108,110,273]. Compared to their male

counterparts, female stroke survivors exhibit poorer functional recovery, a diminished ability to engage in daily activities, and a higher prevalence of mental disorders[101,105–107,275,276]. Hence, research that focuses on enhancing the physical and mental health of female stroke survivors holds as a high priority in the field of health[105–108,110,275].

A number of international stroke guidelines recommend that post-stroke individuals should engage in self-management practices like adopting a healthy lifestyle[65–69]. While physical activity, alcohol consumption, and smoking are well-established components of lifestyle behaviour, the use of dietary supplements is also often regarded as an important aspect of maintaining health[65,96-99]. Stroke survivors frequently encounter nutritional deficiencies due to several reasons, such as dysphagia, changes in appetite, and the adverse effects of medications [65,96-99]. Dietary supplements can help address these deficiencies by providing essential vitamins and minerals that are crucial for recovery and overall health[65,96-99]. Maintaining a healthy lifestyle, including engaging in adequate physical activity, refraining from smoking, drinking no or less harmful amounts of alcohol, and taking nutritional supplements, can improve post-stroke symptoms management, functional ability, neurological recovery, prevention of secondary strokes, cardiovascular outcome, survival rate, and overall long-term rehabilitation outcome[65,73,84,76–83].

Given the immense healthcare burden caused by stroke on females, attention should be given to research exploring the impacts of adopting key healthy lifestyle behaviours on physical and mental health outcomes among women living with stroke. To date, only limited and inconclusive evidence is available, which is primarily based on cross-sectional or randomised controlled trials[77,83,110,277–280] (with the exception of a single longitudinal study that examined the effects of exercise on self-reported health among stroke survivors with a 2-year follow-up[280]). To directly address this gap, this longitudinal study was undertaken to explore the impacts of a healthy lifestyle on self-reported physical and mental health in female stroke survivors in Australia.

6.3 Methods

6.3.1 Data Source and Sample

This study conforms to the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines for cohort studies[174]. The study utilised data retrieved from the Australian Longitudinal Study on Women's Health (ALSWH)[176]. The ALSWH commenced data collection in 1996, focusing on three distinct age groups of women: young (18–23 years / born 1973-1978), mid-age (45–50 years / born 1946-1951) and old (70–75 years / born 1921-1926) to track changes in women's health over time, identify associated factors that may influence their health outcomes, and evaluate the effects of changes in policy and practise[176]. From the database of the Health Insurance Commission (currently known as Medicare Australia), the participants of the baseline surveys of the ALSWH study were selected using a random sampling method within each of the age groups (except for women residing in rural and remote areas, who were oversampled at a double rate than urban women)[180]. The participants are broadly representative of the nationwide female population within the specified age groups[180]. Details about ALSWH can be found elsewhere[180]. The Human Research Ethics Committees at the University of Newcastle and the University of Queensland, Australia, granted ethics approval for ALSWH. The participants gave clear written consent to participate in the ALSWH. We received approval from the ALSWH Data Access Committee to use the de-identified ALSWH Core dataset for this study.

This present study utilised the dataset of the ALSWH mid-age cohort, of which 13,714 women participated in the baseline survey in 1996[176]. The data from this cohort of participants was collected through mailed surveys at intervals of approximately three years. If required, proxy respondents—typically family members or close friends—were permitted to complete the survey on their behalf[176]. Proxy respondents are reliable and valid sources for assessing stroke-related health outcomes, including health-related quality of life[281]. This cohort has undergone a total of nine surveys so far, with participants aged between 45-50 years during survey 1 in 1996 and 68-73 years during survey 9 in 2019[183]. Due to the availability and consistency of the variables associated with a healthy lifestyle, the present study employed data from surveys 5 through to 9. The questionnaire item *"In the Past 3 years, have you been diagnosed with or treated for stroke"* was utilised across all surveys to identify stroke patients.

Several studies have examined the validity of self-reported stroke, providing support for the utilisation of self-administered questionnaires in epidemiological research to determine the prevalence of stroke in population-based studies where hospital-recorded data are unavailable[248-249]. For instance, a study by Engstad et al.[248] found that self-reported stroke results closely correspond with medical records, exhibiting a positive predictive value of 79%, sensitivity of 80%, and specificity of 99%. Attrition is common in longitudinal investigations[195,198]. Figure 6.1 illustrates the longitudinal progression of participant engagement, providing a detailed listing of participant retention rates and reasons for attrition at each follow-up interval over the course of the investigation. A total of 531 stroke survivors were identified in different surveys. Among them, 456 stroke survivors participated in survey 5 (2007); 433 stroke survivors participated in survey 6 (2010); 402 in survey 7 (2013); 360 in survey 8 (2016); and 333 in survey 9 (2019). This study is based on the information of those 531 stroke survivors (Table 6.1).

6.3.2 Dependent variables

The dependent variables considered in this study were the self-reported physical and mental health status of the participants. The self-reported physical and mental health status was determined using the Physical Component Summary (PCS) scores and Mental Component Summary (MCS) scores obtained from the Short Form 36 Health Survey Questionnaire (SF-36)[189,190]. The SF-36 questionnaire comprises eight distinct multi-item scales, consisting of a total of 36 items. These scales evaluate various aspects of an individual's health, including physical function (PF), bodily pain (BP), role limitations due to physical health problems (RP), general health (GH), vitality, social functioning (SF), role limitations due to emotional problems (RE), and mental health (MH)[189,190]. Two summary measures of health status, namely PCS scores and MCS scores, are calculated using standard scoring algorithms based on the eight scales[189,191]. The PCS score is comprised of PF, BP, RP, and GH, whereas the MCS score is comprised of vitality, SF, RE, and MH[189,191]. PCS and MCS scores range from 0 to 100 (mean = 50, standard deviation=10), with higher scores indicating better health[189,191]. The SF-36 is commonly used to measure self-reported physical and mental health status in various populations. This questionnaire has also been shown to have high reliability and validity for use with stroke survivors[192,193].

6.3.3 Independent variables

The independent variables for this study were physical activity, smoking, alcohol consumption, and supplement use. The Active Australia Survey questionnaire was utilised to measure physical activity levels[185], whose validity and reliability have been demonstrated to be acceptable[186]. Participants reported the frequency and amount of time they spent (that lasted ≥10-minute periods) engaging in brisk walking, moderate physical activities (such as social tennis, moderate exercise classes, dancing, recreational swimming), and vigorous physical activities (that caused them to breathe harder or puff and pant such as aerobics, vigorous cycling, running, competitive sports, swimming) during the preceding week. Physical activity score was measured using metabolic equivalent (MET) minutes per week, which was calculated using the formula: (3.0* walking minutes + 4.0* moderate activities minutes + 7.5* vigorous activities minutes[186]. Based on total MET.minutes per week, physical activity was categorised as inactive/sedentary (<600) or moderate/high (≥600), where moderate/high physical activity is equivalent to the recommended physical activities for Australian adults (≥150 min/week of moderate activities)[186].

The participants were asked to report the number of standard alcoholic drinks they usually consumed daily. The risk associated with alcohol consumption was categorised as: no/low-risk (≤14 drinks/week) and risky/high-risk (>14 drinks/week)[188]. The smoking status was determined by asking participants how often they currently smoke cigarettes or any tobacco products. Supplement use was determined by asking participants if they had consumed vitamins/minerals during the 12-month period preceding the survey.

6.3.4 Confounding variables

Age, body mass index (BMI), marital status, the number of comorbidities, and survey period were included as confounding variables in the regression models. Marital status was categorised as: married/de facto and widowed/divorced/separated/never married. The BMI was computed using the formula kg/m^2, utilising self-reported measurements of height and weight. According to the World Health Organisation (WHO), the classification of BMI was as follows: underweight/normal (<25.0 kg/m^2), overweight (25.0-30.0 kg/m^2), and obese (≥30.0 kg/m^2)[213]. The survey questionnaires asked about a range of doctor-diagnosed chronic conditions within the previous three years. The number of comorbidities calculated from the conditions: diabetes,

arthritis, hypertension, heart disease, cancer, asthma, depression, anxiety, bronchitis, low iron level, and osteoporosis.

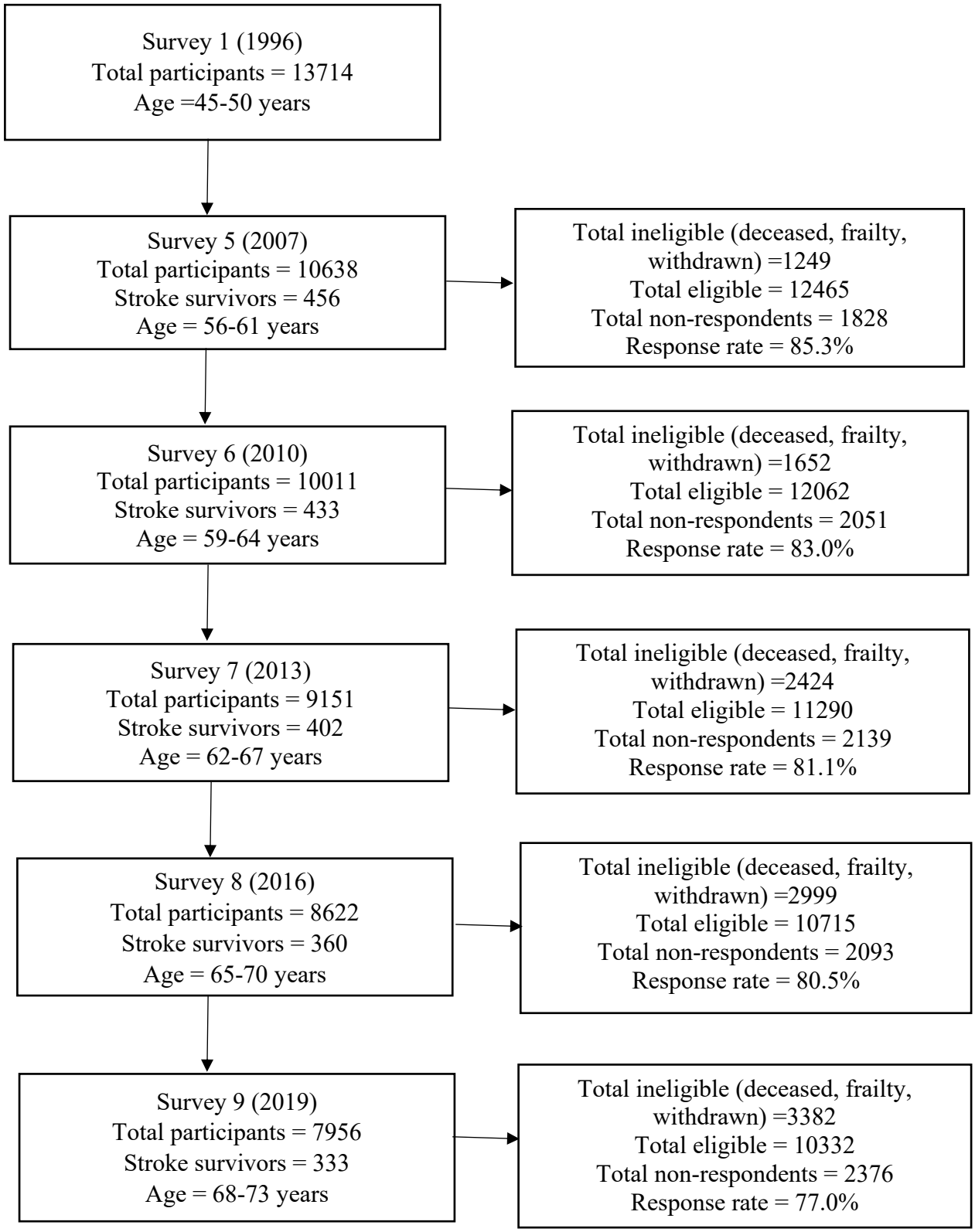

Figure 6.1: Longitudinal trajectory of participant engagement.

6.3.5 Statistical analysis

We analysed the longitudinal association between the dependent variable and the independent and confounding variables using Generalised Estimating Equation (GEE) models, specifying the Gaussian family with a log link function. The physical and mental health status of the participants were treated as continuous variables. To account for temporal trends and varying follow-up durations, the 'time (year of survey)' variable was included in the GEE models. This approach ensures that the natural trend of SF-36 scores over time is captured independently from the effects of other covariates. We expressed the effect size as Exp(β) (the exponentiated regression coefficient), which represents the relative change in the dependent variable associated with a one-unit change in the independent variable. The initial multivariable GEE models included variables with Exp(β) p-values less than 0.25. A backward stepwise regression approach was then employed to identify the most parsimonious model for each dependent variable. The final model provides the adjusted Exp(β) estimates.

GEE can provide robust estimates in the presence of dropouts and missing points, assuming the data are missing completely at random (MCAR) or missing at random (MAR). [194,195,198,199] To address biases caused by non-random missing data (e.g., cases where participants dropped out due to mortality or severe health issues potentially related to poorer lifestyle choices) and ensure reliable estimates, we performed sensitivity analysis utilising multiple imputation and weighted GEE with inverse probability weighting approaches,[194,195,198,199] and found that our adjusted analyses were robust, with potential attrition bias had no significant impact on the main associations. A p-value of <0.05 was deemed statistically significant. The statistical software Stata 17.0 was employed throughout the analysis procedures.

6.4 Results

A total of 531 stroke survivors participated in different surveys over the course of five survey periods (2007-2019). The demographic and health status characteristics of the participants are shown in Table 6.1. The average age of the participants was 58.1 (SD=1.4) years in survey 5 (conducted in 2007) and 70.5 (SD=1.5) years in survey 9 (conducted in 2019). Physical health (PCS) showed a declining trend from 43.1 (SD=11.5) in 2007 to 39.6 (SD=11.4) in 2019. Conversely, mental health showed an increasing trend from 48.4 (SD=12.0) in 2007 to 50.3 (SD=10.8) in 2016, and 50.0 (SD=10.5) in 2019.

The prevalence of smoking among the participants was reported as 17.5% in the year 2007, which subsequently decreased to 7.6% in 2016 and 7.9% in 2019. The prevalence of risky/high-risk alcohol consumption showed a gradual decline from 10% in 2007 to 4.3% in 2019. The percentage of participants with moderate to high levels of physical activity was its highest level in 2010 (57.3%), and its level lowest in 2019 (47.4%). There was a consistent prevalence of supplement utilisation across the five surveys, with a range of 77.0% to 79.4%. The prevalence of three or more comorbidities increased from 37.3% in 2007 to 47.5% in 2019.

Table 6.1 Demographic and health status characteristics of study participants across five survey periods (2007-2019).

Characteristics	Survey 5 (2007) (n=456)	Survey 6 (2010) (n=433)	Survey 7 (2013) (n=402)	Survey 8 (2016) (n=360)	Survey 9 (2019) (n=333)
	Mean (SD)	**Mean (SD)**	**Mean (SD)**	**Mean (SD)**	**Mean (SD)**
Age	58.1 (1.4)	61.2 (1.4)	64.4 (1.5)	67.1 (1.4)	70.5 (1.5)
Number of comorbidities	2.4 (2.5)	2.5 (2.4)	2.6 (2.1)	2.6 (1.8)	2.5 (1.8)
Physical health summary scores	43.1 (11.5)	42.2 (11.7)	40.9 (11.4)	39.9 (11.8)	39.6 (11.4)
Mental health summary scores	48.4 (12.0)	48.7 (11.7)	49.8 (11.3)	50.3 (10.8)	50.0 (10.5)
	n (%)	**n (%)**	**n (%)**	**n (%)**	**n (%)**
Marital Status					
Married/De facto	334 (73.7)	307 (71.2)	275 (68.9)	230 (65.0)	205 (63.7)
Widowed/Divorced/Separated/Never married	119 (26.3)	124 (28.8)	124 (31.1)	124 (35.0)	117 (36.3)
Current smoking					
No	372 (82.5)	367 (85.2)	357 (88.8)	327 (92.4)	302 (92.1)
Yes	79 (17.5)	64 (14.8)	45 (11.2)	27 (7.6)	26 (7.9)
Alcohol consumption risk					
None/Low risk	405 (90.0)	394 (91.6)	364 (92.4)	326 (93.4)	291 (95.7)
Risky/High risk	45 (10.0)	36 (8.4)	30 (7.6)	23 (6.6)	13 (4.3)
BMI (kg/m^2)					
Underweight or Normal (<25.0)	162 (36.6)	139 (33.3)	127 (32.7)	111 (32.8)	96 (35.0)
Overweight (25.0-29.9)	151 (34.1)	138 (33.0)	134 (34.5)	106 (31.4)	84 (30.7)
Obese (≥30.0)	130 (29.3)	141 (33.7)	127 (32.7)	121 (35.8)	94 (34.3)
Physical activity					
Inactive/Sedentary (<150 min)	196 (45.7)	167 (42.7)	184 (47.7)	152 (44.6)	162 (52.6)
Moderate/High (≥150 min)	233 (54.3)	224 (57.3)	202 (52.3)	189 (55.4)	146 (47.4)
Number of comorbidities					
0	98 (21.5)	76 (17.6)	68 (16.9)	39 (10.8)	39 (11.7)
1	97 (21.3)	101 (23.3)	85 (21.1)	80 (22.2)	74 (22.2)
2	91 (20.0)	83 (19.2)	77 (19.1)	73 (20.3)	62 (18.6)
≥3	170 (37.3)	173 (40.0)	172 (42.8)	168 (46.7)	158 (47.5)
Supplements use					
No	103 (23.0)	99 (23.2)	89 (22.3)	73 (20.6)	74 (22.8)

Yes	344 (77.0)	328 (76.8)	310 (77.7)	282 (79.4)	251 (77.2)

The results of the two GEE models —one adjusted for age, marital status, and year of survey, and the other additionally adjusted for BMI and number of comorbidities— are presented in Table 6.2. To assess the potential mediating effects of BMI and number of comorbidities on health outcomes, we compared these two models. Using two distinct models, our analyses demonstrated that adjusted Exp(β) for the associations between lifestyle factors and health outcomes showed minimal differences, suggesting that BMI and comorbidities are not mediators. However, after adjusting for age, marital status, BMI, number of comorbidities and year of survey, the findings illustrate that current smokers exhibited 7% poorer physical health (Exp(β): 0.93; 95% CI: 0.89, 0.96) and mental health (Exp(β): 0.93; 95% CI: 0.90, 0.96) than non-smokers. Likewise, stroke survivors who were risky/high-risk alcohol consumers had 7% lower mental health (Exp(β): 0.93; 95% CI: 0.89, 0.97) status than stroke survivors who abstained from or had low-risk alcohol use. In contrast, stroke survivors who engaged in moderate or high levels of physical activity had 1.17 times (Exp(β): 1.17; 95% CI: 1.15, 1.20) and 1.05 times (Exp(β): 1.05; 95% CI: 1.02, 1.07) better physical and mental health, respectively compared to their inactive or sedentary counterparts. Supplement use was not significantly associated with either physical health or mental health.

Table 6.2 GEE model for determining the significant longitudinal predictors of physical and mental wellbeing.

Characteristics	Physical wellbeing		Mental wellbeing	
	Exp(β)* (95% C.I.); p-value	Exp(β)** (95% C.I.); p-value	Exp(β)* (95% C.I.); p-value	Exp(β)** (95% C.I.); p-value
Current Smoking				
No	1.00	1.00	1.00	1.00
Yes	0.93 (0.89, 0.97); <0.001	0.93 (0.89, 0.96); <0.001	0.92 (0.89, 0.96); <0.001	0.93 (0.90, 0.96); <0.001
Alcohol consumption risk				
None/Low risk	-	-	1.00	1.00
Risky/High risk	-	-	0.93 (0.89, 0.97); 0.001	0.93 (0.89, 0.97); < 0.001
Physical activity				
Inactive/Sedentary	1.00	1.00	1.00	1.00
Moderate/High	1.21 (1.18, 1.24); <0.001	1.17 (1.14, 1.20); <0.001	1.07 (1.05, 1.09); <0.001	1.05 (1.02, 1.08); <0.001
Supplements use				
No	-	-	-	-
Yes	-	-	-	-

** Adjusted for age, marital status, and year of survey.*

*** Adjusted for age, marital status, BMI, number of comorbidities and year of survey.*

Figure 6 presents a Directed Acyclic Graph (DAG) illustrating the impacts of health behaviours (risky/high-risk alcohol consumption, smoking, and moderate-to-high physical activity) on

wellbeing outcomes (physical and mental wellbeing), while accounting for confounding factors (age, BMI, marital status, number of comorbidities, and year of survey). The DAG shows that higher levels of physical activity positively impact both physical and mental wellbeing. In contrast, smoking and risky alcohol consumption have negative impacts on wellbeing. Dashed lines represent confounding paths, indicating that variables such as age and a number of comorbidities influence both health behaviours and wellbeing outcomes.

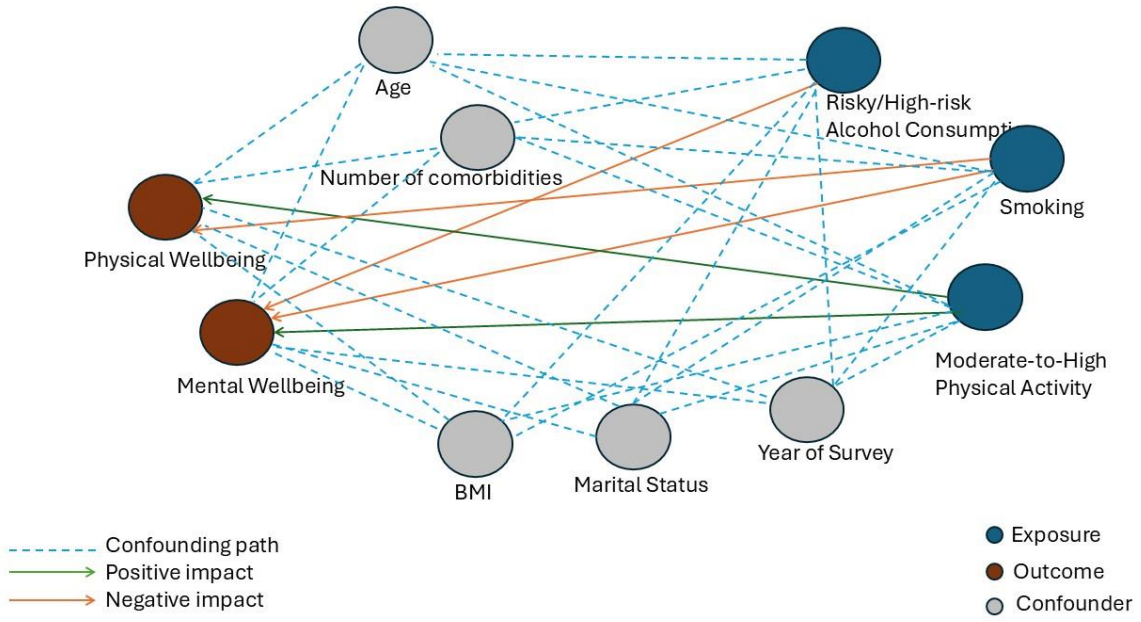

Figure 6.2: The Association Between Health Behaviours, Confounders, and Wellbeing Among Female Survivors of Stroke.

6.5 Discussion

This is the first longitudinal study that provides in-depth analyses of the impacts of a healthy lifestyle on self-reported physical and mental health status in female stroke survivors in Australia. Our analyses of a nationally representative dataset of Australian women (aged 45-50 years at baseline) reveal some important findings. We found that female stroke survivors who engage in moderate/high levels of physical activity have better physical and mental health. Moreover, stroke survivors who smoke have poorer physical and mental health. Likewise, stroke survivors who consume alcohol at a risky/high-risk level have poorer mental health. The findings of our study may be important for policymakers, healthcare professionals, and

researchers to make evidence-based decisions, develop public health initiatives, and conduct further research in this area.

Our results show that stroke survivors who adhere to the recommended level of physical activity (>150 minutes per week) have significantly better physical and mental health compared to those who do not meet the recommended threshold. A meta-analysis based on randomised controlled trials[279] found beneficial effects of physical activity/exercise on physical and mental health among stroke survivors. There are numerous plausible health benefits associated with physical activity for post-stroke individuals[73,77,91,251,252,256,282,78,84–90]. For example, adequate physical activity can improve the functional recovery, muscle strength, motor movement, brain recovery, cardiovascular health, mood, and social participation, as well as reduce the risk of stroke-related complications, stroke recurrence, hospitalisation, and cognitive impairments among those living post-stroke[73,77,91,251,252,256,282,78,84–90]. These benefits may explain why stroke survivors in our study who maintain the recommended level of physical activity report better physical and mental health. Nevertheless, we observed that nearly half of the stroke survivors report physical inactivity/sedentary behaviour throughout surveys 5-9, indicating that urgent attention is required to help introduce appropriate initiatives promoting the recommended amounts of physical activity in female stroke survivors.

The negative association between smoking and both physical and mental health among stroke survivors in our study may be explained as follows. First, stroke survivors who smoke may have had a higher prevalence of several conditions due to their smoking behaviour, including fatigue, cardiovascular and respiratory issues, and mental/cognitive disorders[283–286]. In general, post-stroke individuals with a greater number of comorbidities report decreased levels of self-reported health and wellbeing[109,287]. Second, as smoking is a significant predictor for stroke recurrence[230], the prevalence of stroke recurrence may have been higher among stroke survivors who smoked than those stroke survivors who were non-smokers. Recurrent stroke is associated with an increased risk of disability, which may adversely affect both physical and mental health[236]. In order to enhance the physical and mental health of female stroke survivors, our findings suggest that appropriate and effective strategies need to be implemented to reduce smoking rates in this population. Specifically, self-management educational programs have the potential to act as useful interventions in reducing smoking prevalence and improving wellbeing in post-stroke females[50].

Our study also demonstrates a significant association between risky/high-risk alcohol consumption and a diminished state of mental health among those living post-stroke. While there is a lack of comparable research specifically focused on stroke survivors, this finding aligns with studies conducted on the general population[288–290], which show poor self-reported mental health among high-risk alcohol consumers. One possible explanation for the negative impact of alcohol consumption on self-reported mental health is that alcohol can disrupt neurotransmitter systems, resulting in mood changes, cognitive deficits, a greater tendency for suicidal thoughts, an increased risk of mental health disorders, and a worsening of pre-existing mental health conditions[290–294]. Alcohol consumption can exacerbate stroke symptoms and interfere with stroke medication[231]; these effects may also contribute to a lower state of mental health among risky/high-risk alcohol consumers in our study sample. Our findings further support the need for the implementation of targeted interventions to reduce risky alcohol consumption among female stroke survivors in an effort to improve their mental health.

Interestingly, our study did not observe a significant association between risky/high-risk alcohol consumption and physical health. A recent cross-sectional study conducted in Sri Lanka also found an insignificant association between alcohol use and physical health among stroke survivors[277]. It is important to interpret this finding cautiously and consider potential factors that may explain this result. One possible explanation is that the participants who continue risky/high-risk alcohol consumption over time may have a lower incidence of stroke-related physical disability and/or fewer medical conditions. However, risky/high-risk alcohol consumption can still have negative effects on physical health status over time. To gain a deeper understanding of the association between alcohol consumption and physical health, additional longitudinal research with extended follow-up is required.

Regarding the physical and mental health of female stroke survivors, our findings underscore the critical importance of maintaining a healthy lifestyle. However, it is important to consider these findings within the existing framework of secondary prevention support in Australia. The Australian Stroke Clinical Registry (AuSCR) identifies notable gaps in the provision of secondary prevention services, such as inadequate post-treatment support and limited access to rehabilitation programmes, which may impede the achievement of optimal recovery, long-term health maintenance, and overall quality of life[114]. Current clinical guidelines for stroke management, as outlined by the Stroke Foundation, recommend comprehensive lifestyle

modifications, including engagement in physical activity, smoking cessation, abstinence from alcohol, and adherence to a proper nutrition[65]. Despite these recommendations, our study indicates that a considerable percentage of stoke survivors do not comply with the guidelines, emphasising the necessity for additional support and resources to ensure that stroke survivors maintain a healthy lifestyle throughout their survivorship. Addressing these gaps through targeted secondary prevention initiatives and strict adherence to clinical guidelines could significantly enhance the quality of life and health status of stroke survivors.

There are several limitations that should be taken into consideration when drawing conclusions from our research outcomes. Firstly, it is important to note that the study relies on self-reported data provided by the participants, which could potentially be influenced by recall bias. Second, participation bias is another limitation that should be considered. The participants in this study may differ in significant ways from those who did not participate or were not eligible for inclusion. These differences might include variations in health status or other sociodemographic factors that influence the adoption of healthy lifestyle behaviours and the impacts on physical and mental wellbeing of such behaviours. These disparities could affect the results and limit the generalisability of the findings to all female survivors of stroke. However, the robustness of the findings was confirmed by sensitivity analyses, suggesting that potential biases had a minimal impact on our study's outcomes. Third, due to a lack of data, we were unable to control for some potential confounders like stroke severity[105], functional status[107,272], and carer roles[110], which may have some effects on the physical and mental health outcomes. Fourth, the participants of our study were middle-aged and older; therefore, the findings may not be generalisable to young female stroke survivors. Nevertheless, our study possesses several strengths including the utilisation of a nationally representative dataset collected over a 12-year period from a large sample of women in Australia. Another strength of this study lies in its ability to control for various demographic and health-related characteristics within the model, thereby strengthening the specific analysis. Additionally, the measures included in this study have been widely used and validated in comparable large population samples.

6.6 Conclusions

The present longitudinal study provides the first specific insights into the impacts of maintaining a healthy lifestyle on the physical and mental health of female stroke survivors in Australia. The longitudinal analyses suggest that engaging in moderate-to-high amounts of physical activity and/or abstaining from smoking can positively affect self-reported physical and mental health and wellbeing among female stroke survivors. Similarly, none/low risk alcohol consumption has been found to have a beneficial impact on the mental health of female stroke survivors. Our findings suggest that women living post-stroke could improve their physical and mental health by maintaining a healthy lifestyle. Targeted and appropriate programmes and strategies may be needed to promote physical activity and reduce smoking and alcohol consumption in female stroke survivors in order to optimise their overall health and health-related quality of life.

6.7 Acknowledgments

The research on which this paper is based was conducted as part of the Australian Longitudinal Study on Women's Health by the University of Queensland and the University of Newcastle. We are grateful to the Australian Government Department of Health and Aged Care for funding and to the women who provided the survey data.

Chapter 7: Discussion

This chapter provides an in-depth discussion of the important insights the thesis research has identified regarding the utilisation of self-management strategies in long-term rehabilitation after stroke, with an emphasis on the significance of maintaining a healthy lifestyle. Additionally, recommendations for future research directions are provided, and the limitations of the study are addressed.

Survivors of stroke, their families, carers, and healthcare providers have increasingly given attention to self-management for post-stroke care[44,57,72,131,132,134,295]. Several international stroke guidelines recommend that all post-stroke individuals should incorporate self-management strategies into their long-term rehabilitation process after stroke[65–69]. The adoption of a healthy lifestyle has become a prominent approach in this context[71]. Therefore, the aim of my thesis was to examine the use of self-management strategies for long-term rehabilitation for those with stroke. The objectives were to investigate the perceptions, experiences, prevalence, and determinants of these approaches, as well as to explore their long-term effects on healthcare use, physical health, and mental health among post-stroke individuals.

7.1 Primary findings from the research

This thesis has resulted in multiple novel contributions to knowledge, including: 1) the first scoping review worldwide to explore the use of self-management strategies for stroke rehabilitation and stroke survivors' experiences with these strategies (Chapter 2); 2) the first longitudinal analysis focusing on the determinants of healthy lifestyle behaviours among stroke survivors in Australia (Chapter 4); 3) the first longitudinal examination of the effects of a healthy lifestyle on reducing healthcare utilisation for survivors of stroke (Chapter 5); and 4) the first comprehensive longitudinal analysis of the impacts of a healthy lifestyle on self-reported physical and mental health status in female survivors of stroke (Chapter 6).

My thesis utilised advanced methodologies across three longitudinal studies and provided important insights into the use of self-management strategies during the long-term rehabilitation process after a stroke. However, the subsequent subsections delve deeper into the most noteworthy findings, which represent the core contributions of this research and hold significant potential to advance self-management-based long-term rehabilitation after stroke.

7.1.1 Utilisation of self-management strategies in stroke rehabilitation

Chapter 2 of this thesis contains a scoping review that provides a comprehensive examination of the use of self-management strategies in stroke rehabilitation. The review addresses research questions 1 and 2, which are related to assessing the available evidence on the use of self-management in stroke rehabilitation, as well as identifying the self-management strategies currently being employed and considered useful for stroke rehabilitation. The findings of Chapter 2 demonstrate self-management as a dynamic, collaborative, and promising approach utilised by survivors of stroke to navigate the challenges of post-stroke life. The review underscores the importance of self-management in long-term rehabilitation after stroke and acts as an important investigation into the diverse strategies adopted by post-stroke individuals.

The scoping review reveals that individuals with stroke utilise a variety of self-management strategies for their stroke rehabilitation. These strategies are associated with various domains, including lifestyle, social support, communication, knowledge and information, and goal-setting. Notably, all these five self-management domains identified in this review align with the current recommendations outlined in multiple international clinical guidelines for stroke rehabilitation[65–69]. Furthermore, the review reveals a majority of stroke survivors simultaneously engage in multiple self-management domains, utilising a wide range of strategies within those domains for their stroke rehabilitation. Previous reviews on individuals living with various chronic conditions also indicate that participants utilise multiple domains of self-management concurrently to manage their specific conditions[58,60,61,287]. Adopting a healthy lifestyle (lifestyle-related self-management); seeking support from family members, friends, and healthcare professionals during post-stroke rehabilitation (social support-related self-management); maintaining good communication with caregivers and health professionals (communication-related self-management); participating in self-management educational programmes (knowledge and information-related self-management); and setting realistic and achievable goals (goal-setting-related self-management) are some examples of self-

management strategies adopted by survivors of stroke, as revealed in the scoping review. Most of the strategies identified in the review are commonly employed by individuals with a range of chronic conditions, including diabetes, arthritis, heart disease, or multiple chronic conditions[58,60,61,287].

The scoping review also identified several factors such as gender, age, stroke-related impairment, fatigue, level of education, level of stroke knowledge, and social support associated with the use of self-management strategies in stroke rehabilitation. These findings illustrate the complex interaction between individual behaviours and external supports in influencing the adoption and maintenance of self-management practices. Additionally, the review chapter focuses on the subjective experiences of stroke survivors regarding self-management utilisation. Many survivors of stroke reported positive outcomes with employing self-management strategies. For instance, the majority of stroke survivors who were participants in the research reported in the review literature and who participated in stroke rehabilitation programmes reported that these programmes facilitated improvements in their behaviours, fostered the development of self-management skills, strengthened social connections, boosted confidence, and enhanced their ability to navigate life after stroke. Previous reviews have also documented comparable benefits of self-management programmes for those with stroke[63,134]. However, as these assessments rely on self-reporting, they inherently include a subjective component. Nevertheless, the viewpoints canvassed offer valuable insights into the lived experiences of individuals with stroke around using self-management strategies for their rehabilitation.

It is important to consider the limitations of the scoping review when interpreting the findings. Limiting the inclusion criteria to studies published solely in English could potentially overlook important insights from non-English literature. A critical future research direction is to broaden the inclusion criteria to incorporate studies in several languages, which may allow a more comprehensive exploration of cultural perspectives on self-management strategies in stroke rehabilitation. Furthermore, the exclusion of studies involving children (<18 years old), due to the relative rarity of stroke in children[160], adds an additional limitation. For future review, considering an expanded scope to include studies involving children could provide valuable insights into the unique challenges and interventions related to self-management approaches in the context of paediatric stroke.

While offering a comprehensive overview of self-management strategies following a stroke, the scoping review also identified gaps in the current body of literature on the topic, including the scarcity of longitudinal studies that examine the determinants influencing the utilisation of self-management for stroke rehabilitation, and the lack of substantial evidence assessing how self-management strategies impact the healthcare utilisation and overall health status of stroke survivors. The identified gaps and the future directions outlined in the review highlight crucial areas for advancing the understanding and implementation of self-management strategies in the context of stroke rehabilitation. One primary recommendation is to conduct large-scale longitudinal studies. Those longitudinal studies can offer evidence-based approaches, providing valuable insights for clinical practice, informing policymaking, and ultimately enhancing outcomes for survivors of stroke. Stroke rehabilitation is usually a long-term and ongoing process[37,66,112], and over time, a number of factors may influence self-management behaviours. Large-scale longitudinal studies are crucial for deeply investigating the factors that influence self-management practices following a stroke as well as facilitating a comprehensive understanding of trends, patterns, causes, and how to best facilitate the sustainability of these practices. Additionally, the review underscores the need for large-scale longitudinal research future research to examine the impacts of self-management strategies on optimising long-term rehabilitation outcomes, specifically by assessing how these strategies influence healthcare utilisation and the health status of stroke survivors. This emphasises the need for a commitment to utilising evidence-based strategies in long-term rehabilitation after stroke. The empirical research in this field would serve as providing crucial information to healthcare professionals, guiding policymakers, and developing interventions that align with the diverse needs of individuals with stroke.

7.1.2 Longitudinal determinants of healthy lifestyle behaviours

Utilising the longitudinal data obtained from the 45 and Up Study's baseline survey (2005-2009) and a sub-study survey (2017) (n=576), Chapter 4 of my thesis addresses research questions 3 and 4 concerning the prevalence and determinants of healthy lifestyle behaviours among post-stroke individuals in Australia. Chapter 4 provides valuable insights into the adoption and maintenance of these behaviours over time. It holds particular significance as the first large-scale, longitudinal analysis of healthy lifestyle behaviours among Australian stroke survivors, addressing a crucial gap in our knowledge by elucidating the changes and determinants of these behaviours over time.

The longitudinal results of my thesis highlight a significant decline in moderate-to-high levels of physical activity (≥150 minutes/week) among stroke survivors over time (Chapter 4). Three previous longitudinal studies conducted on stroke survivors, with follow-up periods ranging from 6 months to 3 years, produced mixed results regarding the trend of physical activity over time[84,209,296]. For example, a study conducted among survivors of stroke in the United Kingdom, with a follow-up period of three years and a relatively small sample size (n=74), identified a gradual increase in physical activity levels over time[209]. Conversely, another study among individuals with stroke in Sweden with a small sample size (n=190) and a short-term follow-up duration of one year observed a declining trend in physical activity among post-stroke individuals[296]. Additionally, a large-scale cohort study in Sweden, involving 1,367 stroke survivors, revealed mixed trends in physical activity levels over only a six-month follow-up period[84]. However, the findings of this thesis align with those from previous large-scale longitudinal studies that have conducted long-term follow-ups, consistently reporting a decline in physical activity levels among the mid-to-older aged general population[297-298]. For example, a Canadian study using National Population Health Survey data from 12,901 adults observed a decrease in physical activity over a 14-year follow-up[297]. Similarly, the Baltimore Longitudinal Study of Aging in the United States, assessing 1,316 men and 776 women, found an overall decline in physical activity over mean follow-ups of 21.2 years for men and 10.2 years for women[298]. The observed decrease in physical activity levels in stroke-specific populations can potentially be attributed to various factors, such as the ageing process and the recurrence of strokes. The existing body of literature consistently indicates that ageing is linked to a decrease in physical function[214,299], and there is a significant association between advancing age and decreased physical activity, especially among those with pre-existing health conditions, including stroke[214,299–302]. Moreover, the impact of stroke recurrence on physical activity levels cannot be overlooked. Recurrent strokes, a common issue among survivors, can exacerbate physical and cognitive impairments[207,216,303], further complicating the maintenance of moderate-to-high levels of physical activity. The challenges related to ageing and/or recurrent strokes, alongside the other impacts of stroke and health conditions, may create a multifaceted barrier to maintaining moderate-to-high intensity physical activity over time[78]. The thesis further supports the findings of previous longitudinal studies that show maintaining physical activity over time in survivors of stroke is challenging. This thesis finding suggests programs and initiatives to help maintain such physical activity require further consideration and should be built upon detailed examination of the enablers and barriers to such activity as experienced by those living post-stroke.

The longitudinal findings presented in Chapter 4 of this thesis also demonstrate a significant association between diabetes (both types 1 and 2) and reduced adherence to recommended levels of physical activity among post-stroke individuals. This association aligns with the outcomes of prior longitudinal research conducted within the general populations of Australia[78] and Germany[217], further evidencing the persistent impact of diabetes on physical activity engagement. The complex complications linked to diabetes can impede the ability of people with stroke to comply with recommended amounts of physical activity[78,220–222,304–307]. Notably, diabetes has been identified in the existing literature as a significant contributor to an increased risk of functional dependency, a higher likelihood of stroke recurrence, and diminished post-stroke recovery outcomes[220–222,305–307]. Considering that both stroke and diabetes are conditions that benefit from moderate-to-high intensity physical activity[77,78,308,309] it is crucial to implement targeted and continuous support strategies that promote physical activity among this specific subgroup of stroke survivors.

In Chapter 4 of this thesis, smoking behaviour has been investigated as a persistent issue among post-stroke individuals throughout the study period. Notably, depression, a prevalent post-stroke condition[30], emerges as a significant determinant of smoking behaviour in this thesis. This finding is in line with prior longitudinal studies that illustrate a strong relationship between depression and active smoking in survivors of stroke[225,259], highlighting several critical aspects. First, it uncovers an additional layer of complexity within post-stroke rehabilitation, where psychological factors significantly influence lifestyle choices, potentially impacting health outcomes[30,226,230,310–312]. For example, this thesis reveals a detrimental cycle where depression may lead to increased smoking, which, in turn, increases healthcare utilisation (as revealed in Chapter 5) and reduces physical and mental health (as revealed in Chapter 6) among those with stroke. Second, previous studies have found that both depression and smoking are individually associated with an increased likelihood of stroke recurrence[30,230] and diminished functional recovery[226,310–312]. This suggests that the combined effect of these two conditions may intensify these risks, leading to poorer outcomes in long-term stroke rehabilitation. The interconnection between depression, smoking, and post-stroke outcomes elucidates the complexity of post-stroke care. It underlines the necessity of addressing these interrelated factors effectively within the context of long-term post-stroke care and rehabilitation.

7.1.3 Healthy lifestyle and healthcare utilisation

Chapter 5 of this thesis reported on the analyses of linked administrative data to assess the impact of maintaining healthy lifestyle behaviours on lowering the utilisation of healthcare professionals and prescription medications among survivors of stroke. The Chapter 5 addresses research question 5.

Chapter 5 of this thesis reveals a significant association between maintaining moderate-to-high levels of physical activity and reduced utilisation of healthcare providers. Furthermore, this chapter elucidates an important association between such levels of physical activity and decreased use of blood-thinning medications (antiplatelets and anticoagulants). These results represent the dual advantages of physical activity in facilitating long-term rehabilitation after stroke and reducing the overall burden on healthcare systems, which is particularly important and promising in the context of long-term stroke rehabilitation research. No study focusing specifically on the stroke-affected population has been identified for a direct comparison with these findings. However, the thesis findings align with existing literature on the general adult population, which indicates a substantial reduction in healthcare utilisation including medication as a result of physical activity[313–318]. The mechanisms underlying the impact of physical activity on healthcare dependency are diverse, encompassing both physiological and psychological aspects. For example, participation in moderate-to-high intensity activities on a regular basis has a positive impact on cardiovascular health, blood flow, muscle strength, neuroplasticity, cognitive function, and secondary stroke prevention[73,77,91,251,252,256,282,78,84–90]. These benefits may collectively lead to a reduced dependence on healthcare providers, as observed in the research presented in this thesis. Furthermore, adhering to recommended levels of physical activity can provide protection against stroke-related medical conditions necessitating the use of blood-thinning medications, such as thromboembolism and clot formation[251–256] . In order to optimise the functional recovery of stroke survivors undergoing rehabilitation, physical activity serves as medication for those with the effects of stroke[78,88]. The inherent therapeutic value of physical activity for post-stroke individuals is further highlighted by the finding of a network meta-analysis that exercise interventions are more effective in reducing mortality outcomes compared to blood-thinning medications[87]. However, the findings presented in this thesis underscore the critical role of physical activity in reducing healthcare utilisation, indicating its beneficial effects on long-term rehabilitation after stroke.

The findings presented in Chapter 5 also reveal that survivors of stroke who smoke are more likely to seek medical attention from specialists in psychiatry and neurosurgery. This observation aligns with results obtained from prior studies[319,320] that demonstrate a greater utilisation of healthcare services by individuals with chronic conditions, such as stroke, who also engage in smoking. However, the finding of this thesis sheds light on the intricate relationship between smoking and its substantial effects on the mental and neurological health of post-stroke individuals. Supporting this, cohort studies focusing on mid-to-older aged individuals have similarly highlighted the detrimental impacts of smoking on mental and neurological health[321–323]. This finding of the thesis regarding smoking and the utilisation of specialist physicians is crucial. It not only confirms a vast array of evidence regarding the detrimental health effects and heightened healthcare utilisation associated with smoking, but also identifies the specific healthcare domains that are most substantially impacted by the smoking behaviours of individuals with stroke.

7.1.4 Impacts of healthy lifestyle on self-reported health outcomes

In Chapter 1 of this thesis (section 1.6), the significance of research focusing on female stroke survivors is discussed. Stroke can profoundly alter the lives of survivors, leading to a range of physical and mental consequences. The annual impact of stroke on the wellbeing of survivors in Australia was estimated at $26.0 billion in 2020, with female survivors experiencing disproportionately higher effects on their wellbeing[13]. Chapter 6 in this thesis presents an analysis of data obtained from *Australian Longitudinal Study on Women's Health*, focusing on the effects of maintaining a healthy lifestyle on the physical and mental health of female stroke survivors in Australia. This chapter offers in-depth insights into the subject, drawing on valuable information from the nationally representative dataset over a 12-year period, and addresses research question 6.

The analyses presented in Chapter 6 of this thesis illustrate the crucial role of moderate-to-high levels of physical activity (≥150 minute/week) in enhancing the self-reported physical and mental health status of female stroke survivors. The findings of this research provide additional support for the notion that physical activity improves the physical and mental wellbeing of post-stroke individuals[282,324–327], while further delving into the gender-specific advantages. It is well-documented that women encounter unique obstacles during their recovery process, such as a greater prevalence of physical limitations and depression[101,106,275,276]. The findings of this

thesis contribute a nuanced understanding to this picture by providing evidence that physical activity, particularly when moderate-to-high intensity, has the potential to significantly improve the health of female survivors. The wide range of benefits associated with adopting and maintaining recommended levels of physical activity may play a crucial role in enhancing the physical and mental health of female stroke survivors. For example, benefits of physical activity encompass improvements in functional recovery, muscle strength, motor coordination, brain function, and cardiovascular health[73,77,91,251,252,256,282,78,84–90]. Furthermore, engaging in physical activity can alleviate symptoms of depression and anxiety, which are commonly experienced by stroke survivors, thus promoting better mental health[328,329]. In addition to inducing the release of endorphins, which serve as naturally occurring mood enhancers and neurotransmitters, physical activity can promote a general sense of wellbeing[330]. Moreover, engaging in physical activities within a social and supportive environment can foster a sense of belonging and community, which may alleviate feelings of isolation and can enhance overall wellbeing[331,332].

Chapter 6 of this thesis also reveals a significant association between smoking and diminished physical and mental health status among female stroke survivors in Australia, highlighting the extensive and multifaceted impact of smoking on health. Although no similar study has been found such direct comparison, the results align with existing literature on stroke survivors documenting the adverse effects of smoking on functional outcomes and the recurrence of stroke[230,310,311,333]. These thesis findings, derived from a large-scale and nationally representative sample with long-term follow-up, underscore the negative implications of smoking behaviour on health and present challenges to the recovery process for stroke survivors. The findings emphasise that the detrimental effects of smoking extend beyond physical health, significantly impairing mental health and possibly complicating the rehabilitation journey for female stroke survivors. By focusing on the specific challenges faced by female stroke survivors who smoke, this research adds a crucial perspective to the discourse on stroke recovery and prevention, underlining the need to address smoking as a key factor in the post-stroke rehabilitation process.

The thesis significantly advances our understanding of the intricate relationship between alcohol consumption and self-reported mental health in female stroke survivors, uncovering a significant association between risky/high-risk drinking behaviours and reduced mental

wellbeing (Chapter 6). This finding suggests a potential link between risky/high-risk alcohol consumption patterns and the development of mental disorders among post-stroke individuals[290,292,293]. Other possible reasons contributing to this association could include the worsening of existing psychological distress due to alcohol consumption, as well as possible interactions between alcohol and medications used to treat stroke and mental health conditions[231,290,292,293] . This finding is pivotal, as it not only aligns with existing research that underscores the broad detrimental effects of risky alcohol consumption on health but also provides a gender-specific perspective that has been less explored in the literature The gender-specific implications of these findings necessitate a deeper exploration into the social, psychological, and biological factors that may predispose female stroke survivors to engage in risky/high-risk drinking behaviours, particularly in the context of managing post-stroke mental health challenges. Understanding these nuances is crucial for developing targeted interventions that address the unique needs of this population. Furthermore, future research should aim to elucidate the mechanisms through which alcohol consumption exacerbates mental health issues in female stroke survivors, potentially focusing on the interplay between gender-specific stressors, hormonal influences, and the impact of stroke-related disabilities. Identifying these pathways is essential for crafting preventative strategies and therapeutic interventions tailored to mitigate the compounded risks faced by female stroke survivors.

7.2 Linking Theoretical Frameworks to Research Outcomes

A framework that draws upon aspects of the Health Belief Model (HBM)[161], Transtheoretical Model (TTM)[162], Chronic Care Model (CCM)[163], and Wilson and Cleary Model of Health-Related Quality of Life[164], served as the central conceptual structure for the study, with a detailed discussion of this framework provided in Chapter 3 of this thesis. As identified in this thesis, the framework helped establish a solid foundation for comprehending the complex aspects of self-management practices in long-term stroke rehabilitation. Each framework played a critical role in developing the research design, guiding the interpretation of data, and providing valuable insights into the determinants of healthy lifestyle behaviour maintenance and health outcomes among those with stroke.

The HBM was crucial in examining how the health beliefs of people with post-stroke influenced their self-management approaches, especially in Chapter 4, which concentrated on the factors that contribute to maintaining healthy lifestyle behaviours. For example, findings

showed that survivors of stroke with chronic conditions, such as diabetes, were less likely to engage in moderate-to-high levels of physical activity over time. This is consistent with the HBM's concept of perceived barriers, as individuals with stroke may perceive their physical condition as a hindrance to participating in the recommended amount of physical activity. Conversely, survivors of stroke with higher levels of education, who may have a better understanding of the benefits of physical activity, were more likely to participate in moderate-to-high levels of physical activity, thereby supporting the HBM's principle that perceived benefits influence behaviour. Moreover, post-stroke individuals with depression and risky alcohol consumption were more likely to smoke, possibly perceiving a lower susceptibility to additional health complications, which may contribute to the continuation of unhealthy behaviours.

The TTM model was key in understanding the dynamic nature of behaviour change among stroke survivors, positing that this change is a process involving five stages: pre-contemplation, contemplation, preparation, action, and maintenance[162]. The findings from Chapters 4 and 5 illustrate how stroke survivors navigate through the TTM stages in their self-management efforts. For example, Chapter 4 revealed a significant decline in moderate-to-high physical activity levels over time, especially among participants with diabetes and lower educational attainment, suggesting that many individuals may struggle to progress beyond the preparation or action stages to achieve sustained behaviour change. Additionally, persistent unhealthy behaviours such as smoking among females, individuals with depression, and those consuming alcohol at moderate to high-risk levels indicate challenges in moving from contemplation to action. Furthermore, Chapter 5 highlighted that stroke survivors who maintained moderate-to-high amounts of physical activity over time were significantly less likely to use healthcare services, including health professionals and prescription medications, which emphasises the importance of advancing to the maintenance stage to reduce dependency on healthcare.

The CCM model provided a valuable framework in Chapters 5 and 6. The findings highlighted the beneficial impacts of moderate-to-high levels of physical activity among post-stroke individuals, including reduced utilisation of healthcare and improved wellbeing. These outcomes are consistent with the CCM, which emphasises that empowering individuals to self-manage their health can lead to improved health outcomes and reduced dependency on healthcare resources.

The Wilson and Cleary Model was essential for understanding the impacts of healthy lifestyle behaviours on health-related quality of life among survivors of stroke in Chapter 6. This model's multi-dimensional approach—spanning physiological factors, symptoms, functional status, general health perceptions, and subjective wellbeing—allowed for a comprehensive analysis of how self-management behaviours influenced both physical and mental health outcomes. For example, stroke survivors who maintained moderate-to-high levels of physical activity reported better physical and mental health, whereas those who smoked and consumed alcohol at high-risk levels reported poorer mental health. These findings align with the Wilson and Cleary Model's prediction that health behaviours influence a wide range of health outcomes, including subjective wellbeing.

7.3 Significance of the research findings

Globally, stroke stands as one of the main causes of disability, exposing survivors to a range of long-term physical, cognitive, emotional, and financial challenges[10,20,21–33]. As the population ages and advanced emergency and acute care have resulted in a substantially reduced early mortality rate after stroke, the number of people with stroke continues to rise[10]. Thus, there is a crucial need to advance our knowledge of effective long-term rehabilitation strategies in order to improve the health outcomes and quality of life for survivors of stroke. Rehabilitation is an ongoing and often lifelong process for people with stroke[39–43,47,53-55]. While current research predominantly focuses on traditional rehabilitation provided by healthcare professionals, my PhD thesis offers novel insights into long-term rehabilitation among Australian stroke survivors, utilising large-scale data with long-term follow-up. The findings of this thesis hold multifaceted significance for the long-term rehabilitation process of stroke survivors by providing actionable insights for clinicians, including general practitioners, and policymakers. These insights can help tailor long-term rehabilitation programs for individuals with diverse risk factor profiles, ultimately improving health outcomes and reducing the burden on healthcare systems.

My PhD thesis presents an extensive examination of the use of self-management strategies in the context of long-term rehabilitation after stroke, revealing valuable insights into perceptions, experiences, determinants, and the long-term impacts of these approaches on health outcomes and healthcare utilisation. The findings highlighted in this thesis are of multifaceted

significance, providing insights regarding various aspects of long-term recovery, post-stroke care, and secondary prevention.

My thesis makes an important contribution to the current body of knowledge by performing the pioneering scoping review (Chapter 2) on the use of self-management strategies for stroke rehabilitation. The review highlights the dynamic and multifaceted nature of self-management approaches utilised by stroke survivors, demonstrating their significance in managing the challenges of post-stroke life. The alignment of the identified self-management domains with international clinical guidelines[65–69] underscores the relevance and potential significance of the findings to practical implementation. Additionally, the review chapter focuses on the subjective experiences of stroke survivors regarding self-management utilisation, providing a nuanced perspective that extends beyond quantitative measures and offers exploratory qualitative insights into the lived experiences of those living post-stroke. The outlined future directions represent a pivotal shift towards a more dynamic, evidence-based, and longitudinal approach to the study of self-management in long-term stroke rehabilitation. By embracing these directions, the field can advance beyond the current limitations, fostering the development of targeted, sustainable, and impactful interventions that address various aspects of post-stroke care.

The thesis makes a significant contribution to stroke research by presenting the findings of three longitudinal studies that utilised data from two prestigious Australian institutions. My thesis addresses a critical gap in the existing literature by conducting the first large-scale longitudinal analysis of healthy lifestyle behaviours among stroke survivors in Australia, as detailed in Chapter 4. By employing a longitudinal approach, my research extensively examines behaviour changes among those with stroke in Australia over time, revealing several critical trends, such as a notable decline in moderate-to-high physical activity levels. This finding is of particular concern given the well-documented advantages of physical activity in the context of post-stroke recovery[73,77,78,84–91,251,252,256,282,]. It not only implies a potential decline in the physical health of stroke survivors but also highlights a deficiency in post-stroke care and existing rehabilitation approaches that fail to maintain or promote lasting lifestyle modifications among post-stroke individuals effectively. Furthermore, my research identifies diabetes and depression as significant determinants impacting post-stroke lifestyle behaviours, thereby adding crucial aspect to our understanding of long-term rehabilitation after stroke.

Specifically, it illustrates that diabetes can diminish adherence to recommended physical activity levels (≥150 minutes/week), which can exacerbate the challenges that survivors of stroke face during their long-term recovery process[78,220–222,304–307]. Similarly, the association between depression and smoking behaviours underscores the complex barriers in addressing detrimental health behaviours following a stroke, as smoking can further complicate health consequences and impair recovery efforts[230,310,311]. These findings regarding the influence of comorbid chronic conditions on the maintenance of a healthy lifestyle following a stroke reinforce the importance of comprehensive longer term effective approaches that focus on not only the effects of the stroke but also concurrent medical conditions. By focusing on specific areas where current post-stroke care and rehabilitation may fall short—such as sustaining physical activity levels, managing coexisting chronic conditions, and addressing mental health issues—this thesis lays a critical foundation for future research, policy development, and clinical practice improvements.

By revealing the relationship between healthy lifestyle behaviours and healthcare utilisation among stroke survivors, my thesis provides valuable insights into the potential benefits of lifestyle interventions in reducing healthcare utilisation (Chapter 5). The significant association between maintaining moderate-to-high levels of physical activity and a reduced dependence on healthcare providers and stroke medication underlines the critical role of recommended physical activity in long-term rehabilitation after stroke. The results of my research provide further evidence in favour of the usefulness of the recommended levels of physical activity as non-pharmacological, cost-effective approach to manage stroke symptoms and reduce the burden on the healthcare system. Moreover, the reduced use of blood thinning medications among active survivors of stroke as highlighted by my thesis research suggests that physical activity can play a role in reducing the risk of polypharmacy. In light of growing concerns regarding the long-term consequences and expenses associated with healthcare reliance caused by stroke effects, the outcomes hold particular significance. Furthermore, the finding that stroke survivors who smoke are more likely to require specialised care from psychiatrists and neurosurgeons emphasises the complex challenges that smoking introduces into the process of recovery after stroke. This insight is critically important for several reasons: it highlights the detrimental effects of smoking on mental and neurological health following a stroke, underscores the increased demand for healthcare resources to mitigate these effects, and emphasises the need to integrate smoking cessation programs into long-term post-stroke care.

Together, the findings elucidated in Chapter 6 of this thesis deepen understanding of the impact of lifestyle behaviour on healthcare utilisation, demonstrating the undeniable benefits of moderate-to-high levels of physical activity and the necessity for targeted strategies to prevent smoking.

By extensively examining the longitudinal effects of lifestyle behaviours on the physical and mental health outcomes of female stroke survivors, this study addresses a significant gap in existing literature and advocates for gender-specific healthcare practices (Chapter 6). The significance of doing a gender-specific analysis lies in its ability to elucidate the distinct impact of different lifestyle behaviours on the health and overall wellbeing of female survivors. This understanding is crucial for providing effective care. By demonstrating a significant association between maintaining moderate-to-high levels of physical activity and enhanced physical and mental health outcomes in female stroke survivors, this research not only indicates the importance of physical activity in the recovery process following a stroke[73,77,78,84–90,91,251,252,256,282] also broadens our understanding of its potential to improve the health-related quality of life of post-stroke females. The findings provide strong empirical evidence supporting the integration of physical activity as a core element of post-stroke care for women. However, a notable observation from the research is that nearly half of the female stroke survivors reported being physically inactive or sedentary across the utilised surveys. This suggests a significant gap in existing rehabilitation strategies and underscores the urgency of implementing effective measures to promote and maintain the recommended levels of physical activity within this demographic. The findings regarding smoking illuminate its comprehensive negative impact on both physical and mental health dimensions among female stroke survivors. This aspect of the research is vital as it sheds light on the multifaceted ways in which smoking may exacerbate post-stroke health challenges. It underscores the necessity for smoking cessation efforts to be a standard part of post-stroke long-term rehabilitation, aiming to mitigate these adverse effects and improve recovery outcomes. The association between risky/high-risk drinking behaviours and diminished mental wellbeing highlights a critical aspect of lifestyle following a stroke that can profoundly influence recovery outcomes. This finding is crucial because it draws attention to the need for guidelines and interventions that address alcohol consumption as part of comprehensive stroke recovery strategies, particularly for female survivors. It suggests that reducing or eliminating risky drinking behaviours could play a key role in enhancing mental health among post-stroke females. Importantly, this thesis contributes

to the growing field of gender-specific stroke research, providing valuable insights into how lifestyle factors affect female stroke survivors' health status. The findings indicate the beneficial effects of maintaining a healthy lifestyle in enhancing physical and mental wellbeing among post-stroke females.

This thesis has illuminated critical aspects of self-management in long-term rehabilitation and post-stroke care. Through a scoping review and longitudinal analyses, it offers valuable insights into the utilisation of self-management strategies in long-term rehabilitation following a stroke. Collectively, these insights may contribute to the broader discourse on long-term rehabilitation and long-term survivorship. The findings hold significant implications for long-term rehabilitation practices and healthcare systems, providing essential guidance for survivors of stroke, healthcare professionals, and policymakers (as discussed in the following section). Additionally, this thesis lays a groundwork for future research endeavours.

7.4 Implications from the research

My PhD research provides significant insights into utilisation of self-management strategies for long-term rehabilitation after stroke, focusing particularly on maintaining healthy lifestyle behaviours. The findings outlined in my thesis have profound implications for public health policy, clinical practices, and long-term rehabilitation strategies within the Australian healthcare system. By integrating the insights from my thesis with current guidelines, practices, and programs, there exists a prime opportunity to refine and advance the overall framework toward a more comprehensive approach to long-term stroke management and rehabilitation. Such an approach not only aligns with but also has the potential to optimise the existing infrastructure for stroke care in Australia, offering a roadmap for the development of more personalised and effective rehabilitation strategies.

Australia has a robust framework for long-term rehabilitation after stroke and the Stroke Foundation's "Clinical Guidelines for Stroke Management" plays a central role[65]. These guidelines emphasise early intervention, personalised care plans, and the importance of adopting a healthy lifestyle. However, the findings from my PhD research identify opportunities for further integration and enhanced specificity in these areas, which are discussed below.

Strategic Policy Development: My thesis underscores the necessity for dynamic public health policies that adapt to the evolving needs of individuals with stroke. While existing guidelines advocate for physical activity[65], the observed decline in moderate-to-high levels of physical activity among survivors of stroke over time highlights a significant gap in maintaining engagement. This gap underlines the urgent need for policy revisions to encourage active lifestyles across all age groups. Proposed policies could include allocating funds for public spaces that facilitate physical activity, providing incentives for participation in exercise programs, and supporting research into effective physical activity promotion, especially for older stroke survivors. For instance, programs like "enable me"[334] could be expanded to offer long-term support mechanisms, such as personal coaching or technology-based tools designed to monitor and encourage activity, with a special focus on addressing the needs of stroke survivors who are older adults[335–338].

Personalised Rehabilitation Programs: My thesis provides insights into how demographic and health factors, such as age, diabetes, and depression, significantly influence the lifestyle behaviours of people with stroke, highlighting the necessity for personalised and adaptable rehabilitation programs. My research findings highlight the importance of considering individual risk factors—such as age, diabetes, and mental health conditions—when designing long-term rehabilitation strategies. Clinicians and policymakers can use these insights to develop targeted rehabilitation programs that address the unique needs of different demographic groups. For instance, older stroke survivors may benefit from low-impact physical activity programs, while those with comorbid conditions like diabetes might require integrated care plans that balance physical activity with blood sugar management. Tailoring these programs can improve the effectiveness of rehabilitation efforts and support better health outcomes. Moreover, expanding support services, similar to those offered by the National Disability Insurance Scheme (NDIS)[339], could provide more comprehensive care for stroke survivors.

Integration of Health Services: My thesis reveals the significant impact of comorbidities like diabetes and depression on lifestyle behaviours, which in turn affect healthcare utilisation and health status in survivors of stroke. It underscores the critical need for an integrated approach in long-term stroke rehabilitation that encompasses both physical and psychological care[340,341]. Effective strategies may include diabetes management, routine depression screening and

treatment, and lifestyle counselling within comprehensive rehabilitation programs. For example, physiotherapists and psychiatrists could collaborate to develop programs focusing on both physical recovery and mental health coping strategies. Similarly, multidisciplinary teams, including general practitioners, nurses, psychologists, dietitians, and physiotherapists, should work together to advise on smoking cessation, reducing alcohol intake, and encouraging physical activity. GPs play a crucial role in developing Chronic Disease Management (CDM) plans for stroke survivors[342]. Based on these findings, GPs can identify patients with different risk factors and tailor CDM plans to address both physical and mental health needs. For instance, GPs can refer stroke survivors with diabetes to exercise physiologists for structured and safe physical activity programs that improve physical fitness and reduce the risk of secondary stroke. For patients with depression, GPs can implement integrated care pathways that include mental health services, ensuring that psychological wellbeing is supported. Implementing this integrated approach might necessitate increased funding for comorbidity management in rehabilitation centres and additional interdisciplinary training for healthcare providers. This training could encompass care integration programs and workshops on the latest stroke research, enhancing providers' understanding of the interplay between physical health, mental health, and lifestyle behaviours.

Behaviour Change Initiatives for Stroke Survivors: The significant impact of lifestyle factors on reducing healthcare use and improving health status, as highlighted in the thesis, underscores the need for educational initiatives that encourage survivors of stroke to adopt healthy lifestyles. Such initiatives could include community-based self-management educational programs, workshops, online resources, and interactive apps that elucidate the importance of maintaining a healthy lifestyle[50,71,335–338]. My research emphasises the need for more effective communication strategies to encourage stroke survivors to adopt and maintain healthy behaviours. To improve mental health and wellbeing, healthcare providers could create tailored educational resources that clearly convey the benefits of maintaining healthy behaviours. This could include developing digital tools, community workshops, or telehealth programs that make it easier for stroke survivors to access information and engage in self-management practices.

The Stroke Foundation of Australia plays a pivotal role in educating stroke survivors and promoting self-management across the country[65]. The findings of my thesis provide the Stroke

Foundation with valuable evidence to enhance its health promotion initiatives for ongoing rehabilitation after stroke. The Stroke Foundation can use the results of this study to create targeted campaigns that emphasise the importance of maintaining a healthy lifestyle and mental health support for long-term rehabilitation after stroke. These campaigns could be tailored to specific risk groups, such as older stroke survivors, those with comorbid conditions like diabetes, and individuals experiencing mental health issues. By working closely with GPs and other health professionals across Australia, the Stroke Foundation can ensure that its educational materials and resources are integrated into the broader healthcare system. In addition, the Stroke Foundation could enhance its long-term self-management support programs by integrating existing initiatives. For example, offering online and in-person workshops on managing risk factors such as smoking, alcohol use, and physical inactivity could empower stroke survivors to take control of their longer-term rehabilitation and reduce the likelihood of secondary strokes.

Overall, the insights obtained from this thesis contribute to the existing body of knowledge on rehabilitation and lay an important foundation for the use of self-management strategies in long-term rehabilitation after stroke. These strategies have the potential to improve the quality and effectiveness of post-stroke care. By integrating the insights from this research into the current framework of public health policy, clinical practices, long-term rehabilitation strategies, and public health initiatives, Australia could lessen the healthcare burden and enhance the wellbeing and outcomes for post-stroke individuals throughout the country. Moreover, the thesis identifies opportunities for further research among stroke survivors, including the development of methods to promote and sustain self-management and an examination of the effectiveness of self-management strategies in long-term rehabilitation following a stroke across diverse demographic groups.

7.5 Limitations of the research

While my PhD thesis presents valuable and novel insights into the utilisation of self-management for long-term rehabilitation after stroke, it is important to acknowledge several limitations that should be considered when interpreting the outcomes. Firstly, it is important to note that the studies involved in this thesis rely on self-reported data provided by the participants. The reliance on self-reported data may introduce the potential for recall bias, as individuals might not accurately remember or report details such as physical activity, smoking,

alcohol consumption, and supplement use. While this bias could influence the accuracy of the information, it is noteworthy that it likely impacts all participants similarly, thus being considered non-differential for data analyses in the thesis[343].

Secondly, in my thesis, a secondary analysis was performed on pre-existing survey data that were chosen for their relevance to the research questions. However, it is important to note that this analysis was limited to the variables that were collected in the surveys. The absence of some critical variables[71] like stroke severity, type of stroke, time since stroke event, and functional status in the datasets restricts the ability to comprehensively control for potential confounding factors, impacting the validity and comparability of the research outcomes across the different datasets used.

Thirdly, another limitation relates to the generalisability of the thesis findings. Specifically, the stroke survivors included in both datasets used for this thesis, the 45 and Up Study and the Australian Longitudinal Study on Women's Health (ALWHS), were middle-aged and older individuals. Consequently, the findings may not be fully applicable to young stroke survivors, given that the effects of stroke and associated rehabilitation factors could vary significantly among different age groups. Furthermore, two studies (Chapter 4 and 5) utilised data from the 45 and Up Study, which are specific to residents of a particular state (NSW) and may not extend to the entire adult population of Australia. These limitations underscore the need for caution when interpreting and applying the results to broader populations or regions.

Fourthly, participation bias is another limitation that needs to be considered. The participants in my thesis research may differ in significant ways from those who chose not to participate or who were not eligible for inclusion. These differences might include variations in health status, motivation, access to resources, or other sociodemographic factors that influence the adoption of healthy lifestyle behaviours. These differences could influence the results and limit the extent to which the findings can be applied to all post-stroke individuals. Additionally, there is a possibility of survivor bias, particularly given the emphasis on long-term recovery after a stroke. Survivor bias may overestimate some health outcomes, as individuals who have survived a stroke for a long time might exhibit characteristics that are not representative of all post-stroke individuals.

Lastly, the absence of information on private prescriptions, which is not included in the Pharmaceutical Benefits Scheme (PBS) dataset, presents a potential limitation in the analysis of medication dispensing patterns, although this may explain the minimal difference in dispensing[265].

7.6 Strengths of the research

My PhD thesis possesses several noteworthy strengths. Firstly, the studies incorporated within my thesis utilised large sample sizes derived from established health datasets provided by two prestigious Australian institutions. This facilitated rigorous analyses and enhanced the statistical power and reliability of the outcomes. The large sample size provided a solid foundation for exploring various aspects of self-management and health outcomes with greater accuracy and confidence.

Additionally, the long-term follow-up allows for the in-depth examination of trends and changes over time. By leveraging longitudinal data, this thesis provides a comprehensive understanding of the progression, sustainability, and long-term effects of self-management utilisation for long-term rehabilitation after stroke.

A pivotal strength of the thesis also lies in the ability to control for various demographic and health-related characteristics within the utilised models. Through careful consideration and inclusion of several potential confounding variables such as gender, age, education, marital status, body mass index (BMI), comorbidities, and survey periods, this thesis ensures greater accuracy and robustness in the analyses, thereby reducing the risk of spurious associations and enhancing the validity of the findings. In addition, I conducted sensitivity analyses to assess the impact of potential biases on my research findings, and the results remained robust.

Moreover, the utilisation of large administrative datasets provided extensive coverage and detailed information on health-related variables. The linked administrative dataset facilitated comprehensive investigations into self-management strategies and health outcomes among individuals with stroke.

Furthermore, the measures employed in this thesis were widely used and validated in comparable large population samples. The use of validated instruments increases the accuracy and consistency of data collection, reduces measurement errors, and strengthens the credibility of the research findings.

By employing a nationally representative dataset of ALSWH spanning a 12-year period and comprising a large sample of women in Australia, Chapter 6 enhances the generalisability of the findings. Analytical techniques in this thesis, including generalised estimating equation models, which are extensively applied in health research and are standard statistical methods for dealing with longitudinal datasets.

The strengths of this thesis, including its robust methodology, comprehensive datasets, appropriate statistical analyses, meticulous control for confounding variables, and broad generalisability, collectively contribute to the significance of the research outcomes in the field of long-term rehabilitation and healthcare.

7.7 Future research directions

Drawing from the insights of my thesis, several promising avenues for future research in the domain of self-management strategies and stroke rehabilitation appear needed and to potentially hold benefit. These potential research directions are aimed at further advancing our understanding, addressing current gaps, and guiding the development of targeted interventions.

A significant finding of my thesis is the notable decrease in moderate-to-high levels of physical activity among survivors of stroke over the study period. This prompts thoughtful consideration of factors contributing to this trend, including advanced age and stroke recurrence. Further investigation into the drivers behind declining physical activity levels among individuals with stroke over time is warranted, with emphasis on age-related factors and stroke recurrence. Additionally, future research should prioritise exploring effective strategies to maintain adherence to recommended physical activity levels, particularly among elderly post-stroke individuals.

This thesis suggests that physically active post-stroke individuals are less likely to take blood-thinning medications. However, considering the risks associated with polypharmacy in long-term rehabilitation after stroke and the potential for physical activity to reduce medication needs, further research is needed to determine optimal medication strategies for individuals adhering to a healthy lifestyle, potentially leading to improved long-term rehabilitation outcomes.

The thesis highlights depression as a significant predictor for smoking among post-stroke individuals, underscoring the need for future research to explore effective strategies for addressing mental health issues in stroke survivors. The thesis highlights the interrelationship between smoking and risky alcohol consumption among those with stroke, emphasising the need for interventions targeting both behaviours to optimise long-term rehabilitation outcomes. Future research should explore the drivers and barriers of these behaviours, considering community-based self-management programs and social support as essential components for smoking cessation and alcohol reduction in this population. Moreover, the thesis findings reveal a significant decrease in moderate/high-risk alcohol consumption among stroke survivors over time. The finding underscores the importance of continued research into the influencing sources and effective strategies for promoting alcohol reduction. Future studies should investigate the roles of healthcare professionals, support groups, self-management programs, and online resources in motivating and facilitating alcohol intake reduction among post-stroke individuals.

This research did not find a significant association between none-to-low risky alcohol consumption among stroke survivors and reduced healthcare utilisation. Further longitudinal research with extended follow-up is needed to assess the impact of moderate-to-high risky alcohol use on healthcare utilisation in this population. Similarly, my thesis did not detect a significant association between risky/high-risk alcohol consumption and physical wellbeing. Nonetheless, the potential long-term adverse effects of such alcohol consumption on physical health warrant further investigation. To comprehensively explore this association, additional longitudinal studies with extended follow-up periods are necessary. Furthermore, future research could explore potential strategies, such as remote monitoring and technology-based solutions, to enhance the adoption and maintenance of healthy lifestyle behaviours among people with stroke.

My thesis reveals a notable decrease in supplement use among post-stroke individuals over time. Considering the potential benefits of dietary supplements in long-term rehabilitation, further research is needed to delve into key aspects of supplement utilisation and to examine the reasons behind the decline in supplement use over time among those with post-stroke. In addition, the thesis observes that female stroke survivors were more likely to use supplements. Thus, future research is recommended to evaluate the gender difference in supplement use among stroke-specific populations. Furthermore, survivors of stroke who consumed supplements showed a higher likelihood of receiving treatment from allied health professionals. Therefore, additional research is needed to explore the factors driving increased utilisation of allied health services among supplement users in this population.

7.8 Conclusions

The findings presented in my thesis offer a comprehensive understanding of the utilisation of self-management strategies for long-term rehabilitation after stroke, with a particular emphasis on the maintenance of a healthy lifestyle. The multifaceted insights derived from the scoping review and longitudinal analyses contribute significantly to the existing knowledge on post-stroke care and long-term rehabilitation. The implications of these findings extend beyond academic discourse, carrying substantial weight for stroke survivors and careers, healthcare practitioners, policymakers, stroke support groups, and researchers alike.

The scoping review of this thesis provides the first specific insights into the use of self-management strategies in stroke rehabilitation, emphasising the importance of personalised and comprehensive approaches in long-term rehabilitation after stroke. The longitudinal analyses reveal several significant trends, including the concerning decline in moderate/high physical activity levels among stroke survivors over time. The findings of the thesis highlight the influence of various demographic and health factors, including age, diabetes, education, and depression, on post-stroke lifestyle behaviours. This improved understanding of the longitudinal determinants is crucial for stakeholders aiming to optimise long-term recovery through tailored interventions to promote healthy lifestyles among survivors of stroke.

My thesis presents valuable insights into the potential benefits of lifestyle interventions for individuals with stroke by revealing the association between healthy lifestyle behaviours and

reduced healthcare utilisation. Additionally, it provides compelling evidence that maintaining healthy lifestyle may significantly enhances the physical and mental wellbeing of those with stroke. These empirical findings can guide stakeholders in prioritising lifestyle modification interventions within long-term stroke rehabilitation programs.

The important findings presented in this thesis make a substantial contribution to the field of long-term rehabilitation after stroke and provide the foundation for the development of tailored interventions, policy guidelines, and future research initiatives. The evidence-based findings hold significant implications for developing comprehensive strategies to promote healthy lifestyle behaviours among survivors of stroke, potentially enhancing quality of life and overall long-term rehabilitation outcomes for post-stroke individuals.

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Appendices

Appendix 1: PRISMA-ScR Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	Page 13
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	Page 13-14
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	Page 14-15
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	Page 15
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	Page 15
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	Page 16
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	Page 16
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Page 16
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	Page 16
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	Page 16-17
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	Page 16
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	Page 18
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	Page 18

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	Page 17 (Figure 1)
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	Page 18-22 (Table 1)
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	Page 24-25 (Table 2, 3)
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	Page 28-35 (Table 4, 5)
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	Page 18-36
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	Page 36-37
Limitations	20	Discuss the limitations of the scoping review process.	Page 38
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	Page 38
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	No funding

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.
* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.
† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).
‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.
§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

Appendix 2: Literature Search Strategies

PubMed

Search Number	Query	Results
1	(stroke[MeSH Terms]) OR (stroke rehabilitation[MeSH Terms]) OR ("thromboembolism"[MeSH Terms]) OR (intracranial hemorrhages[MeSH Terms]) OR (brain ischemia[MeSH Terms]) OR ("ischemic attack,	280730

	transient"[MeSH Terms]) OR (stroke[Title/Abstract]) OR ("hemorrhage"[Title/Abstract]) OR (Transient Ischemic Attack[Title/Abstract]) OR ("tia"[Title/Abstract])	
2	("self care"[MeSH Terms]) OR ("self efficacy"[MeSH Terms]) OR ("self-management"[MeSH Terms]) OR ("self management"[Title/Abstract]) OR ("self administration"[Title/Abstract]) OR ("self directed"[Title/Abstract])	59680
3	#1 AND #2	1188

From 2010-2020

Scopus

Search Number	Query	Results
1	TITLE-ABS-KEY (cerebrovascular strokes) OR TITLE-ABS-KEY (strokes) OR TITLE-ABS-KEY (cerebral stroke) OR TITLE-ABS-KEY (stroke rehabilitation) OR TITLE-ABS-KEY (acute stroke) OR TITLE-ABS-KEY (brain damage) OR TITLE-ABS-KEY (hemiplegia) OR TITLE-ABS-KEY (paresis) OR TITLE-ABS-KEY (aphasia) OR TITLE-ABS-KEY (thromboembolism) OR TITLE-ABS-KEY (intracranial hemorrhages) OR TITLE-ABS-KEY (brain ischemia) OR TITLE-ABS-KEY (hemorrhage) OR TITLE-ABS-KEY (Transient Ischemic Attack) OR TITLE-ABS-KEY (tia) OR TITLE-ABS-KEY (cerebrovascular accident) OR TITLE-ABS-KEY (apoplexy) OR TITLE-ABS-KEY (brain injury) OR TITLE-ABS-KEY (brain ischemi*) OR TITLE-ABS-KEY (brain vasc*) OR TITLE-ABS-KEY (brain intracran*) OR TITLE-ABS-KEY (brain cerebro*)	499758
2	TITLE-ABS-KEY (self-care) OR TITLE-ABS-KEY (self-management) OR TITLE-ABS-KEY (self-help) OR TITLE-ABS-KEY (self-administration) OR TITLE-ABS-KEY (self-monitor)	85677
3	#1 AND #2	2456

Limit 2010-2021

ProQuest

Search Number	Query	Results
1	ab (Cerebrovascular strokes OR strokes OR cerebral stroke OR stroke rehabilitation OR acute stroke OR brain damage OR hemiplegia OR paresis)	91227
2	ab (brain vascular OR cerebral vascular OR cva OR apoplexy OR aphasia OR thromboembolism OR intracranial hemorrhages OR brain ischemia OR transient ischemic attack OR tia OR hemiplegia OR hemiparesis)	64619
3	#1 OR #2	120179

4	ab (Self-care OR self-management OR self-help OR self-administration OR self-monitor OR self-efficacy OR self-directed)	23419
5	#3 AND #4	4329

Narrowed by: Date: 2010 – 2020; Document type: Article.

CINAHL (EBSCOhost)

Search Number	Query	Results
1	AB Cerebrovascular strokes OR strokes OR cerebral stroke OR stroke rehabilitation OR acute stroke OR brain damage OR hemiplegia OR paresis OR aphasia	928
2	AB Stroke OR poststroke OR post-stroke OR following-stroke OR after-stroke OR cerebrovascular OR brain vascular OR cerebral vascular OR cva OR apoplexy	1072
3	AB Brain OR cerebro OR cerebra OR cerebell OR intracran OR intracerebral OR vertebrobasilar	920
4	AB Ischemia OR ischaemi OR infarction OR thrombosis OR embolic OR oculus OR hemorrhage OR hematoma OR bleed	117
5	#3 AND #4	36
6	AB Brain injury OR brain injuries OR brain-injured	475
7	AB Hemiplegia OR hemiparesis	65
8	#1 OR #2 OR #5 OR #6 OR #7	2083
9	AB Self-care OR self-management OR self-help OR self-administration OR self-monitor OR self-efficacy OR lifestyle OR self-directed	2427
10	#8 AND #9	65

Limiters - Published Date: 2010.01.01-2020.12.31; English Language; Research Article; Exclude MEDLINE records; Publication Type: Journal Article; Language: English ; Expanders - Apply related words; Apply equivalent subjects; Search modes - Boolean/Phrase

Embase (OVID)

Search Number	Query	Results
1	(cerebrovascular or strokes or cerebral or stroke rehabilitation or acute stroke or brain damage or hemiplegia or paresis).m_titl	1584
2	(stroke OR poststroke OR following stroke OR after stroke OR cerebrovascular OR brain vascular OR cerebral vascular OR cva OR apoplexy).mp	48303
3	(brain OR cerebro OR cerebra OR cerebell OR intracran OR intracerebral OR vertebrobasilar).mp	16750
4	(ischemia OR ischaemi OR infarction OR thrombosis OR embolic OR oculus OR hemorrhage OR hematoma OR bleed).mp	76357
5	#3 AND #4	1334
6	(brain injury OR brain injuries OR brain injured).mp	718
7	(hemiplegia OR hemiparesis).mp	2489
8	#1 OR #2 OR #5 OR #6 OR #7	52050
9	(self-care or self-management or self-help or self-administration or self-monitor or self-efficacy or lifestyle).mp	104065
10	#8 AND #9	1287

[mp=title, abstract, heading word, original title, keyword, floating subheading word, candidate term word]; Limit: 2010-2020; Exclude: Medline

Appendix 3: Newcastle - Ottawa Quality Assessment Scale (adapted for cross sectional studies)

Selection: (Maximum 5 stars)

1) Representativeness of the sample:

a) Truly representative of the average in the target population.* (all subjects or random sampling)
b) Somewhat representative of the average in the target population.* (non-random sampling)
c) Selected group of users.
d) No description of the sampling strategy.

2) Sample size:

a) Justified and satisfactory.*
b) Not justified.

3) Non-respondents:

a) Comparability between respondents and non-respondents' characteristics is established, and the response rate is satisfactory.*
b) The response rate is unsatisfactory, or the comparability between respondents and non-respondents is unsatisfactory.
c) No description of the response rate or the characteristics of the responders and the non-responders.

4) Ascertainment of the exposure (risk factor):

a) Validated measurement tool.**
b) Non-validated measurement tool, but the tool is available or described.*
c) No description of the measurement tool.

Comparability: (Maximum 2 stars)

1) The subjects in different outcome groups are comparable, based on the study design or analysis. Confounding factors are controlled.

a) The study controls for the most important factor (select one).*
b) The study control for any additional factor.*

Outcome: (Maximum 3 stars)

1) Assessment of the outcome:

a) Independent blind assessment.**
b) Record linkage. **
c) Self report.*
d) No description.

2) Statistical test:

a) The statistical test used to analyze the data is clearly described and appropriate, and the measurement of the association is presented, including confidence intervals and the probability level (p value).*
b) The statistical test is not appropriate, not described or incomplete.

Appendix 4: Critical Appraisal Skills Programme for Qualitative Studies

Questions	Answer	Comments
Section A: Are the results valid?		
1. Was there a clear statement of the aims of the research?	o Yes o Can't Tell o No	
2. Is a qualitative methodology appropriate?	o Yes o Can't Tell o No	
3. Was the research design appropriate to address the aims of the research?	o Yes o Can't Tell o No	
4. Was the recruitment strategy appropriate to the aims of the research?	o Yes o Can't Tell o No	
5. Was the data collected in a way that addressed the research issue?	o Yes o Can't Tell o No	
6. Has the relationship between researcher and participants been adequately considered?	o Yes o Can't Tell o No	
Section B: What are the results?		
7. Have ethical issues been taken into consideration?	o Yes o Can't Tell o No	
8. Was the data analysis sufficiently rigorous?	o Yes o Can't Tell o No	
9. Is there a clear statement of the findings?	o Yes o Can't Tell o No	
Section C: Will the results help locally?		
10. How valuable is the research?	o Yes o Can't Tell o No	

Appendix 5: Medicare Benefits Schedule (MBS) Items List

Services	MBS items
General Practitioner	3 to 51, 193, 195, 197, 199, 585, 597, 599, 2497 to 2559, 5000 to 5067
Nurse practitioner	10983, 10984, 10986, 10987, 10988, 10989, 10993 to 10999, 82200, 82205, 82210, 82215
Allied mental health professionals (provided by eligible psychologists, occupational therapists, social workers, and mental health workers**)**	80100 to 80170, 80000 to 80020, 10956, 10968
Physiotherapists	10960
Occupational therapists	10958
Audiologist	10952
Dietitians	10954
Exercise physiologists	10953
Podiatrists	10962
Speech pathologists	10970
Psychiatrist	291,293, 296 to 299, 300,302,304,306,308, 310,312,314,316, 318-320,322, 324,326,328,330,332,334,336,338,342,344,346,348,350,352
Neurosurgery specialist	6007 to 6015

Appendix 6: Pharmaceutical Benefits Scheme (PBS) Items List

	PBS dispensing of:	PBS Codes
Blood-thinning medication (**Antiplatelet medication**)	ASPIRIN	08202Q, 01010E, 04078P, 04077N, 04076M
	CLOPIDOGREL	02275R, 09317J, 05436D, 08358X, 09354X
	ASPIRIN + CLOPIDOGREL	09296G
	DIPYRIDAMOLE	08335Q
	DIPYRIDAMOLE + ASPIRIN	08382E
	TICAGRELOR	01418P
	EPTIFIBATIDE	08683B, 08684C
	PRASUGREL	09496T, 09495R
	TICLOPIDINE	02095G
	ABCIXIMAB	08048N
Blood-thinning medication (**Anticoagulant medication**)	TIROFIBAN	08350L
	RETEPLASE	08253J
	TENECTEPLASE	08527T, 08526R
	BIVALIRUDIN	08844L
	DABIGATRAN	02753X, 02769R, 09321N, 09320M, 09319L, 09318K, 09323Q, 09322P
	APIXABAN	05500L, 05054B, 02744K, 02735Y, 05061J

	RIVAROXABAN	09467G, 09465E, 09468H, 09466F, 09469J, 02691P, 02160Q, 02268J
	FONDAPARINUX	08775W
	ANTIFIBRINOLYTICS	02180R
	PHENYTOIN	02692Q, 01249R, 01874P, 01873N
	WARFARIN	02843P, 02209G, 02844Q, 02211J
	DALTEPARIN SODIUM	08603T, 02816F, 08642W, 08959M, 08960N, 08957K, 8958L, 08956J, 01229Q, 01296F, 08641T, 08643X, 08269F, 05445N, 08271H
	ENOXAPARIN SODIUM	05435C, 08716R, 09196B, 08639Q, 08640R, 05434B, 08264Y, 08558K, 09195Y, 08510X, 08262W, 08263X
	HEPARIN SODIUM	01466E, 01076P, 01463B
Cholesterol-lowering medication		
	ATORVASTATIN	08213G, 08214H, 08215J, 08521L, 09230T, 09231W, 09232X, 09233Y
	FLUVASTATIN	08023G, 08024H, 02863Q, 09234B, 09235C, 09236D
	PRAVASTATIN	02833D, 02834E, 08197K, 08829Q, 09237E, 09238F, 09239G, 09240H
	ROSUVASTATIN	02584B, 02609H, 02636R, 02590H, 02628H, 02606E, 03403D, 03404E, 03405F, 03402C, 09043Y, 09042X, 02574L, 09044B, 02594M, 09045C
	SIMVASTATIN	02011W, 02012X, 08173E, 02013Y, 08313M, 09242K, 09243L, 09244M, 09241J, 09245N
	FENOFIBRATE	09023X, 09022W, 09247Q, 09246P
	GEMFIBROZIL	01453L, 09248R
	CHOLESTYRAMINE	02967E, 09249T, 01224K, 09250W
	EZETIMIBE	08757X
	ATORVASTATIN (&) EZETIMIBE	02874G, 02821L, 10006P, 10002K
	EZETIMIBE + SIMVASTATIN	09483D, 09484E, 08881K, 08882L
Blood pressure medication	MOXONIDINE	09019Q, 09020R
	ENALAPRIL + HYDROCHLOROTHIAZIDE	08477E
	FOSINOPRIL + HYDROCHLOROTHIAZIDE	08400D, 08401E
	PERINDOPRIL + INDAPAMIDE	02190G, 02845R, 08449Q
	QUINAPRIL + HYDROCHLOROTHIAZIDE	08590D, 08589C
	LERCANIDIPINE + ENALAPRIL	09144G, 09145H
	PERINDOPRIL + AMLODIPINE	09349C, 09348B, 09347Y, 09346X
	RAMIPRIL + FELODIPINE	02626F, 02629J
	TRANDOLAPRIL + VERAPAMIL	09387C, 02857J
	CANDESARTAN + HYDROCHLOROTHIAZIDE	08504N, 09314F, 09315G
	EPROSARTAN + HYDROCHLOROTHIAZIDE	08624X

	IRBESARTAN + HYDROCHLOROTHIAZIDE	08404H, 08405J, 02136K
	OLMESARTAN MEDOXOMIL + HYDROCHLOROTHIAZIDE	02161R, 02166B, 02170F
	TELMISARTAN + HYDROCHLOROTHIAZIDE	08622T, 08623W, 09381R
	VALSARTAN + HYDROCHLOROTHIAZIDE	09373H, 09374J, 09372G, 09481B, 09482C
	AMLODIPINE + VALSARTAN	09377M, 05460J, 09376L, 05459H, 09375K
	OLMESARTAN MEDOXOMIL + AMLODIPINE	05292M, 05294P, 05293N
	TELMISARTAN + AMLODIPINE	08979N, 08978M, 08981Q, 08980P
	AMLODIPINE + VALSARTAN + HYDROCHLOROTHIAZIDE	05287G, 05288H, 05289J, 05285E, 05286F
	OLMESARTAN + AMLODIPINE + HYDROCHLOROTHIAZIDE	10005N, 02836G, 02953K, 02880N, 02864R
	AMLODIPINE + ATORVASTATIN	09053L, 09054M, 09055N, 09056P, 09049G, 09050H, 09051J, 09052K
	LOSARTAN	05452Y, 08203R

Appendix 7: 45 and Up Study Baseline Questionnaire for Men

THE 45 AND UP STUDY

Research to improve health and wellbeing

45 and Up Study Questionnaire for Men

The *45 and Up Study* relies on the willingness of people in New South Wales to share information about their lives and experiences, to provide knowledge that will help people live healthy and fulfilling lives for as long as possible. Participation is completely voluntary, and you are free to withdraw from the Study at any time. To take part, please read the participant information leaflet, then complete the questionnaire and consent form and return them in the envelope provided. We very much hope you will be able to take part.

Any questions or comments? Please call the Study helpline: **1300 45 11 45** or go to **www.45andUp.org.au**

Auspiced by the sax institute — RESEARCH PARTNERSHIPS FOR BETTER HEALTH

In collaboration with The Cancer Council New South Wales; Heart Foundation; NSW HEALTH; beyondblue; New South Wales Government; DADHC Department of Ageing, Disability & Home Care

Your answers and experiences are important to us.
To help us read your answers, please write as clearly as possible using a **BLACK** or **BLUE** pen, and be sure to complete the questionnaire as shown:

Please put a cross in the appropriate box(es) [X] Yes [ ] No
OR put numbers in the appropriate box, e.g. *21st June 1945*
2 1 / 0 6 / 1 9 4 5 age 6 2

General questions about you

1. **What is your date of birth?** day / month / year 1 9
2. **What is today's date?** day / month / year 2 0
3. **How tall are you without shoes?** (please give to the nearest cm or inch) ____ cm OR ____ feet ____ inches
4. **About how much do you weigh?** ____ kg OR ____ stone ____ lbs
5. **What is the highest qualification you have completed?** (please put a cross in the most appropriate box)
   - [ ] no school certificate or other qualifications
   - [ ] school or intermediate certificate (or equivalent)
   - [ ] higher school or leaving certificate (or equivalent)
   - [ ] trade/apprenticeship (e.g. hairdresser, chef)
   - [ ] certificate/diploma (e.g. child care, technician)
   - [ ] university degree or higher
6. **Are you of Aboriginal or Torres Strait Islander origin?** (you can cross more than one box)
   - [ ] No [ ] Yes, Aboriginal [ ] Yes, Torres Strait Islander
7. **In which country were you born?**
   - [ ] Australia ▶ please go to question 9
   - [ ] UK [ ] Ireland [ ] Italy [ ] China
   - [ ] Greece [ ] New Zealand [ ] Germany [ ] Lebanon
   - [ ] Philippines [ ] Netherlands [ ] Vietnam [ ] Malta
   - [ ] Poland [ ] other *(please specify)* _____
8. **What year did you first come to live in Australia for one year or more?** (e.g. 1970) ____
9. **What is your ancestry?** (please cross up to 2 boxes)
   - [ ] Australian [ ] English [ ] Irish [ ] Chinese
   - [ ] Italian [ ] Greek [ ] Scottish [ ] German
   - [ ] Lebanese [ ] Dutch [ ] Maltese [ ] Polish
   - [ ] Filipino [ ] Indian [ ] Croatian [ ] Vietnamese
   - [ ] other *(please specify)* _____
10. **Do you speak a language other than English at home?**
    - [ ] Yes [ ] No
11. **Have you ever been a regular smoker?**
    - [ ] Yes ▼ [ ] No ▶ *If No – please go to question 12*
    - How old were you when you started smoking regularly? ____ years old
    - Are you a regular smoker now? [ ] Yes [ ] No
    - *If No* – how old were you when you stopped smoking regularly? ____ years old
    - About how much do you/did you smoke on average each day? (If you are an ex-smoker, how much did you smoke on average when you smoked?)
      ____ cigarettes per day ____ pipes and cigars per day
12. **About how many alcoholic drinks do you have each week?** one drink = a glass of wine, middy of beer or nip of spirits (put "0" if you do not drink, or have less than one drink each week)
    ____ number of alcoholic drinks each week
13. **On how many days each week do you usually drink alcohol?** ____ days each week

BLFM0710

14. What best describes your current situation? (please cross one box)

☐ single ☐ married ☐ de facto/living with a partner
☐ widowed ☐ divorced ☐ separated

15. What best describes your current housing? (please cross one box)

☐ house ☐ flat, unit, apartment ☐ house on farm
☐ hostel for the aged ☐ mobile home ☐ other
☐ nursing home ☐ retirement village, self care unit

16. How many TIMES did you do each of these activities LAST WEEK?
(put "0" if you did not do this activity)

	times in the last week
Walking continuously, for at least 10 minutes *(for recreation or exercise or to get to or from places)*	☐☐
Vigorous physical activity *(that made you breathe harder or puff and pant, like jogging, cycling, aerobics, competitive tennis, but not household chores or gardening)*	☐☐
Moderate physical activity *(like gentle swimming, social tennis, vigorous gardening or work around the house)*	☐☐

17. If you add up all the time you spent doing each activity LAST WEEK, how much time did you spend ALTOGETHER doing each type of activity?
(put "0" if you did not do this activity)

	hours	minutes
Walking continuously, for at least 10 minutes *(for recreation or exercise or to get to or from places)*	☐☐ :	☐☐
Vigorous physical activity *(that made you breathe harder or puff and pant, like jogging, cycling, aerobics, competitive tennis, but not household chores or gardening)*	☐☐ :	☐☐
Moderate physical activity *(like gentle swimming, social tennis, vigorous gardening or work around the house)*	☐☐ :	☐☐

Questions about your family

18. Have your mother, father, brother(s) or sister(s) ever had:
(blood relatives only: please put a cross in the appropriate box(es))

	mother	father	brother	sister		mother	father	brother/ sister
heart disease	☐	☐	☐		breast cancer	☐	☐	☐
high blood pressure	☐	☐	☐		bowel cancer	☐	☐	☐
stroke	☐	☐	☐		lung cancer	☐	☐	☐
diabetes	☐	☐	☐		melanoma	☐	☐	☐
dementia/Alzheimer's	☐	☐	☐		prostate cancer		☐	☐
Parkinson's disease	☐	☐	☐		ovarian cancer	☐		☐
severe depression	☐	☐	☐		osteoporosis	☐	☐	☐
severe arthritis	☐	☐	☐		hip fracture	☐	☐	☐
do not know	☐	☐	☐					

19. How many children have you fathered? ☐☐ children
(please include stillbirths but do not include miscarriages, please write "0" if you have not had any children)

How old were you when you fathered your FIRST child? ☐☐ years old

How old were you when you fathered your LAST child? ☐☐ years old

20. Have you ever tried for more than 1 year but have been unable to father children?

☐ Yes ☐ No

Questions about your health

21. About how many hours a week are you exposed to someone else's tobacco smoke?

hours per week ☐☐ at home
hours per week ☐☐ in other places *(e.g. work, going out, cars)*

22. Over the last month, how often have you:

	not at all	some times	often	almost always
found it difficult to postpone urination?	☐	☐	☐	☐
had to push or strain to start urination?	☐	☐	☐	☐
had a weak urinary stream?	☐	☐	☐	☐
stopped and started again several times when you urinated?	☐	☐	☐	☐
had to urinate again less than 2 hours after you finished urinating?	☐	☐	☐	☐
had the feeling that you had not emptied your bladder completely after urinating?	☐	☐	☐	☐

Over the past month, how many times did you usually get up from bed to urinate during the night?

☐ never ☐ some nights ☐☐ times each night

23. Have you taken any medications, vitamins or supplements for most of the last 4 weeks?

☐ Yes ▼ ☐ No

If Yes, was it:

☐ multivitamins + minerals	☐ multivitamins alone	
☐ fish oil	☐ glucosamine	☐ omega 3
☐ paracetamol	☐ aspirin for the heart	☐ aspirin for other reasons
☐ Lipitor	☐ Avapro, Karvea	☐ warfarin, Coumadin
☐ Pravachol	☐ Coversyl, Coversyl Plus	☐ Lasix, frusemide
☐ Zocor, Lipex	☐ Cardizem, Vasocordol	☐ Micardis
☐ Nexium	☐ Norvasc	☐ Fosamax
☐ Somac	☐ Tritace	☐ Caltrate
☐ Losec, Acimax *omeprazole*	☐ Noten, Tenormin *atenolol*	☐ Oroxine *thyroxine*
☐ Ventolin *salbutamol*	☐ Zyloprim, Progout 300 *allopurinol*	☐ Diabex, Diaformin *metformin*
☐ Zoloft *sertraline*	☐ Cipramil *citaloprim*	☐ Efexor *venlafaxine*

please list any other regular medications or supplements here

24. Has a doctor EVER told you that you have:
(If YES, please cross the box and give your age when the condition was first found)

	Yes	Age when condition was first found
skin cancer (not melanoma)	☐	☐☐ age
melanoma	☐	☐☐ age
prostate cancer	☐	☐☐ age
other cancer	☐	☐☐ age
type of cancer *(please describe)*		
heart disease	☐	☐☐ age
type of heart disease *(please describe)*		
high blood pressure	☐	☐☐ age
stroke	☐	☐☐ age
diabetes	☐	☐☐ age
blood clot (thrombosis)	☐	☐☐ age
enlarged prostate	☐	☐☐ age
asthma	☐	☐☐ age
hayfever	☐	☐☐ age
depression	☐	☐☐ age
anxiety	☐	☐☐ age
Parkinson's disease	☐	☐☐ age
none of these	☐	

25. In the last month have you been treated for:
(If YES, please cross the box and give your age when the treatment started)

	Yes	Age started treatment
cancer	☐	☐☐ age
heart attack or angina	☐	☐☐ age
other heart disease	☐	☐☐ age
high blood pressure	☐	☐☐ age
high blood cholesterol	☐	☐☐ age
blood clotting problems	☐	☐☐ age
asthma	☐	☐☐ age
osteoarthritis	☐	☐☐ age
thyroid problems	☐	☐☐ age
osteoporosis or low bone density	☐	☐☐ age
depression	☐	☐☐ age
anxiety	☐	☐☐ age
none of these	☐	

26. Are you NOW suffering from any other important illness?
☐ Yes ▼ ☐ No

Please describe this illness and its treatment

27. Do you regularly need help with daily tasks because of long-term illness or disability?
(e.g. personal care, getting around, preparing meals)
☐ Yes ☐ No

28. Does your health now LIMIT YOU in any of the following activities?

	yes, limited a lot	**yes**, limited a little	**no**, not limited at all
VIGOROUS activities *(e.g. running, strenuous sports)*	☐	☐	☐
MODERATE activities *(e.g. pushing a vacuum cleaner, playing golf)*	☐	☐	☐
lifting or carrying shopping	☐	☐	☐
climbing several flights of stairs	☐	☐	☐
climbing one flight of stairs	☐	☐	☐
walking one kilometre	☐	☐	☐
walking half a kilometre	☐	☐	☐
walking 100 metres	☐	☐	☐
bending, kneeling or stooping	☐	☐	☐
bathing or dressing yourself	☐	☐	☐

29. Have you ever had any of the following operations?
(If YES, please cross the box and give your age when you had the operation; give your age at the **most recent operation** if you have had more than one)

	Yes	Age when had operation
removal of skin cancer	☐	☐☐ age
vasectomy	☐	☐☐ age
part of prostate removed	☐	☐☐ age
whole prostate removed	☐	☐☐ age
knee replacement	☐	☐☐ age
hip replacement	☐	☐☐ age
gallbladder removed	☐	☐☐ age
heart or coronary bypass surgery *(include stents and balloons)*	☐	☐☐ age

other *(please describe any other operations you have had in the last 10 years, with your age when you had them)*

30. Do you regularly care for a sick or disabled family member or friend?
☐ Yes ▼ ☐ No

If Yes, about how much time each week do you usually spend caring for this person?
☐ full time OR ☐☐ hours/wk

31. In general, how would you rate your:

	excellent	very good	good	fair	poor
overall health?	☐	☐	☐	☐	☐
quality of life?	☐	☐	☐	☐	☐
eyesight? *(with glasses or contact lenses, if you wear them)*	☐	☐	☐	☐	☐
memory?	☐	☐	☐	☐	☐
teeth and gums?	☐	☐	☐	☐	☐

32. Do you feel you have a hearing loss? ☐ Yes ☐ No

33. How many of your own teeth do you have left?
☐ None – all of my teeth are missing ☐ 1-9 teeth left
☐ 10-19 teeth left ☐ 20 or more teeth left

34. During the past 12 months, how many times have you fallen to the floor or ground? (put "0" if you haven't fallen in this time)
☐☐ times

35. Have you had a broken/fractured bone in the last 5 years?
☐ Yes ▼ ☐ No

If Yes, which bones were broken?
☐ wrist ☐ arm ☐ hip ☐ ankle
☐ rib ☐ finger/toe ☐ other_____

How old were you when it happened? (give age at most recent fracture if more than one) ☐☐ years old

36. About how many times a week are you usually troubled by leaking urine?
☐ never ☐ once a week or less
☐ 2-3 times ☐ 4-6 times ☐ every day

37. How often are you able to get and keep an erection that is firm enough for satisfactory sexual activity?
☐ always ☐ usually ☐ sometimes
☐ never ☐ I would rather not answer this question

38. Have you ever had a blood test ordered by your doctor to check for prostate disease? (PSA test)
☐ Yes ▼ ☐ No

If Yes, what year did you have your last PSA test? (e.g. 2005) ☐☐☐☐

How many times have you had a PSA test altogether? ☐☐ times

39. Have you ever been screened for colorectal (bowel) cancer?
☐ Yes ▼ ☐ No

If Yes, please indicate which test(s) you had:
☐ faecal occult blood test *(test for blood in the stool/faeces)*
☐ sigmoidoscopy *(a tube is used to examine the lower bowel: this is usually done in a doctor's office without pain relief)*
☐ colonoscopy *(a long tube is used to examine the whole large bowel; you would usually have to have an enema or drink large amounts of special liquid to prepare the bowel for this)*

What year did you have the most recent one of these tests? (e.g. 2005) ☐☐☐☐

Questions about your diet

40. About how many times each week do you eat: (please count all meals and snacks. put '0' if never eaten or eaten less than once a week)

	number of times eaten each week
beef, lamb or pork	☐☐
chicken, turkey or duck	☐☐
processed meat *(include bacon, sausages, salami, devon, burgers, etc)*	☐☐
fish or seafood	☐☐
cheese	☐☐

41. About how many of the following do you usually eat:
slices or pieces of brown/wholemeal bread each week *(also include multigrain, rye bread, etc.)* ☐☐
bowls of breakfast cereal each week ☐☐

If you eat breakfast cereal is it usually: (please cross)
☐ bran cereal *(allbran, branflakes, etc.)* ☐ muesli
☐ biscuit cereal *(weetbix, shredded wheat, etc.)* ☐ other *(cornflakes, rice bubbles,etc.)*
☐ oat cereal *(porridge, etc.)*

42. Which type of milk do you mostly have?
☐ whole milk ☐ reduced fat milk ☐ skim milk
☐ soy milk ☐ other milk ☐ I don't drink milk

43. About how many serves of vegetables do you usually eat each day? A serve is half a cup of cooked vegetables or one cup of salad (please include potatoes and put "0" if less than one a day)
☐☐ number of serves of cooked vegetables each day
☐☐ number of serves of raw vegetables each day (e.g. salad)
☐ I don't eat vegetables

44. About how many serves of fruit or glasses of fruit juice do you usually have each day? A serve is 1 medium piece or 2 small pieces or 1 cup of diced or canned fruit pieces (put "0" if you eat less than one serve a day)
☐☐ number of serves of fruit each day
☐☐ number of glasses of fruit juice each day
☐ I don't eat fruit

45. Please put a cross in the box if you NEVER eat:
☐ red meat ☐ chicken/poultry ☐ pork/ham ☐ dairy products
☐ any meat ☐ eggs ☐ sugar ☐ wheat products
☐ fish ☐ seafood ☐ cream ☐ cheese

Questions about time and work

46. What is your usual yearly HOUSEHOLD income before tax, from all sources? (please include benefits, pensions, superannuation, etc)
☐ less than $5,000 per year ☐ $30,000-$39,999 per year
☐ $5,000-$9,999 per year ☐ $40,000-$49,999 per year
☐ $10,000-$19,999 per year ☐ $50,000-$69,999 per year
☐ $20,000-$29,999 per year ☐ $70,000 or more per year
☐ I would rather not answer this question

47. What is your current work status? (you can cross more than one box)

- ☐ in full time paid work
- ☐ in part time paid work
- ☐ completely retired/pensioner
- ☐ partially retired
- ☐ disabled/sick
- ☐ other
- ☐ self-employed
- ☐ doing unpaid work
- ☐ studying
- ☐ looking after home/family
- ☐ unemployed

48. If you are partially or completely retired, how old were you when you retired? ☐☐ years old

Why did you retire? (you can cross more than one box)

- ☐ reached usual retirement age
- ☐ to care for family member/friend
- ☐ made redundant
- ☐ other
- ☐ lifestyle reasons
- ☐ ill health
- ☐ could not find a job

49. About how many HOURS each WEEK do you usually spend doing the following? (please put "0" if you do not spend any time doing it)

hours per week ☐☐ paid work

hours per week ☐☐ voluntary/unpaid work

50. Which of the following do you have? (excluding Medicare)

- ☐ Private health insurance – with extras
- ☐ Private health insurance – without extras
- ☐ Department of Veterans' Affairs white or gold card
- ☐ Health care concession card
- ☐ none of these

51. What best describes the colour of the skin on the inside of your upper arm, that is your skin colour without any tanning?

- ☐ very fair
- ☐ fair
- ☐ light olive
- ☐ dark olive
- ☐ brown
- ☐ black

52. What would happen if your skin was repeatedly exposed to bright sunlight during summer without any protection? Would it:

- ☐ Get very tanned?
- ☐ Get moderately tanned?
- ☐ Get mildly or occasionally tanned?
- ☐ Never tan, or only get freckled?

53. About how many hours a DAY would you usually spend outdoors on a weekday and on the weekend?

hours per day ☐☐ weekday

hours per day ☐☐ weekend

54. About how many HOURS in each 24 hour DAY do you usually spend doing the following?
(please put "0" if you do not spend any time doing it)

hours per day		hours per day	
☐☐	sleeping (including at night & naps)	☐☐	sitting
☐☐	watching television or using a computer	☐☐	standing

55. How many TIMES in the LAST WEEK did you:
(please put "0" if you did not spend any time doing it)

	times in the last week
spend time with friends or family who do not live with you?	☐☐
talk to someone (friends, relatives or others) on the telephone?	☐☐
go to meetings of social clubs, religious groups or other groups you belong to?	☐☐

56. How many people outside your home, but within one hour of travel, do you feel you can depend on or feel very close to? ☐☐ people

57. During the past 4 weeks, about how often did you feel:

	none of the time	a little of the time	some of the time	most of the time	all of the time
tired out for no good reason?	☐	☐	☐	☐	☐
nervous?	☐	☐	☐	☐	☐
so nervous that nothing could calm you down?	☐	☐	☐	☐	☐
hopeless?	☐	☐	☐	☐	☐
restless or fidgety?	☐	☐	☐	☐	☐
so restless that you could not sit still?	☐	☐	☐	☐	☐
depressed?	☐	☐	☐	☐	☐
that everything was an effort?	☐	☐	☐	☐	☐
so sad that nothing could cheer you up?	☐	☐	☐	☐	☐
worthless?	☐	☐	☐	☐	☐

58. During the past 4 weeks, have you had any of the following problems with your work or daily activities because of any emotional problems (such as being depressed or anxious)?

- cut down on the amount of time you spent on work or other activities ☐ Yes ☐ No
- achieved less than you would have liked to ☐ Yes ☐ No
- did work or other activities less carefully than usual ☐ Yes ☐ No

Thank you very much for filling in the questionnaire
DON'T FORGET TO SIGN THE CONSENT FORM OVERLEAF

Are your name and address correct on the front of this questionnaire? ☐ Yes ☐ No

If INCORRECT, give details below.

Surname:

Given name(s):

Postal address:

Town or Suburb:

State or Territory: Postcode:

Consent form

THE 45 AND UP STUDY
Research to improve health and wellbeing

The *45 and Up Study* relies on the willingness of people in New South Wales to share information about their lives and experiences and to have their health followed over time. By signing this form you are agreeing to take part in the *45 and Up Study* and for the Study team to follow your health over time. Participation is completely voluntary, and you are free to ask questions or to withdraw from the Study at any time, by calling the Study helpline on 1300 45 11 45. More information on the Study can be found at www.45andup.org.au

I agree to have my health followed over time through:

the 45 and Up Study team following health and other records relating to me, including NSW hospital records, cancer records, death records and other health-related records, as outlined in the Study leaflet: *The 45 and Up Study: Information for participants*;

Medicare Australia releasing to the 45 and Up Study my enrolment details, including Medicare number, and information concerning services provided to me under Medicare, the Department of Veterans' Affairs, the Pharmaceutical Benefits Scheme and the Repatriation Pharmaceutical Benefits Scheme, including past information, until the end of the Study or for the duration of my involvement in the Study;

being contacted in the future to provide information on changes to my health and lifestyle. I may also be asked to provide further information including questionnaire responses or biological samples; my participation in any of these would be completely voluntary.

I give my consent on the understanding that:

my information will only be used for the purposes outlined in the Study leaflet entitled *The 45 and Up Study: Information for participants*, of which I have a copy;

my information will be kept strictly confidential and will be used for health research only;

reports and publications from the Study will be based on de-identified information and will not identify any individual taking part;

my participation in this Study is entirely voluntary and my consent will continue to be valid following death or disablement unless withdrawn by my next of kin or other person responsible. I am free to withdraw from the Study at any time by calling the **Study helpline on 1300 45 11 45;**

my decision on whether or not to take part in the Study or in any additional research will not disadvantage me or affect my future health care in any way.

I have been provided with information about the 45 and Up Study including how it will gather, store, use and disclose information about me, in the Study leaflet. I have been given an opportunity to ask questions and have been fully informed about the Study.

Name (Print): _____

Signature: _____ Date today: day ☐☐ / month ☐☐ / 2 0 ☐☐

Extra contact details

It would be very helpful and reduce Study costs if we could contact you in future by email. If you are happy for us to do this, please write your email address here:

Email address: _____

Sometimes we find that people have moved when we try to contact them again. It would be very helpful if you could give us your mobile phone number and/or the contact details of someone close to you (such as a relative or friend) who would be happy for us to contact them if we are unable to reach you. We would only get in touch with that person if we were unable to contact you directly and we would need to tell them our reason for contacting you. Please leave this section blank if you do not wish to provide these extra contact details.

Your home phone number: (☐☐) _____ Your mobile phone number: _____

Full name of contact person: _____

Phone number of contact person: (☐☐) _____

If you have any questions about the Study, please ring the Study helpline on **1300 45 11 45**.
You can also write to or send your questionnaire (no stamp required) directly to:

Associate Professor Emily Banks, Scientific Director,
The 45 and Up Study, Reply paid 5289, Sydney NSW 2001.

Thank you very much for taking part

Appendix 8: 45 and Up Study Baseline Questionnaire for Women

THE 45 AND UP STUDY
Research to improve health and wellbeing

45 and Up Study Questionnaire for Women

The *45 and Up Study* relies on the willingness of people in New South Wales to share information about their lives and experiences, to provide knowledge that will help people live healthy and fulfilling lives for as long as possible. Participation is completely voluntary, and you are free to withdraw from the Study at any time. To take part, please read the participant information leaflet, then complete the questionnaire and consent form and return them in the envelope provided. We very much hope you will be able to take part.

Any questions or comments? Please call the Study helpline: **1300 45 11 45** or go to **www.45andUp.org.au**

Auspiced by: the sax institute — RESEARCH PARTNERSHIPS FOR BETTER HEALTH

In collaboration with: The Cancer Council New South Wales; Heart Foundation; NSW HEALTH; beyondblue; New South Wales Government; DADHC Department of Ageing, Disability & Home Care

Your answers and experiences are important to us.
To help us read your answers, please write as clearly as possible using a **BLACK** or **BLUE** pen, and be sure to complete the questionnaire as shown:

Please put a cross in the appropriate box(es) [X] Yes [ ] No
OR put numbers in the appropriate box, e.g. *21st June 1945*
2 1 / 0 6 / 1 9 4 5 age 6 2

General questions about you

1. **What is your date of birth?** day / month / year 1 9
2. **What is today's date?** day / month / year 2 0
3. **How tall are you without shoes?** (please give to the nearest cm or inch) ___ cm OR ___ feet ___ inches
4. **About how much do you weigh?** ___ kg OR ___ stone ___ lbs
5. **What is the highest qualification you have completed?** (please put a cross in the most appropriate box)
   - [ ] no school certificate or other qualifications
   - [ ] school or intermediate certificate (or equivalent)
   - [ ] higher school or leaving certificate (or equivalent)
   - [ ] trade/apprenticeship (e.g. hairdresser, chef)
   - [ ] certificate/diploma (e.g. child care, technician)
   - [ ] university degree or higher
6. **Are you of Aboriginal or Torres Strait Islander origin?** (you can cross more than one box)
   - [ ] No [ ] Yes, Aboriginal [ ] Yes, Torres Strait Islander
7. **In which country were you born?**
   - [ ] Australia ▶ please go to question 9
   - [ ] UK [ ] Ireland [ ] Italy [ ] China
   - [ ] Greece [ ] New Zealand [ ] Germany [ ] Lebanon
   - [ ] Philippines [ ] Netherlands [ ] Vietnam [ ] Malta
   - [ ] Poland [ ] other *(please specify)*_____
8. **What year did you first come to live in Australia for one year or more?** (e.g. 1970) ____
9. **What is your ancestry?** (please cross up to 2 boxes)
   - [ ] Australian [ ] English [ ] Irish [ ] Chinese
   - [ ] Italian [ ] Greek [ ] Scottish [ ] German
   - [ ] Lebanese [ ] Dutch [ ] Maltese [ ] Polish
   - [ ] Filipino [ ] Indian [ ] Croatian [ ] Vietnamese
   - [ ] other *(please specify)* _____
10. **Do you speak a language other than English at home?**
    - [ ] Yes [ ] No
11. **Have you ever been a regular smoker?**
    - [ ] Yes ▼ [ ] No ▶ *If No – please go to question 12*
    - How old were you when you started smoking regularly? ___ years old
    - Are you a regular smoker now? [ ] Yes [ ] No
    - *If No* – how old were you when you stopped smoking regularly? ___ years old
    - About how much do you/did you smoke on average each day? (If you are an ex-smoker, how much did you smoke on average when you smoked?)
      ___ cigarettes per day ___ pipes and cigars per day
12. **About how many alcoholic drinks do you have each week?** one drink = a glass of wine, middy of beer or nip of spirits (put "0" if you do not drink, or have less than one drink each week)
    ___ number of alcoholic drinks each week
13. **On how many days each week do you usually drink alcohol?** ___ days each week

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14. What best describes your current situation? (please cross one box)

☐ single ☐ married ☐ de facto/living with a partner
☐ widowed ☐ divorced ☐ separated

15. What best describes your current housing? (please cross one box)

☐ house ☐ flat, unit, apartment ☐ house on farm
☐ hostel for the aged ☐ mobile home ☐ other
☐ nursing home ☐ retirement village, self care unit

16. How many TIMES did you do each of these activities LAST WEEK?
(put "0" if you did not do this activity)

	times in the last week
Walking continuously, for at least 10 minutes *(for recreation or exercise or to get to or from places)*	☐☐
Vigorous physical activity *(that made you breathe harder or puff and pant, like jogging, cycling, aerobics, competitive tennis, but not household chores or gardening)*	☐☐
Moderate physical activity *(like gentle swimming, social tennis, vigorous gardening or work around the house)*	☐☐

17. If you add up all the time you spent doing each activity LAST WEEK, how much time did you spend ALTOGETHER doing each type of activity?
(put "0" if you did not do this activity)

	hours	minutes
Walking continuously, for at least 10 minutes *(for recreation or exercise or to get to or from places)*	☐☐ :	☐☐
Vigorous physical activity *(that made you breathe harder or puff and pant, like jogging, cycling, aerobics, competitive tennis, but not household chores or gardening)*	☐☐ :	☐☐
Moderate physical activity *(like gentle swimming, social tennis, vigorous gardening or work around the house)*	☐☐ :	☐☐

Questions about your family

18. Have your mother, father, brother(s) or sister(s) ever had:
(blood relatives only: please put a cross in the appropriate box(es))

	mother	father	brother/ sister		mother	father	brother/ sister
heart disease	☐	☐	☐	breast cancer	☐	☐	☐
high blood pressure	☐	☐	☐	bowel cancer	☐	☐	☐
stroke	☐	☐	☐	lung cancer	☐	☐	☐
diabetes	☐	☐	☐	melanoma	☐	☐	☐
dementia/Alzheimer's	☐	☐	☐	prostate cancer		☐	☐
Parkinson's disease	☐	☐	☐	ovarian cancer	☐		☐
severe depression	☐	☐	☐	osteoporosis	☐	☐	☐
severe arthritis	☐	☐	☐	hip fracture	☐	☐	☐
do not know	☐	☐	☐				

19. How many children have you given birth to? ☐☐ children
(please include stillbirths but do not include miscarriages, please write "0" if you have not had any children)

How old were you when you gave birth to your FIRST child? ☐☐ years old

How old were you when you gave birth to your LAST child? ☐☐ years old

For how many months, in total, have you breastfed? ☐☐ months
(please add together all the time you spent breastfeeding all of your children; put "0" if you never breastfed)

Questions about your health

20. About how many hours a week are you exposed to someone else's tobacco smoke?

hours per week ☐☐ at home
hours per week ☐☐ in other places *(e.g. work, going out, cars)*

21. Have you ever used the pill or other hormonal contraceptives?
(e.g. the combined pill, mini pill, contraceptive implant or injections)

☐ Yes ▼ ☐ No

If Yes, for how long altogether have you used hormonal contraceptives? ☐☐ years
(please write '0' if you used them for less than a year in total)

If Yes, how old were you when you LAST used hormonal contraceptives? ☐☐ age
(please write your current age if you are still using them)

Which type of pill or other hormonal contraceptive did you use MOST RECENTLY?

☐ "the pill", combined pill *(e.g. Microgynon, Levlen)*
☐ progesterone-only pill ("mini pill") *(e.g. Micronor, Noriday, Microval)*
☐ Depo Provera
☐ contraceptive implant *(e.g. Implanon, Norplant)*
☐ do not know

22. Have you ever used hormone replacement therapy (HRT)?

☐ Yes ▼ ☐ No

If Yes, for how long altogether have you used HRT? ☐☐ years
(please write '0' if you used HRT for less than a year in total)

Are you currently taking HRT? ☐ Yes ☐ No

If No, at what age did you stop? ☐☐ age

23. Have you taken any medications, vitamins or supplements for most of the last 4 weeks, including HRT and the pill?

☐ Yes ▼ ☐ No

If Yes, was it:

☐ multivitamins + minerals	☐ multivitamins alone	
☐ fish oil	☐ glucosamine	☐ omega 3
☐ paracetamol	☐ aspirin for the heart	☐ aspirin for other reasons
☐ Lipitor	☐ Avapro, Karvea	☐ warfarin, Coumadin
☐ Pravachol	☐ Coversyl, Coversyl Plus	☐ Lasix, frusemide
☐ Zocor, Lipex	☐ Cardizem, Vasocordol	☐ Micardis
☐ Nexium	☐ Norvasc	☐ Fosamax
☐ Somac	☐ Tritace	☐ Caltrate
☐ Losec, Acimax *omeprazole*	☐ Noten, Tenormin *atenolol*	☐ Oroxine *thyroxine*
☐ Ventolin *salbutamol*	☐ Zyloprim, Progout 300 *allopurinol*	☐ Diabex, Diaformin *metformin*
☐ Zoloft *sertraline*	☐ Cipramil *citaloprim*	☐ Efexor *venlafaxine*

please list any other regular medications or supplements here

24. Has a doctor EVER told you that you have:
(If YES, please cross the box and give your age when the condition was first found)

	Yes	Age when condition was first found
skin cancer (not melanoma)	☐	☐☐ age
melanoma	☐	☐☐ age
breast cancer	☐	☐☐ age
other cancer	☐	☐☐ age
type of cancer *(please describe)*		
heart disease	☐	☐☐ age
type of heart disease *(please describe)*		
high blood pressure – when pregnant	☐	☐☐ age
high blood pressure – when not pregnant	☐	☐☐ age
stroke	☐	☐☐ age
diabetes	☐	☐☐ age
blood clot (thrombosis)	☐	☐☐ age
asthma	☐	☐☐ age
hayfever	☐	☐☐ age
depression	☐	☐☐ age
anxiety	☐	☐☐ age
Parkinson's disease	☐	☐☐ age
none of these	☐	

25. In the last month have you been treated for:
(If YES, please cross the box and give your age when the treatment started)

	Yes	Age started treatment
cancer	☐	☐☐ age
heart attack or angina	☐	☐☐ age
other heart disease	☐	☐☐ age
high blood pressure	☐	☐☐ age
high blood cholesterol	☐	☐☐ age
blood clotting problems	☐	☐☐ age
asthma	☐	☐☐ age
osteoarthritis	☐	☐☐ age
thyroid problems	☐	☐☐ age
osteoporosis or low bone density	☐	☐☐ age
depression	☐	☐☐ age
anxiety	☐	☐☐ age
none of these	☐	

26. Are you NOW suffering from any other important illness?
☐ Yes ▼ ☐ No

Please describe this illness and its treatment

27. Do you regularly need help with daily tasks because of long-term illness or disability?
(e.g. personal care, getting around, preparing meals)
☐ Yes ☐ No

28. Does your health now LIMIT YOU in any of the following activities?

	yes, limited a lot	**yes**, limited a little	**no**, not limited at all
VIGOROUS activities *(e.g. running, strenuous sports)*	☐	☐	☐
MODERATE activities *(e.g. pushing a vacuum cleaner, playing golf)*	☐	☐	☐
lifting or carrying shopping	☐	☐	☐
climbing several flights of stairs	☐	☐	☐
climbing one flight of stairs	☐	☐	☐
walking one kilometre	☐	☐	☐
walking half a kilometre	☐	☐	☐
walking 100 metres	☐	☐	☐
bending, kneeling or stooping	☐	☐	☐
bathing or dressing yourself	☐	☐	☐

29. Have you ever had any of the following operations?
(If YES, please cross the box and give your age when you had the operation; give your age at the **most recent operation** if you have had more than one)

	Yes	Age when had operation
removal of skin cancer	☐	☐☐ age
hysterectomy	☐	☐☐ age
both ovaries removed	☐	☐☐ age
sterilisation (tubes tied)	☐	☐☐ age
repair of prolapsed womb, bladder or bowel	☐	☐☐ age
knee replacement	☐	☐☐ age
hip replacement	☐	☐☐ age
gallbladder removed	☐	☐☐ age
heart or coronary bypass surgery *(include stents and balloons)*	☐	☐☐ age

other *(please describe any other operations you have had in the last 10 years, with your age when you had them)*

30. Do you regularly care for a sick or disabled family member or friend?

☐ Yes ▼ ☐ No

If Yes, about how much time each week do you usually spend caring for this person?

☐ full time OR ☐☐ hours/wk

31. In general, how would you rate your:

	excellent	very good	good	fair	poor
overall health?	☐	☐	☐	☐	☐
quality of life?	☐	☐	☐	☐	☐
eyesight? *(with glasses or contact lenses, if you wear them)*	☐	☐	☐	☐	☐
memory?	☐	☐	☐	☐	☐
teeth and gums?	☐	☐	☐	☐	☐

32. Do you feel you have a hearing loss? ☐ Yes ☐ No

33. How many of your own teeth do you have left?

☐ None – all of my teeth are missing ☐ 1-9 teeth left
☐ 10-19 teeth left ☐ 20 or more teeth left

34. During the past 12 months, how many times have you fallen to the floor or ground? (put "0" if you haven't fallen in this time)

☐☐ times

35. Have you had a broken/fractured bone in the last 5 years?

☐ Yes ▼ ☐ No

If Yes, which bones were broken?

☐ wrist ☐ arm ☐ hip ☐ ankle
☐ rib ☐ finger/toe ☐ other _____

How old were you when it happened? (give age at most recent fracture if more than one) ☐☐ years old

36. About how many times a week are you usually troubled by leaking urine?

☐ never ☐ once a week or less
☐ 2-3 times ☐ 4-6 times ☐ every day

37. Have you been through menopause?

☐ No
☐ Not sure *(because hysterectomy, taking HRT, etc.)*
☐ My periods have become irregular
☐ Yes – How old were you when you went through menopause? ☐☐ years old

38. Have you ever been for a breast screening mammogram?

☐ Yes ▼ ☐ No

If Yes, what year did you have your last mammogram? (e.g. 2005) ☐☐☐☐

How many times have you been for breast screening altogether? ☐☐ times

39. Have you ever been screened for colorectal (bowel) cancer?

☐ Yes ▼ ☐ No

If Yes, please indicate which test(s) you had:

☐ faecal occult blood test *(test for blood in the stool/faeces)*
☐ sigmoidoscopy *(a tube is used to examine the lower bowel: this is usually done in a doctor's office without pain relief)*
☐ colonoscopy *(a long tube is used to examine the whole large bowel; you would usually have to have an enema or drink large amounts of special liquid to prepare the bowel for this)*

What year did you have the most recent one of these tests? (e.g. 2005) ☐☐☐☐

Questions about your diet

40. About how many times each week do you eat: (please count all meals and snacks. put '0' if never eaten or eaten less than once a week)

	number of times eaten each week
beef, lamb or pork	☐☐
chicken, turkey or duck	☐☐
processed meat *(include bacon, sausages, salami, devon, burgers, etc)*	☐☐
fish or seafood	☐☐
cheese	☐☐

41. About how many of the following do you usually eat:

slices or pieces of brown/wholemeal bread each week ☐☐ *(also include multigrain, rye bread, etc.)*

bowls of breakfast cereal each week ☐☐

If you eat breakfast cereal is it usually: (please cross)

☐ bran cereal *(allbran, branflakes, etc.)* ☐ muesli
☐ biscuit cereal *(weetbix, shredded wheat, etc.)* ☐ other *(cornflakes, rice bubbles,etc.)*
☐ oat cereal *(porridge, etc.)*

42. Which type of milk do you mostly have?

☐ whole milk ☐ reduced fat milk ☐ skim milk
☐ soy milk ☐ other milk ☐ I don't drink milk

43. About how many serves of vegetables do you usually eat each day? A serve is half a cup of cooked vegetables or one cup of salad (please include potatoes and put "0" if less than one a day)

☐☐ number of serves of cooked vegetables each day
☐☐ number of serves of raw vegetables each day (e.g. salad)
☐ I don't eat vegetables

44. About how many serves of fruit or glasses of fruit juice do you usually have each day? A serve is 1 medium piece or 2 small pieces or 1 cup of diced or canned fruit pieces (put "0" if you eat less than one serve a day)

☐☐ number of serves of fruit each day
☐☐ number of glasses of fruit juice each day
☐ I don't eat fruit

45. Please put a cross in the box if you NEVER eat:

☐ red meat ☐ chicken/poultry ☐ pork/ham ☐ dairy products
☐ any meat ☐ eggs ☐ sugar ☐ wheat products
☐ fish ☐ seafood ☐ cream ☐ cheese

Questions about time and work

46. What is your usual yearly HOUSEHOLD income before tax, from all sources? (please include benefits, pensions, superannuation, etc)

☐ less than $5,000 per year ☐ $30,000-$39,999 per year
☐ $5,000-$9,999 per year ☐ $40,000-$49,999 per year
☐ $10,000-$19,999 per year ☐ $50,000-$69,999 per year
☐ $20,000-$29,999 per year ☐ $70,000 or more per year
☐ I would rather not answer this question

47. What is your current work status? (you can cross more than one box)

- ☐ in full time paid work
- ☐ in part time paid work
- ☐ completely retired/pensioner
- ☐ partially retired
- ☐ disabled/sick
- ☐ other
- ☐ self-employed
- ☐ doing unpaid work
- ☐ studying
- ☐ looking after home/family
- ☐ unemployed

48. If you are partially or completely retired, how old were you when you retired? ☐☐ years old

Why did you retire? (you can cross more than one box)

- ☐ reached usual retirement age
- ☐ to care for family member/friend
- ☐ made redundant
- ☐ other
- ☐ lifestyle reasons
- ☐ ill health
- ☐ could not find a job

49. About how many HOURS each WEEK do you usually spend doing the following? (please put "0" if you do not spend any time doing it)

hours per week ☐☐ paid work

hours per week ☐☐ voluntary/unpaid work

50. Which of the following do you have? (excluding Medicare)

- ☐ Private health insurance – with extras
- ☐ Private health insurance – without extras
- ☐ Department of Veterans' Affairs white or gold card
- ☐ Health care concession card
- ☐ none of these

51. What best describes the colour of the skin on the inside of your upper arm, that is your skin colour without any tanning?

- ☐ very fair
- ☐ fair
- ☐ light olive
- ☐ dark olive
- ☐ brown
- ☐ black

52. What would happen if your skin was repeatedly exposed to bright sunlight during summer without any protection? Would it:

- ☐ Get very tanned?
- ☐ Get moderately tanned?
- ☐ Get mildly or occasionally tanned?
- ☐ Never tan, or only get freckled?

53. About how many hours a DAY would you usually spend outdoors on a weekday and on the weekend?

hours per day ☐☐ weekday

hours per day ☐☐ weekend

54. About how many HOURS in each 24 hour DAY do you usually spend doing the following?
(please put "0" if you do not spend any time doing it)

hours per day		hours per day	
☐☐	sleeping (including at night & naps)	☐☐	sitting
☐☐	watching television or using a computer	☐☐	standing

55. How many TIMES in the LAST WEEK did you:
(please put "0" if you did not spend any time doing it)

	times in the last week
spend time with friends or family who do not live with you?	☐☐
talk to someone (friends, relatives or others) on the telephone?	☐☐
go to meetings of social clubs, religious groups or other groups you belong to?	☐☐

56. How many people outside your home, but within one hour of travel, do you feel you can depend on or feel very close to? ☐☐ people

57. During the past 4 weeks, about how often did you feel:

	none of the time	a little of the time	some of the time	most of the time	all of the time
tired out for no good reason?	☐	☐	☐	☐	☐
nervous?	☐	☐	☐	☐	☐
so nervous that nothing could calm you down?	☐	☐	☐	☐	☐
hopeless?	☐	☐	☐	☐	☐
restless or fidgety?	☐	☐	☐	☐	☐
so restless that you could not sit still?	☐	☐	☐	☐	☐
depressed?	☐	☐	☐	☐	☐
that everything was an effort?	☐	☐	☐	☐	☐
so sad that nothing could cheer you up?	☐	☐	☐	☐	☐
worthless?	☐	☐	☐	☐	☐

58. During the past 4 weeks, have you had any of the following problems with your work or daily activities because of any emotional problems (such as being depressed or anxious)?

cut down on the amount of time you spent on work or other activities	☐ Yes	☐ No
achieved less than you would have liked to	☐ Yes	☐ No
did work or other activities less carefully than usual	☐ Yes	☐ No

Thank you very much for filling in the questionnaire
DON'T FORGET TO SIGN THE CONSENT FORM OVERLEAF

Are your name and address correct on the front of this questionnaire? ☐ Yes ☐ No

If INCORRECT, give details below.

Surname:

Given name(s):

Postal address:

Town or Suburb:

State or Territory: Postcode:

Consent form

THE 45 AND UP STUDY
Research to improve health and wellbeing

The *45 and Up Study* relies on the willingness of people in New South Wales to share information about their lives and experiences and to have their health followed over time. By signing this form you are agreeing to take part in the *45 and Up Study* and for the Study team to follow your health over time. Participation is completely voluntary, and you are free to ask questions or to withdraw from the Study at any time, by calling the Study helpline on 1300 45 11 45. More information on the Study can be found at www.45andup.org.au

I agree to have my health followed over time through:

the 45 and Up Study team following health and other records relating to me, including NSW hospital records, cancer records, death records and other health-related records, as outlined in the Study leaflet: *The 45 and Up Study: Information for participants*;

Medicare Australia releasing to the 45 and Up Study my enrolment details, including Medicare number, and information concerning services provided to me under Medicare, the Department of Veterans' Affairs, the Pharmaceutical Benefits Scheme and the Repatriation Pharmaceutical Benefits Scheme, including past information, until the end of the Study or for the duration of my involvement in the Study;

being contacted in the future to provide information on changes to my health and lifestyle. I may also be asked to provide further information including questionnaire responses or biological samples; my participation in any of these would be completely voluntary.

I give my consent on the understanding that:

my information will only be used for the purposes outlined in the Study leaflet entitled *The 45 and Up Study: Information for participants*, of which I have a copy;

my information will be kept strictly confidential and will be used for health research only;

reports and publications from the Study will be based on de-identified information and will not identify any individual taking part;

my participation in this Study is entirely voluntary and my consent will continue to be valid following death or disablement unless withdrawn by my next of kin or other person responsible. I am free to withdraw from the Study at any time by calling the **Study helpline on 1300 45 11 45;**

my decision on whether or not to take part in the Study or in any additional research will not disadvantage me or affect my future health care in any way.

I have been provided with information about the 45 and Up Study including how it will gather, store, use and disclose information about me, in the Study leaflet. I have been given an opportunity to ask questions and have been fully informed about the Study.

Name (Print): _____

Signature: _____ Date today: day ☐☐ / month ☐☐ / 2 0 ☐☐ (year)

Extra contact details

It would be very helpful and reduce Study costs if we could contact you in future by email. If you are happy for us to do this, please write your email address here:

Email address: _____

Sometimes we find that people have moved when we try to contact them again. It would be very helpful if you could give us your mobile phone number and/or the contact details of someone close to you (such as a relative or friend) who would be happy for us to contact them if we are unable to reach you. We would only get in touch with that person if we were unable to contact you directly and we would need to tell them our reason for contacting you. Please leave this section blank if you do not wish to provide these extra contact details.

Your home phone number: (☐☐) _____ Your mobile phone number: _____

Full name of contact person: _____

Phone number of contact person: (☐☐) _____

If you have any questions about the Study, please ring the Study helpline on **1300 45 11 45.**
You can also write to or send your questionnaire (no stamp required) directly to:

Associate Professor Emily Banks, Scientific Director,
The 45 and Up Study, Reply paid 5289, Sydney NSW 2001.

Thank you very much for taking part

Appendix 9: 45 and Up Sub-study Stroke Questionnaire

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saxinstitute THE 45 AND UP STUDY

A study of self-care strategies for coping and living with chronic illness
Stroke

UTS

The research project ***A study of self-care strategies for coping and living with chronic illness*** is being conducted by researchers at the University of Technology Sydney. The aim of the project is to collect information on what people do to improve their health that are outside of conventional medical care (self-care) to better understand how they cope and live with high blood pressure or having had a stroke.

This is the stroke questionnaire. If you have experienced both of these chronic conditions, we would like you to complete this questionnaire for your stroke. If you have not had a stroke please advise us by contacting the 45 and Up Study on 1300 45 11 45 or by email to 45andUp@saxinstitute.org.au

Participation is completely voluntary. All information that you provide will be kept strictly confidential and will be used for health research only. To participate in the research project, please read the participant information leaflet, then fill in the questionnaire and consent form and return them in the envelope provided.

COMPLETION GUIDELINES

Your answers and experiences are important to us. Fully shade the appropriate box(es)/circle(s) ● Yes ○ No

To help us read your answers, please write as clearly as possible using a **BLACK** or **DARK BLUE** pen. Place a cross over any incorrect selection you wish to cancel ✖ Yes ○ No

Place numbers or CAPITAL letters in appropriate boxes | A | B | C | | 1 | 2 | 3 | Circles are provided where only one choice is permitted ○ Boxes indicate that multiple responses are permitted □

For written responses, please cross out your incorrect response and write your new response just above or below the one you have crossed out. I N C O R R E C T CORRECT

YOUR GENERAL HEALTH

Q1. Please indicate which statements best describe your own health state today.

Mobility *(Choose one only)*

○ I have no problems in walking around
○ I have some problems in walking around
○ I am confined to bed

Personal care *(Choose one only)*

○ I have no problems with personal care
○ I have some problems washing or dressing myself
○ I am unable to wash or dress myself

Usual activities (e.g. work, study, housework, family or leisure activities) *(Choose one only)*

○ I have no problems with performing my usual activities
○ I have some problems with performing my usual activities
○ I am unable to perform my usual activities

Pain/discomfort *(Choose one only)*

○ I have no pain or discomfort
○ I have moderate pain or discomfort
○ I have extreme pain or discomfort

Anxiety/depression *(Choose one only)*

○ I am not anxious or depressed
○ I am moderately anxious or depressed
○ I am extremely anxious or depressed

Q2. To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 10 and the worst state you can imagine is marked 1.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by shading the circle on whichever point on the scale indicates how good or bad your health state is today.

Worst state									Best state
○ 1	○ 2	○ 3	○ 4	○ 5	○ 6	○ 7	○ 8	○ 9	○ 10

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Q3. **Below is a list of ways you might have felt or behaved. Please indicate how often you have felt this way during the last week.**

(Choose one on each line)	Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of the time (3-4 days)	Most or all of the time (5-7 days)
I was bothered by things that don't usually bother me	○	○	○	○
I had trouble keeping my mind on what I was doing	○	○	○	○
I felt depressed	○	○	○	○
I felt everything I did was an effort	○	○	○	○
I felt hopeful about the future	○	○	○	○
I felt fearful	○	○	○	○
My sleep was restless	○	○	○	○
I was happy	○	○	○	○
I felt lonely	○	○	○	○
I could not "get going"	○	○	○	○
I felt terrific	○	○	○	○

Q4. **Please indicate how much you agree or disagree with each of the following statements:**

(Choose one on each line)	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree
I can avoid illness if I take care of myself	○	○	○	○	○	○
Luck plays a big part in determining how soon I will recover from an illness	○	○	○	○	○	○
I am in control of my health	○	○	○	○	○	○
My good health is largely a matter of good fortune	○	○	○	○	○	○
No matter what I do, if I am going to get sick, I will get sick	○	○	○	○	○	○
The main thing which affects my health is what I do myself	○	○	○	○	○	○
Setting goals for health is realistic	○	○	○	○	○	○
Most things that affect my health happen to me by accident	○	○	○	○	○	○
If I get sick, it is my own behaviour that determines how soon I will get well	○	○	○	○	○	○
I will stay healthy if it's meant to be	○	○	○	○	○	○
No matter what I do, I am likely to get sick	○	○	○	○	○	○
If I take the right actions, I can stay healthy	○	○	○	○	○	○
I can be as healthy as I want to be	○	○	○	○	○	○
I have little influence over my health	○	○	○	○	○	○

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Q5. **In the past 12 months, have you been diagnosed or treated by a doctor for any of the following:**
(Choose all that apply)

- ☐ Anxiety/nervous disorder
- ☐ Asthma
- ☐ Cancer (excluding skin cancer)
- ☐ Dementia, Alzheimer's disease
- ☐ Depression
- ☐ Diabetes
- ☐ Heart disease (incl. heart attack, angina)
- ☐ High cholesterol
- ☐ Hypertension
- ☐ Osteoarthritis
- ☐ Osteoporosis
- ☐ Parkinson's disease
- ☐ Other 1 (specify) _____
- ☐ Other 2 (specify) _____

Q6. **Have you taken or used any prescription medication other than those for your stroke, prescribed by a doctor/specialist during the past 12 months?**
○ Yes ▼ if Yes, please list ○ No ▶ if No, go to Question 7

1.	**4.**
2.	**5.**
3.	**6.**

PHYSICAL ACTIVITY

Q7. **How many *times* did you do each type of activity last week (Monday to Sunday)?**
If you add up all the times you spent in each activity last week, how much time did you spend altogether doing each type of activity?

Only count the number of times when the activity lasted for 10 minutes or more. (If you did not do an activity, please write "0" in the box)	Number of times in last week	Time spent altogether hours	minutes
Walking briskly *(for recreation or exercise, or to get from place to place)*		:	
Moderate leisure activity *(like social tennis, moderate exercise classes, recreational swimming, dancing)*		:	
Vigorous leisure activity *(that makes you breathe harder or puff and pant like aerobics, competitive sport, vigorous cycling, running, swimming)*		:	
Vigorous household or garden chores *(that make you breathe harder or puff and pant)*		:	

SMOKING AND TOBACCO

Q8. **How often do you currently smoke cigarettes or any tobacco products?** *(Choose one only)*
○ Daily ▶ go to Question 9
○ At least weekly (but not daily) ▶ go to Question 10
○ Less often than weekly ▶ go to Question 11
○ Not at all ▶ go to Question 13

Q9. **If you smoke daily, on average how many cigarettes do you smoke each day?**
☐☐ cigarettes per day ▶ go to Question 13

Q10. **If you smoke, but not daily, on average how many cigarettes do you smoke per week?**
☐☐☐ cigarettes per week

Q11. **Have you ever smoked daily?**
○ Yes ▼ ○ No ▶ if No, go to Question 13

Q12. **At what age did you finally stop smoking daily?**
☐☐

years old

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ALCOHOL AND DRINKING

Q13. Do you drink alcohol? *(Choose one only)*
- ○ I have never drunk alcohol in my life ▶ go to Question 17
- ○ I never drink alcohol, but I have in the past ▶ go to Question 17
- ○ Yes

Q14. How many alcoholic drinks do you have each week?
One drink = a small glass of wine, middy of beer or nip of spirits *(put "0" if you do not drink, or have less than one drink each week).*

☐☐ number of alcoholic drinks each week

Q15. On how many days each week do you usually drink alcohol?

☐ days each week

Q16. How often do you have four or more drinks of alcohol on one occasion? *(Choose one only)*
○ Never ○ Less than once a month ○ About once a month ○ About once a week ○ More than once a week

HEIGHT AND WEIGHT

Q17. How much do you weigh? *(No clothes or shoes)* kg ☐☐☐ OR stone ☐☐ lbs ☐☐

Q18. How tall are you without shoes? cm ☐☐☐ OR feet ☐ inches ☐☐

YOUR STROKE(S)

Q19. How long ago was your most recent stroke? *(Please specify number of years/months)* ☐☐ years ☐☐ months

Q20. How many strokes have you had in total?
○ 1 ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 ○ 8 ○ 9 ○ 10

Q21. How would you rate your stroke related symptoms? *(Choose one only)*
- ○ No symptoms at all
- ○ No significant disability despite symptoms; able to carry out all usual duties and activities
- ○ Slight disability; unable to carry out all previous activities, but able to look after own affairs without assistance
- ○ Moderate disability; requiring some help, but able to walk without assistance
- ○ Moderate to severe disability; unable to walk without assistance and unable to attend to own bodily needs without assistance
- ○ Severe disability; bedridden, incontinent and requiring constant nursing and attention

Q22. Fatigue is a feeling of physical tiredness and lack of energy. Please read each statement below carefully, and then shade the circle that best indicates how often fatigue has affected you in this way during the past 4 weeks.

Because of my fatigue in the past 4 weeks…

(Choose one on each line)	Never	Rarely	Sometimes	Often	Almost always
I have been less alert	○	○	○	○	○
I have been limited in my ability to do things away from home	○	○	○	○	○
I have had trouble maintaining physical effort for long periods	○	○	○	○	○
I have been less able to complete tasks that require effort	○	○	○	○	○

I have had trouble concentrating	○	○	○	○	○

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MEDICAL/ALLIED HEALTH PROFESSIONAL VISITS

Q23. **Did you consult with any of the health practitioners listed below <u>for your stroke</u> during the <u>past 12 months</u>?**

○ Yes ▼ ○ No ▶ if No, go to Question 24A

If Yes, how many times did you consult with the following practitioners?

(Choose one on each line as relevant)	1 or 2	3 - 6	7 or more
General practitioner	○	○	○
Neurologist	○	○	○
Cardiologist	○	○	○
Hospital doctor	○	○	○
Nurse	○	○	○
Pharmacist/chemist	○	○	○
Counsellor	○	○	○
Psychologist	○	○	○
Dietician	○	○	○
Physiotherapist	○	○	○
Occupational therapist	○	○	○
Speech pathologist	○	○	○

Q24. **How much did it cost you in total for these consultations during the <u>past 12 months</u>?**
(Choose one only)

○ Up to $100 ○ $100 - $499 ○ $500 - $999 ○ $1,000 - $1,499 ○ $1,500 or above

Q24A. **Have you ever accessed a support service for your stroke?**
(Choose all that apply)

☐ Yes, online

☐ Yes, on the phone

☐ Yes, I have attended support group meetings

☐ No

Q25. **Have you taken any <u>prescription</u> medication <u>for your stroke</u> during the <u>past 12 months</u> prescribed by a doctor/specialist?**

○ Yes ▼ if Yes, please list ○ No ▶ if No, go to Question 26A

1.	**5.**
2.	**6.**
3.	**7.**
4.	**8.**

Q26. **How much did it cost you in total for these medications listed in Question 25 during the <u>past 12 months</u>?**
(Choose one only)

○ Up to $100 ○ $100 - $499 ○ $500 - $999 ○ $1,000 - $1,499 ○ $1,500 or above

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Q26A. Have you taken any non-prescription medication (i.e. aspirin, laxatives, painkillers bought in a supermarket or pharmacy) for your stroke during the past 12 months?

○ Yes ▼ if Yes, please list ○ No ▶ if No, go to Question 26C

1.	**5.**
2.	**6.**
3.	**7.**
4.	**8.**

Q26B. How much did it cost you in total for these medications listed in Question 26A during the past 12 months? *(Choose one only)*

○ Up to $100 ○ $100 - $499 ○ $500 - $999 ○ $1,000 - $1,499 ○ $1,500 or above

Q26C. In the past 12 months have you:

	Yes	No
Slipped, tripped or stumbled?	○	○
Had a fall to the ground?	○	○
Been injured as a result of a fall?	○	○
Needed to seek medical attention for an injury from a fall?	○	○
Had any other injury from an accident at your home?	○	○
Broken or fractured any bone/s?	○	○

COMPLEMENTARY HEALTH PRACTITIONER VISITS

Q27. Did you consult with any complementary health practitioners listed below for your stroke during the past 12 months?

○ Yes ▼ ○ No ▶ if No, go to Question 29

If Yes, how many times did you consult with the following practitioners during the past 12 months?

(Choose one on each line as relevant)	1 or 2	3 - 6	7 or more
Acupuncturist	○	○	○
Chiropractor	○	○	○
Naturopath/herbalist	○	○	○
Homeopath	○	○	○
Massage therapist	○	○	○
Meditation instructor	○	○	○
Yoga instructor	○	○	○
Tai chi instructor	○	○	○
Nutritionist	○	○	○
Osteopath	○	○	○
Traditional Chinese medicine practitioner	○	○	○
Other (please specify)	○	○	○

Q28. How much did it cost you in total for these consultations during the past 12 months? *(Choose one only)*

○ Up to $100 ○ $100 - $499 ○ $500 - $999 ○ $1,000 - $1,499 ○ $1,500 or above

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USE OF COMPLEMENTARY HEALTH PRODUCTS/PRACTICES

Q29. Did you use any of the complementary health products or practices listed below for your stroke during the past 12 months?

○ Yes ▼ ○ No ▶ if No, go to Question 35

If Yes, how many times did you take/use them during the past 12 months?

(Choose one on each line as relevant)	At least once daily	At least weekly	At least monthly
Caffeine based products or drinks	○	○	○
CoQ10	○	○	○
Folic acid	○	○	○
Garlic	○	○	○
Ginkgo	○	○	○
Herbal medicines	○	○	○
Homeopathic remedies	○	○	○
Meditation by yourself (i.e. without instructor)	○	○	○
Mindfulness	○	○	○
Multi B vitamin	○	○	○
Multivitamins/minerals	○	○	○
Omega 3/fish oil	○	○	○
Physical activities/exercises	○	○	○
St John's wort (hypericum)	○	○	○
Tai chi by yourself (i.e. without instructor)	○	○	○
Vitamin B12	○	○	○
Vitamin C	○	○	○
Vitamin D	○	○	○
Vitamin E	○	○	○
Yoga by yourself (i.e. without instructor)	○	○	○
Other 1 (please specify)	○	○	○
Other 2 (please specify)	○	○	○

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Q30. Did any of the following health practitioners recommend the following complementary health products or practices for your stroke during the past 12 months? Are any of the health practitioners monitoring/ managing your ongoing use of these products or practices?

(Choose one option for 'Recommend' and one option for 'Monitor' on each line as relevant)	**Medical practitioner** (e.g. GP, neurologist)		**Allied health practitioner** (e.g. dietician, pharmacist)		**Complementary health practitioner** (e.g. naturopath, acupuncturist)	
	Recommend	**Monitor**	**Recommend**	**Monitor**	**Recommend**	**Monitor**
Caffeine based products or drinks	☐	☐	☐	☐	☐	☐
CoQ10	☐	☐	☐	☐	☐	☐
Folic acid	☐	☐	☐	☐	☐	☐
Garlic	☐	☐	☐	☐	☐	☐
Ginkgo	☐	☐	☐	☐	☐	☐
Herbal medicines	☐	☐	☐	☐	☐	☐
Homeopathic remedies	☐	☐	☐	☐	☐	☐
Meditation by yourself (i.e. without instructor)	☐	☐	☐	☐	☐	☐
Mindfulness	☐	☐	☐	☐	☐	☐
Multi B vitamin	☐	☐	☐	☐	☐	☐
Multivitamins/minerals	☐	☐	☐	☐	☐	☐
Omega 3/fish oil	☐	☐	☐	☐	☐	☐
Physical activities/exercises	☐	☐	☐	☐	☐	☐
St John's wort (hypericum)	☐	☐	☐	☐	☐	☐
Tai chi by yourself (i.e. without instructor)	☐	☐	☐	☐	☐	☐
Vitamin B12	☐	☐	☐	☐	☐	☐
Vitamin C	☐	☐	☐	☐	☐	☐
Vitamin D	☐	☐	☐	☐	☐	☐
Vitamin E	☐	☐	☐	☐	☐	☐
Yoga by yourself (i.e. without instructor)	☐	☐	☐	☐	☐	☐
Other 1 (as specified in Q29)	☐	☐	☐	☐	☐	☐
Other 2 (as specified in Q29)	☐	☐	☐	☐	☐	☐

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Q31. Where did you purchase the following complementary health products that you used for your stroke, during the past 12 months?

(Choose all that apply)	Supermarket/ health food store	Pharmacy/ chemist	Complementary health practitioner	Internet
Caffeine based products or drinks	☐	☐	☐	☐
CoQ10	☐	☐	☐	☐
Folic acid	☐	☐	☐	☐
Garlic	☐	☐	☐	☐
Ginkgo	☐	☐	☐	☐
Herbal medicines	☐	☐	☐	☐
Homeopathic remedies	☐	☐	☐	☐
Multi B vitamin	☐	☐	☐	☐
Multivitamins/minerals	☐	☐	☐	☐
Omega 3/fish oil	☐	☐	☐	☐
St John's wort (hypericum)	☐	☐	☐	☐
Vitamin B12	☐	☐	☐	☐
Vitamin C	☐	☐	☐	☐
Vitamin D	☐	☐	☐	☐
Vitamin E	☐	☐	☐	☐
Other 1 (as specified in Q29)	☐	☐	☐	☐
Other 2 (as specified in Q29)	☐	☐	☐	☐

Q32. How much did it cost you in total for these products and practices during the past 12 months?
(Choose one only)

○ Up to $100 ○ $100 - $499 ○ $500 - $999 ○ $1,000 - $1,499 ○ $1,500 or above

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Q33. How effective did you find the following complementary health products and practices for the relief of symptoms associated with your stroke?

(Choose one on each line as relevant)	Effective	Somewhat effective	Not at all effective
Caffeine based products or drinks	○	○	○
CoQ10	○	○	○
Folic acid	○	○	○
Garlic	○	○	○
Ginkgo	○	○	○
Herbal medicines	○	○	○
Homeopathic remedies	○	○	○
Meditation by yourself (i.e. without instructor)	○	○	○
Mindfulness	○	○	○
Multi B vitamin	○	○	○
Multivitamins/minerals	○	○	○
Omega 3/fish oil	○	○	○
Physical activities/exercises	○	○	○
St John's wort (hypericum)	○	○	○
Tai chi by yourself (i.e. without instructor)	○	○	○
Vitamin B12	○	○	○
Vitamin C	○	○	○
Vitamin D	○	○	○
Vitamin E	○	○	○
Yoga by yourself (i.e. without instructor)	○	○	○
Other 1 (as specified in Q29)	○	○	○
Other 2 (as specified in Q29)	○	○	○

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Q34. Did you talk to any of the following health practitioners about your use of these complementary health products or practices for your stroke?

(Please choose all that apply)	**Medical practitioner** (e.g. GP, neurologist)	**Allied health practitioner** (e.g. dietician, pharmacist)	**Complementary health practitioner** (e.g. naturopath, acupuncturist)
Caffeine based products or drinks	☐	☐	☐
CoQ10	☐	☐	☐
Folic acid	☐	☐	☐
Garlic	☐	☐	☐
Ginkgo	☐	☐	☐
Herbal medicines	☐	☐	☐
Homeopathic remedies	☐	☐	☐
Meditation by yourself (i.e. without instructor)	☐	☐	☐
Mindfulness	☐	☐	☐
Multi B vitamin	☐	☐	☐
Multivitamins/minerals	☐	☐	☐
Omega 3/fish oil	☐	☐	☐
Physical activities/exercises	☐	☐	☐
St John's wort (hypericum)	☐	☐	☐
Tai chi by yourself (i.e. without instructor)	☐	☐	☐
Vitamin B12	☐	☐	☐
Vitamin C	☐	☐	☐
Vitamin D	☐	☐	☐
Vitamin E	☐	☐	☐
Yoga by yourself (i.e. without instructor)	☐	☐	☐
Other 1 (as specified in Q29)	☐	☐	☐
Other 2 (as specified in Q29)	☐	☐	☐

Q35. If you did not consult with a complementary health practitioner or use complementary health products during the last 12 months for your stroke, please indicate why.

(Choose all that apply)	**Yes**
I would like to use complementary medicine but it is too expensive	○
It didn't occur to me to use complementary medicine for my stroke	○
I didn't know complementary medicine could help my recovery from stroke	○
I wasn't sure which type of complementary health practitioner to see or product to use for my stroke	○
I don't think complementary medicine works	○
I didn't think complementary medicine could help prevent another stroke	○
My family advised against it	○
My doctor/specialist advised against it	○
I was worried about side-effects	○
I was worried about interactions with the medications I take after the stroke	○
I would like to see more evidence before using complementary medicine	○
Other (please specify)	○

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SOURCES OF INFORMATION ABOUT COMPLEMENTARY HEALTH CARE

Q36. Apart from professional advice, have any of the following information sources been influential in your decision to use complementary health products and/or practitioners for your stroke?

○ I did not use complementary health products and/or practitioners ▶ go to Question 37

(Choose one on each line as relevant)	Not influential	Moderately influential	Very influential
Family or relatives	○	○	○
Friends or colleagues	○	○	○
Internet or website	○	○	○
Facebook or Twitter	○	○	○
Manufacturer's website or helpline	○	○	○
Book	○	○	○
Mass media (e.g. newspaper, TV, magazine, radio)	○	○	○
Scientific literature (medical journal)	○	○	○
Telephone helpline	○	○	○
Self-help or support group	○	○	○
Other (please specify)	○	○	○

ABOUT YOU

Q37. Do you have private health insurance?

○ Yes ▼ ○ No ▶ if No, go to Question 38

If Yes, does your policy give you a rebate for any of the following? *(Choose all that apply)*

☐ GP
☐ Medical specialist
☐ Chiropractor
☐ Acupuncturist
☐ Herbalist/Naturopath
☐ Physiotherapist
☐ Massage therapist
☐ Osteopath
☐ Yoga
☐ Tai Chi
☐ Meditation classes
☐ Gym membership/exercise classes

Q38. How confident are you filling out medical forms by yourself? *(Choose one only)*

○ Extremely
○ Quite a bit
○ Somewhat
○ A little bit
○ Not at all

Q39. What is the highest qualification you have completed? *(Choose the most appropriate)*

○ No school certificate or other qualifications
○ School or intermediate certificate (or equivalent)
○ Higher school or leaving certificate (or equivalent)
○ Trade/apprenticeship (e.g. hairdresser, chef)
○ Certificate/diploma (e.g. child care, technician)
○ University degree or higher

Q40. What best describes your current situation? *(Choose one only)*

○ Single
○ Married
○ De facto/living with a partner
○ Widowed
○ Divorced
○ Separated

Q41. How do you manage on the income you have available? *(Choose one only)*

○ It is impossible
○ It is difficult all the time
○ It is difficult some of the time

○ It is not too bad
○ It is easy

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Please return your questionnaire AND the signed consent form in the reply paid envelope or post (no stamp required) to:
The 45 and Up Study, Self Care Strategies Project, Reply Paid 1005, BROADWAY NSW 2007
Infoline 1300 45 11 45 **Email** 45andUp@saxinstitute.org.au

Appendix 10: ALSWH Questionnaire for 1946-51 Cohort Survey (2007)

How to complete this survey

This is the fifth "main" survey for mid-age women.
As the purpose of the project is to look at changes over time, some of the questions are the same as those in previous surveys.

Please answer every question you can. If you are unsure about how to answer a question, mark the response for the closest answer to how you feel.

Please write any comments or important information on page 30. We are not able to read comments written elsewhere throughout the survey.

Please read the instructions above each question carefully. Some require you to only answer those options which are applicable to you. Other questions require you to mark one answer on each line. The questions may also refer to different time periods.

INSTRUCTIONS:

- Use a black/blue biro
- Do not fold or bend this survey
  - **Cross the boxes like this:**

In general, would you say your health is:
(*Mark one only*)

Excellent	☐	
Very good	☐	
Good	☒	*You would mark this one if you think your health is good*
Fair	☐	
Poor	☐	

- **Print clearly in the boxes like this:**

What is your postcode?
(PRINT clearly in the boxes)

2	3	0	8

- **Correct mistakes like this:**

When you go to a General Practitioner:
(*Mark one on each line*)

	Always	Most of the time	Some-times	Rarely or never
Do you go to the same place?	☐	☒	☒	☐

If you make a mistake simply scribble it out and clearly mark the correct answer with a cross

If you need help to answer any questions, please ring 1800 068 081
(This is a FREECALL number)

* *If you are concerned about any of your health experiences and would like some help, you may like to contact:*

- *your nearest Women's Health Centre or Community Health Centre;*
- *your General Practitioner for advice about who would be the best person in your community for you to talk to.*

* *If you feel distressed NOW and would like someone to talk to, you could ring Lifeline on 131 114 (local call).*

women's health *is about how you are feeling*

The questions on the first page ask only about NOW - how your health is NOW and about how your health limits certain activities NOW.

Q1 **In general, would you say your health is:**
(Mark one only)

- Excellent ☐
- Very good ☐
- Good ☐
- Fair ☐
- Poor ☐

Q2 **Compared to one year ago, how would you rate your health in general now?**
(Mark one only)

- Much better now than one year ago ☐
- Somewhat better now than one year ago ☐
- About the same now as one year ago ☐
- Somewhat worse now than one year ago ☐
- Much worse now than one year ago ☐

Q3 **The following questions are about activities you might do during a typical day. Does YOUR HEALTH NOW LIMIT YOU in these activities? If so, how much?**
(Mark one on each line)

		Yes, limited a lot	Yes, limited a little	No, not limited at all
a	VIGOROUS activities, such as running, lifting heavy objects, participating in strenuous sports	☐	☐	☐
b	MODERATE activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf	☐	☐	☐
c	Lifting or carrying groceries	☐	☐	☐
d	Climbing SEVERAL flights of stairs	☐	☐	☐
e	Climbing ONE flight of stairs	☐	☐	☐
f	Bending, kneeling or stooping	☐	☐	☐
g	Walking MORE THAN ONE kilometre	☐	☐	☐
h	Walking HALF a kilometre	☐	☐	☐
i	Walking 100 metres	☐	☐	☐
j	Bathing or dressing yourself	☐	☐	☐

The questions on this page and the next one ask about your health IN THE LAST FOUR WEEKS.

Q4 **During the PAST FOUR WEEKS, have you had any of the following problems with your work *(including your work outside the home and housework)* or other regular daily activities AS A RESULT OF YOUR PHYSICAL HEALTH?**

(Mark one on each line)

		Yes	No
a	Cut down on the amount of time you spent on work or other activities	☐	☐
b	Accomplished less than you would like	☐	☐
c	Were limited in the kind of work or other activities	☐	☐
d	Had difficulty performing the work or other activities *(eg it took extra effort)*	☐	☐

Q5 **During the PAST FOUR WEEKS, have you had any of the following problems with your work or other regular daily activities AS A RESULT OF ANY EMOTIONAL PROBLEMS *(such as feeling depressed or anxious)*?**

(Mark one on each line)

		Yes	No
a	Cut down on the amount of time you spent on work or other activities	☐	☐
b	Accomplished less than you would like	☐	☐
c	Didn't do work or other activities as carefully as usual	☐	☐

Q6 **During the PAST FOUR WEEKS, to what extent have your PHYSICAL HEALTH OR EMOTIONAL PROBLEMS interfered with your normal social activities with family, friends, neighbours or groups?**

(Mark one only)

- Not at all ☐
- Slightly ☐
- Moderately ☐
- Quite a bit ☐
- Extremely ☐

Q7 **How much BODILY pain have you had during the PAST FOUR WEEKS?**

(Mark one only)

- No bodily pain ☐
- Very mild ☐
- Mild ☐
- Moderate ☐
- Severe ☐
- Very severe ☐

Q8 **During the PAST FOUR WEEKS, how much did PAIN interfere with your normal work *(including both work outside the home and housework)*?**

(Mark one only)

- ☐ Not at all
- ☐ A little bit
- ☐ Moderately
- ☐ Quite a bit
- ☐ Extremely

Q9 **For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the PAST FOUR WEEKS:**

(Mark one on each line)

		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
a	Did you feel full of life?	☐	☐	☐	☐	☐	☐
b	Have you been a very nervous person?	☐	☐	☐	☐	☐	☐
c	Have you felt so down in the dumps that nothing could cheer you up?	☐	☐	☐	☐	☐	☐
d	Have you felt calm and peaceful?	☐	☐	☐	☐	☐	☐
e	Did you have a lot of energy?	☐	☐	☐	☐	☐	☐
f	Have you felt down?	☐	☐	☐	☐	☐	☐
g	Did you feel worn out?	☐	☐	☐	☐	☐	☐
h	Have you been a happy person?	☐	☐	☐	☐	☐	☐
i	Did you feel tired?	☐	☐	☐	☐	☐	☐

Q10 **During the PAST FOUR WEEKS, how much of the time have your PHYSICAL HEALTH OR EMOTIONAL PROBLEMS interfered with your social activities *(like visiting friends, relatives, etc)*?**

(Mark one only)

- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

Q11 **How TRUE or FALSE is EACH of the following statements for you?**

(Mark one on each line)

		Definitely true	Mostly true	Don't know	Mostly false	Definitely false
a	I seem to get sick a little easier than other people	☐	☐	☐	☐	☐
b	I am as healthy as anybody I know	☐	☐	☐	☐	☐
c	I expect my health to get worse	☐	☐	☐	☐	☐
d	My health is excellent	☐	☐	☐	☐	☐

Q12 **How many times have you consulted the following people for YOUR OWN HEALTH in the LAST TWELVE MONTHS?**
(Mark one on each line)

		None	Once or twice	3 or 4 times	5 or 6 times	7-12 times	13-24 times	25 or more times
a	A family doctor or another General Practitioner (GP)	☐	☐	☐	☐	☐	☐	☐
b	A hospital doctor *(eg in outpatients or casualty)*	☐	☐	☐	☐	☐	☐	☐
c	A specialist doctor	☐	☐	☐	☐	☐	☐	☐

Q13 **Have you consulted the following people for YOUR OWN HEALTH in the LAST TWELVE MONTHS?**
(Mark one on each line)

		Yes	No
a	Physiotherapist	☐	☐
b	Counsellor / Psychologist / Social worker	☐	☐
c	A community nurse, practice nurse, or nurse practitioner	☐	☐
d	Optician / Optometrist	☐	☐
e	Dietitian	☐	☐
f	Podiatrist	☐	☐
g	Massage therapist	☐	☐
h	Naturopath / Herbalist	☐	☐
i	Chiropractor	☐	☐
j	Osteopath	☐	☐
k	Acupuncturist	☐	☐
l	Other alternative health practitioner *(eg aromatherapist, homeopath, reflexologist, iridologist)*	☐	☐

Q14 **How often have you used the following therapies for YOUR OWN HEALTH in the LAST TWELVE MONTHS?**
(Mark one on each line)

		Never	Rarely	Sometimes	Often
a	Vitamins / Minerals	☐	☐	☐	☐
b	Yoga or meditation	☐	☐	☐	☐
c	Herbal medicines	☐	☐	☐	☐
d	Aromatherapy oils	☐	☐	☐	☐
e	Chinese medicines	☐	☐	☐	☐
f	Prayer or spiritual healing	☐	☐	☐	☐
g	Other alternative therapies	☐	☐	☐	☐

Q15 **When you go to a General Practitioner:**
(Mark one on each line)

		Always	Most of the time	Some-times	Rarely or never
a	Do you go to the same place?	☐	☐	☐	☐
b	Do you usually see the same doctor?	☐	☐	☐	☐

■

Q16 **How would you rate the cost to you of your LAST visit to a General Practitioner?**
(Mark one only)

- ☐ No cost to me
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ Don't know

Q17 **Do you have a Health Care Card?**
This is a card that entitles you to discounts and assistance with medical expenses.
This is not the same as a Medicare card.
(Mark one only)

- ☐ Yes
- ☐ No

Q18a **Do you have private health insurance for HOSPITAL COVER?**
(Mark one only)

- ☐ Yes
- ☐ No – I am covered by Veterans' Affairs
- ☐ No – because I can't afford the cost
- ☐ No – because I don't think you get value for money
- ☐ No – because I don't think I need it
- ☐ No – other reason

Q18b **Do you have private health insurance for ANCILLARY services (eg dental, physiotherapy)?**
(Mark one only)

- ☐ Yes
- ☐ No – I am covered by Veterans' Affairs
- ☐ No – because I can't afford the cost
- ☐ No – because I don't think you get value for money
- ☐ No – because I don't think I need it
- ☐ No - because the services are not available where I live
- ☐ No – other reason

Q19 **Have you been admitted to hospital in the LAST TWELVE MONTHS?**
(Mark one only)

- ☐ No
- ☐ Yes, day only
- ☐ Yes, spent at least one night

Q20 **When did you last have:**
(Mark one on each line)

		In the last 2 years	2-5 years ago	More than 5 years ago	Never	Don't know
a	A Pap test?	☐	☐	☐	☐	☐
b	A mammogram?	☐	☐	☐	☐	☐

Q21 **Have you EVER had an abnormal result from:** *(Mark one on each line)*

		Yes	No	Don't know
a	A Pap test?	☐	☐	☐
b	A mammogram?	☐	☐	☐

Q22 **In the PAST THREE YEARS, have you:** *(Mark all that apply on each line)*

		Doctor	Nurse	Other	Not checked
a	Had your blood pressure checked?	☐	☐	☐	☐
b	Had your cholesterol checked?	☐	☐	☐	☐
c	Had your blood sugar level checked?	☐	☐	☐	☐
d	Had your skin checked *(eg spots, lesions, moles)*?	☐	☐	☐	☐

Q23 **In the PAST THREE YEARS, have you:** *(Mark one on each line)*

		Yes	No
a	Had your breasts examined by a doctor or nurse?	☐	☐
b	Carried out *regular monthly* breast self examination?	☐	☐
c	Had a bone density test?	☐	☐
d	Had a test for bowel cancer?	☐	☐
e	Had a reminder from your general practice to have a screening test *(eg blood pressure, cholesterol, blood sugar, skin)?*	☐	☐

Q24 **In the PAST THREE YEARS, have you received advice/information about lifestyle changes from any of these sources?** *(Mark one on each line)*

		Yes	No
a	A doctor	☐	☐
b	A nurse	☐	☐
c	Other health professional *(eg physiotherapist, naturopath)*	☐	☐
d	Program or organisation *(eg weight loss program, gym, self help group)*	☐	☐
e	Books, magazines	☐	☐
f	The internet	☐	☐
g	Television	☐	☐
h	Radio	☐	☐
i	Family or friends	☐	☐
j	Private health fund	☐	☐

Q25 **Are you CURRENTLY taking:** *(Mark one on each line)*

		Yes	No
a	The oral contraceptive pill?	☐	☐
b	Hormone Replacement Therapy (HRT)?	☐	☐

Q26 **Have you:** *(Mark one on each line)*

		Yes	No	
a	Had a hysterectomy?	☐ ← If Yes, go to Q29	☐	
b	Had a period or menstrual bleeding in the last 12 months?	☐	☐	← If No, go to Q28
c	Had a period or menstrual bleeding in the last 3 months?	☐	☐	

Q27 **Compared with twelve months ago, are your periods:** *(Mark one only)*

- Less frequent ☐
- About the same ☐
- More frequent ☐
- Changeable ☐

Q28 **If you have reached menopause, at what age did your periods completely stop?**

(Please write the age in the box) ☐☐ years Not applicable ☐

Q29 **Have you ever had Gestational Diabetes (diabetes during pregnancy)?**
(Mark one only)

- ☐ Yes
- ☐ No

Q30 **Thinking about your own health care, how would you rate the following:**
(Mark one on each line)

		Excellent	Very good	Good	Fair	Poor	Don't know
a	Access to medical specialists if you need them	☐	☐	☐	☐	☐	☐
b	Access to a hospital if you need it	☐	☐	☐	☐	☐	☐
c	Access to medical care in an emergency	☐	☐	☐	☐	☐	☐
d	Access to after-hours medical care	☐	☐	☐	☐	☐	☐
e	Access to a GP who bulk bills	☐	☐	☐	☐	☐	☐
f	Access to a female GP	☐	☐	☐	☐	☐	☐
g	Hours when a GP is available	☐	☐	☐	☐	☐	☐
h	Number of GPs you have to choose from	☐	☐	☐	☐	☐	☐
i	Ease of seeing the GP of your choice	☐	☐	☐	☐	☐	☐
j	How long you wait to get a GP appointment	☐	☐	☐	☐	☐	☐
k	The outcomes of your medical care *(how much you are helped)*	☐	☐	☐	☐	☐	☐
l	Ease of obtaining a mammogram	☐	☐	☐	☐	☐	☐
m	Ease of obtaining a Pap test	☐	☐	☐	☐	☐	☐
n	Access to a counselling service if you need it	☐	☐	☐	☐	☐	☐

Q31 **In the LAST TWELVE MONTHS have you consulted a dentist?** *(Mark one only)*

- ☐ No, I did not need to see a dentist
- ☐ No, because there was no dentist available locally
- ☐ No, I could not get there because of travel difficulties
- ☐ No, because it would cost more than I could afford
- ☐ No, I did not go to the dentist because of another reason
- ☐ Yes, I saw a dentist

Q32 **How would you rate the overall condition of your teeth, dentures or gums?**
(Mark one only)

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor

Q33 **There are 16 teeth, including wisdom teeth in the upper jaw. How many teeth do you have remaining in your UPPER jaw?**

(Please write number in boxes) ☐☐

Q34 **There are 16 teeth, including wisdom teeth in the lower jaw. How many teeth do you have remaining in your LOWER jaw?**

(Please write number in boxes) ☐☐

Q35 **Do you wear a denture or false teeth in your upper jaw?** *(Mark one only)*

Yes ☐
No ☐

Q36 **Do you wear a denture or false teeth in your lower jaw?** *(Mark one only)*

Yes ☐
No ☐

Q37 **In the LAST TWELVE MONTHS have you:** *(Mark all that apply)*

		Yes
a	Slipped, tripped or stumbled?	☐
b	Had a fall to the ground?	☐
c	Been injured as a result of a fall?	☐
d	Needed to seek medical attention for an injury from a fall?	☐
e	Had any other injury from an accident at your home?	☐
f	Broken or fractured any bone/s?	☐
g	None of the above	☐

Q38 **In the PAST THREE YEARS, have you been diagnosed or treated for:** *(Mark all that apply)*

		Yes, in the past 3 years
a	Diabetes *(high blood sugar)*	☐
b	Impaired glucose tolerance	☐
c	Osteoarthritis	☐
d	Rheumatoid arthritis	☐
e	Other arthritis	☐
f	Heart disease *(including heart attack, angina)*	☐
g	Hypertension *(high blood pressure)*	☐
h	Stroke	☐
i	Low iron level *(iron deficiency or anaemia)*	☐
j	Asthma	☐
k	Bronchitis / emphysema	☐
l	Osteoporosis	☐
m	Breast cancer	☐
n	Cervical cancer	☐
o	Skin cancer *(including melanoma)*	☐
p	Other cancer *(please specify on page 30)*	☐
q	Depression	☐
r	Anxiety / nervous disorder	☐
s	Other psychiatric disorder	☐
t	Chronic Fatigue Syndrome	☐
u	Sexually transmitted infection *(eg genital herpes or warts, chlamydia)*	☐
v	Other major illness or disability *(please specify on page 30)*	☐
w	None of these conditions	☐

Q39 **Compared to when you were in your twenties, how good are you at:**

(Mark one on each line)

		Much better now	Somewhat better now	About the same	Somewhat worse now	Much worse now
a	Remembering the name of a person just introduced to you?	☐	☐	☐	☐	☐
b	Recalling telephone numbers or other numbers that you use on a daily or weekly basis?	☐	☐	☐	☐	☐
c	Recalling where you put objects *(such as keys)* in your home?	☐	☐	☐	☐	☐
d	Remembering specific facts from a newspaper or magazine article you have just finished reading?	☐	☐	☐	☐	☐
e	Remembering the item(s) you intend to buy when you arrive at the shops?	☐	☐	☐	☐	☐
f	In general, how would you describe your memory compared to when you were in your twenties?	☐	☐	☐	☐	☐

Q40 **In the PAST THREE YEARS, have you had any of the following operations or procedures**

(Mark all that apply)

		Yes, in the past 3 years
a	Both ovaries removed	☐
b	Repair of prolapsed vagina, bladder or bowel?	☐
c	Endometrial ablation *(removal of the lining of the uterus)*	☐
d	Joint replacement *(eg hip, knee)*	☐
e	Mastectomy *(removal of one or both breasts)*	☐
f	Lumpectomy *(removal of lump from breasts)*	☐
g	Removal of skin cancer	☐
h	Any cancer surgery *(other than skin or breast)*	☐
i	Chemotherapy or radiotherapy for any cancer	☐
j	Breast biopsy *(taking a sample of breast tissue)*	☐
k	Hysteroscopy *(investigative procedure to examine the uterus)*	☐
l	Cholecystectomy *(gall bladder removed)*	☐
m	Gastroscopy / colonoscopy	☐
n	None of these	☐

Q41 **Do you have any of these sleeping problems?**

(Mark all that apply)

		Yes
a	Waking up in the early hours of the morning	☐
b	Lying awake for most of the night	☐
c	Taking a long time to get to sleep	☐
d	Worry keeping you awake at night	☐
e	Sleeping badly at night	☐
f	None of these problems	☐

Q42 **In the PAST FOUR WEEKS, have you taken any:**

(Mark one on each line)

		Yes	No	
a	Medications prescribed by a doctor?	☐	☐	If No to both, go to Q44
b	Medications / vitamins / supplements or herbal therapies bought without a prescription at the chemist, supermarket or health food shop?	☐	☐	

Q43 **Please write down the names of all your medications, vitamins, supplements or herbal therapies. Where possible, copy names from the packets. (Please write in block letters)**

Q44 **In the LAST 12 MONTHS, have you had any of the following:**
(Mark one on each line in column A.
For all that apply also answer column B.)

		A				B
		Never	Rarely	Some-times	Often	For the problems you had, DID you seek help? Mark here if you DID seek help
a	Allergies, hayfever, sinusitis	☐	☐	☐	☐	☐
b	Breathing difficulty	☐	☐	☐	☐	☐
c	Indigestion / heartburn	☐	☐	☐	☐	☐
d	Chest pain	☐	☐	☐	☐	☐
e	Headaches / migraines	☐	☐	☐	☐	☐
f	Severe tiredness	☐	☐	☐	☐	☐
g	Stiff or painful joints	☐	☐	☐	☐	☐
h	Back pain	☐	☐	☐	☐	☐
i	Urine that burns or stings	☐	☐	☐	☐	☐
j	Heamorrhoids *(piles)*	☐	☐	☐	☐	☐
k	Other bowel problems	☐	☐	☐	☐	☐
l	Vaginal discharge or irritation	☐	☐	☐	☐	☐
m	Hot flushes	☐	☐	☐	☐	☐
n	Night sweats	☐	☐	☐	☐	☐
o	Eyesight problems	☐	☐	☐	☐	☐
p	Leaking urine	☐	☐	☐	☐	☐
q	Mouth, teeth or gum problems	☐	☐	☐	☐	☐
r	Avoided eating some foods because of problems with your teeth, mouth or dentures	☐	☐	☐	☐	☐
s	Toothache	☐	☐	☐	☐	☐
t	Hearing problems	☐	☐	☐	☐	☐
u	Depression	☐	☐	☐	☐	☐
v	Anxiety	☐	☐	☐	☐	☐
w	Episodes of intense anxiety *(eg panic attacks)*	☐	☐	☐	☐	☐
x	Palpitations *(feeling that your heart is racing or fluttering in your chest)*	☐	☐	☐	☐	☐

Q45 **In the PAST WEEK, have you been feeling that life isn't worth living?** *(Mark one only)*

Yes ☐
No ☐

Q46 **In the PAST 6 MONTHS, have you EVER deliberately hurt yourself or done anything that you knew might have harmed or even killed you?** *(Mark one only)*

Yes ☐
No ☐

If you answered YES to either of the last 2 questions, you might like to talk to someone about how you are feeling. You could ring Lifeline on 131114 (local call).

■ *women's health is about coping with stress*

Q47 **Over the LAST TWELVE MONTHS, how stressed have you felt about the following areas of your life:** *(Mark one on each line)*

		Not applicable	Not at all stressed	Somewhat stressed	Moderately stressed	Very stressed	Extremely stressed
a	Own health		☐	☐	☐	☐	☐
b	Health of family members	☐	☐	☐	☐	☐	☐
c	Work / Employment	☐	☐	☐	☐	☐	☐
d	Living arrangements		☐	☐	☐	☐	☐
e	Study	☐	☐	☐	☐	☐	☐
f	Money		☐	☐	☐	☐	☐
g	Relationship with parents	☐	☐	☐	☐	☐	☐
h	Relationship with partner / spouse	☐	☐	☐	☐	☐	☐
i	Relationship with children	☐	☐	☐	☐	☐	☐
j	Relationship with other family members	☐	☐	☐	☐	☐	☐

Q48 **How much do you agree or disagree with each of the following statements?**
(Mark one on each line)

		Disagree strongly	Disagree	Disagree slightly	Agree slightly	Agree	Agree strongly
a	At home, I feel I have control over what happens in most situations	☐	☐	☐	☐	☐	☐
b	I feel that what happens in my life is often determined by factors beyond my control	☐	☐	☐	☐	☐	☐
c	Over the next 5-10 years I expect to have more positive than negative experiences	☐	☐	☐	☐	☐	☐
d	I often have the feeling that I am being treated unfairly	☐	☐	☐	☐	☐	☐
e	In the past 10 years my life has been full of changes without my knowing what will happen next	☐	☐	☐	☐	☐	☐
f	I gave up trying to make big improvements or changes in my life a long time ago	☐	☐	☐	☐	☐	☐

Q49 **Thinking about your current approach to life, please indicate how much you think each statement describes you:**
(Mark one on each line)

		Strongly disagree	Disagree	Neutral	Agree	Strongly agree
a	In uncertain times, I usually expect the best	☐	☐	☐	☐	☐
b	If something can go wrong for me, it will	☐	☐	☐	☐	☐
c	I'm always optimistic about my future	☐	☐	☐	☐	☐
d	I hardly ever expect things to go my way	☐	☐	☐	☐	☐
e	I rarely count on good things happening to me	☐	☐	☐	☐	☐
f	Overall, I expect more good things to happen to me than bad	☐	☐	☐	☐	☐

■

Q50 **What is your Postcode?**

a What is your RESIDENTIAL postcode? *(where you live)*

b What is the postcode of your POSTAL ADDRESS? *(if different from residential)*

Q51 **Which of the following events have you experienced?**
(Mark all that apply)

		A Yes, in the last 12 months	B Yes, more than 12 months ago
a	Major personal illness	☐	☐
b	Major personal injury or involvement in a serious accident	☐	☐
c	Major personal achievement	☐	☐
d	Birth of a grandchild	☐	☐
e	Major surgery *(not including dental work)*	☐	☐
f	Going through menopause	☐	☐
g	Major decline in health of spouse or partner	☐	☐
h	Major decline in health of other close family member or close friend	☐	☐
i	Starting a new, close personal relationship	☐	☐
j	Infidelity of spouse or partner	☐	☐
k	Break-up of a close personal relationship	☐	☐
l	Divorce	☐	☐
m	Major conflict with teenage or older children	☐	☐
n	Child or other family member leaving home *(due to marriage, to attend university etc)*	☐	☐
o	Death of a spouse or partner	☐	☐
p	Death of a child	☐	☐
q	Death of other close family member	☐	☐
r	Death of close friend	☐	☐
s	Changing your type of work / hours / conditions / responsibilities at work	☐	☐
t	Retirement	☐	☐
u	Your spouse or partner retiring from work	☐	☐
v	Being made redundant	☐	☐
w	Your spouse / partner being made redundant	☐	☐
x	Decreased income	☐	☐
y	Moving house	☐	☐
z	Natural disaster (*fire, flood, drought, earthquake etc*) or house fire	☐	☐
aa	Major loss or damage to personal property	☐	☐
bb	Being robbed	☐	☐
cc	Being pushed, grabbed, shoved, kicked or hit	☐	☐
dd	Being forced to take part in unwanted sexual activity	☐	☐
ee	Legal troubles or involved in a court case	☐	☐
ff	Family member / close friend being arrested / in gaol	☐	☐
gg	You or a family member involved in problem gambling	☐	☐
hh	None of these events	☐	

Q52 **Below is a list of the ways you might have felt or behaved. Please indicate how often you have felt this way DURING THE LAST WEEK.**
(Mark one on each line)

		Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of the time (3-4 days)	Most or all of the time (5-7 days)
a	I was bothered by things that don't usually bother me	☐	☐	☐	☐
b	I had trouble keeping my mind on what I was doing	☐	☐	☐	☐
c	I felt depressed	☐	☐	☐	☐
d	I felt that everything I did was an effort	☐	☐	☐	☐
e	I felt hopeful about the future	☐	☐	☐	☐
f	I felt fearful	☐	☐	☐	☐
g	My sleep was restless	☐	☐	☐	☐
h	I was happy	☐	☐	☐	☐
i	I felt lonely	☐	☐	☐	☐
j	I could not "get going"	☐	☐	☐	☐
k	I felt terrific	☐	☐	☐	☐

Q53 **In the past month:** *(Mark one on each line)*

		Yes	No
a	Have you felt keyed up or on edge?	☐	☐
b	Have you been worrying a lot?	☐	☐
c	Have you been irritable?	☐	☐
d	Have you had difficulty relaxing?	☐	☐
e	Have you been sleeping poorly?	☐	☐
f	Have you had headaches or neck aches?	☐	☐
g	Have you had any of the following: trembling, tingling, dizzy spells, sweating, diarrhoea or needing to pass urine more often than normal?	☐	☐
h	Have you been worried about your health?	☐	☐
i	Have you had difficulty falling asleep?	☐	☐

Q54 **Do you regularly NEED help with daily tasks because of long-term illness, disability or frailty *(eg personal care, getting around, preparing meals etc)*?**
(Mark one only)

Yes ☐
No ☐

The following sections are about other health habits, time use and your relationships.

Often there are no "right" or "wrong" answers – we are interested only in your opinion or feelings.

If you feel uncomfortable about answering a question, just leave it and go on to the next one, but please try to finish the survey if you can.

You may like to take a break now and do the second part later.

■ *women's health is about healthy weight and shape*

Q55 **a** **How much do you weigh?** *(no clothes or shoes)*

☐☐☐ **kg** **OR** ☐☐ **stones** ☐☐ **pounds**

b **How tall are you without shoes?**

☐☐☐ **cm** **OR** ☐☐ **feet** ☐☐ **inches**

Q56 **What is your waist measurement?**

*Please measure your waist while in your underwear. If possible, get someone to help you take the measurement. Find your navel (belly button) and measure at that level. Be careful not to have the tape too tight. You should be able to slip your little finger under it comfortably. Write the measurement to the **nearest** centimetre (or inch if this is the only measure you have available).*

☐☐☐ **cm** **OR** ☐☐ **inches**

Q57 **In the LAST THREE YEARS, have you:**

(Mark one on each line)

		Yes	No
a	Lost 5 kg or more on purpose?	☐	☐
b	Lost 5 kg or more for any other reason?	☐	☐
c	Gained 5 kg or more?	☐	☐

Q58 **Have you used any of these methods to lose weight or to control your weight or shape in the LAST TWELVE MONTHS?**

(Mark one on each line)

		Yes	No
a	Commercial weight loss programs *(eg Weight Watchers, Lite n' Easy, Sureslim, Jenny Craig)*	☐	☐
b	Meal replacements or slimming products *(eg OPTIFAST, Herbalife)*	☐	☐
c	Exercise	☐	☐
d	Cut down on the size of meals or between meal snacks	☐	☐
e	Cut down on fats *(low fat)* and / or sugars	☐	☐
f	Low glycaemic index (GI) diet	☐	☐
g	Diet book diets *(eg Atkins, Zone, CSIRO diet, Liver Cleansing diet)*	☐	☐
h	Laxatives, diuretics or diet pills *(eg Xenical, Reductil)*	☐	☐
i	Fasting	☐	☐
j	Smoking	☐	☐
k	Other *(please specify on page 30)*	☐	☐

■

Q59 **How often do you usually drink alcohol?**
(Mark one only)

- I have never drunk alcohol in my life ☐
- I never drink alcohol, but I have in the past ☐ → Go to Q62
- I drink rarely ☐
- Less than once a week ☐
- On 1 or 2 days a week ☐
- On 3 or 4 days a week ☐
- On 5 or 6 days a week ☐
- Every day ☐

Q60 **On a day when you drink alcohol, how many drinks do you usually have?**
(Mark one only)

- 1 or 2 drinks per day ☐
- 3 or 4 drinks per day ☐
- 5 to 8 drinks per day ☐
- 9 or more drinks per day ☐

Q61 **How often do you have five or more drinks of alcohol on one occasion?**
(Mark one only)

- Never ☐
- Less than once a month ☐
- About once a month ☐
- About once a week ☐
- More than once a week ☐

Q62 **The next question is about your alcohol consumption during different stages of your life. On average, how many drinks did you usually drink PER WEEK in your:**
(Mark one on each line)

		No alcohol	1-7 drinks	8-14 drinks	15 or more drinks
a	Late teens	☐	☐	☐	☐
b	20s	☐	☐	☐	☐
c	30s	☐	☐	☐	☐
d	40s	☐	☐	☐	☐
e	50s	☐	☐	☐	☐

Q63 **How many glasses / cups of non-alcoholic drinks do you usually have each day**
(eg juice, tea, coffee, water, milk, etc)?
(Mark one only)

- 0 - 2 glasses ☐
- 3 - 5 glasses ☐
- 6 - 8 glasses ☐
- 9 or more glasses ☐

Questions 64 to 74 are modified from the Cancer Council of Victoria Food Frequency Questionnaire and are used with permission.

This section is about your **usual** eating habits over the **LAST TWELVE MONTHS**. Where possible, give only **one answer per question** for the type of food you eat **most often** *(if you can't decide which type you have most often, answer for the types you usually eat)*.

Q64 **How many pieces of FRESH fruit do you usually eat per day?**
(Count 1/2 cup diced fruit, berries or grapes as one piece)

- I don't eat fruit ☐
- Less than 1 piece of fruit per day ☐
- 1 piece of fruit per day ☐
- 2 pieces of fruit per day ☐
- 3 pieces of fruit per day ☐
- 4 pieces of fruit per day ☐
- 5 or more pieces of fruit per day ☐

Q65 **How many DIFFERENT vegetables do you usually eat per day?**
(Count all types, fresh, frozen or tinned)

- Less than 1 vegetable per day ☐
- 1 vegetable per day ☐
- 2 vegetables per day ☐
- 3 vegetables per day ☐
- 4 vegetables per day ☐
- 5 vegetables per day ☐
- 6 or more vegetables per day ☐

Q66 **How many SERVES of vegetables do you usually eat each day?**
(A serve = half a cup of cooked vegetables or a cup of salad vegetables)

- None ☐
- 1 serve ☐
- 2-3 serves ☐
- 4 serves ☐
- 5 serves or more ☐

Q67 **What type of milk do you usually use?**

- **a** None ☐
- **b** Full cream milk ☐
- **c** Reduced fat milk ☐
- **d** Skim milk ☐
- **e** Soya milk ☐

Q68 **How much milk do you usually use per day?** *(Include flavoured milk and milk added to tea, coffee, cereal etc)*

- None ☐
- Less than 250ml *(1 large cup or mug)* ☐
- Between 250ml and 500ml *(1-2 cups)* ☐
- Between 500ml and 750ml *(2-3 cups)* ☐
- 750ml *(3 cups)* or more ☐

Q69 **What type of bread do you usually eat?**

- **a** I don't eat bread ☐
- **b** High fibre white bread ☐
- **c** White bread ☐
- **d** Wholemeal bread ☐
- **e** Rye bread ☐
- **f** Multi-grain bread ☐

Q70 **How many slices of bread do you usually eat per day?** *(Include all types, fresh or toasted and count one bread roll as 2 slices)*

- Less than 1 slice per day ☐
- 1 slice per day ☐
- 2 slices per day ☐
- 3 slices per day ☐
- 4 slices per day ☐
- 5-7 slices per day ☐
- 8 or more slices per day ☐

Q71 **Which spread do you usually put on bread?**

- **a** I don't use any fat spread ☐
- **b** Margarine of any kind ☐
- **c** Polyunsaturated margarine ☐
- **d** Monounsaturated margarine ☐
- **e** Butter and margarine blends ☐
- **f** Butter ☐

Q72 **On average, how many eggs do you usually eat per week?**

- I don't eat eggs ☐
- Less than 1 egg per week ☐
- 1 to 2 eggs per week ☐
- 3 to 5 eggs per week ☐
- 6 or more eggs per week ☐

Q73 **What types of cheese do you usually eat?**

- **a** I don't eat cheese ☐
- **b** Hard cheeses eg parmesan, romano ☐
- **c** Firm cheeses eg cheddar, edam ☐
- **d** Soft cheeses eg camembert, brie ☐
- **e** Ricotta or cottage cheese ☐
- **f** Cream cheese ☐
- **g** Low fat cheese ☐

Q74a **Over the LAST 12 MONTHS, on average, how often did you eat the following foods?**
(Mark one on each line)

		Never	Less than once a week	Once a week or more
a	All Bran	☐	☐	☐
b	Sultana Bran™, Fibre Plus™, Branflakes™	☐	☐	☐
c	Weet Bix™, Vita Brits™, Weeties™	☐	☐	☐
d	Cornflakes, Nutrigrain™, Special K™	☐	☐	☐
e	Porridge	☐	☐	☐
f	Muesli	☐	☐	☐
g	Rice	☐	☐	☐
h	Pasta or noodles (*include lasagne*)	☐	☐	☐
i	Nuts	☐	☐	☐
j	Peanut butter or peanut paste	☐	☐	☐
k	Vegemite™, Marmite™, Promite™	☐	☐	☐
l	Tinned or frozen fruit (*any kind*)	☐	☐	☐
m	Oranges or other citrus fruit	☐	☐	☐
n	Apples	☐	☐	☐
o	Pears	☐	☐	☐
p	Bananas	☐	☐	☐
q	Watermelon, rockmelon, honey dew etc	☐	☐	☐
r	Pineapple	☐	☐	☐
s	Strawberries	☐	☐	☐
t	Apricots	☐	☐	☐
u	Peaches or nectarines	☐	☐	☐
v	Mango or paw paw	☐	☐	☐
w	Avocado	☐	☐	☐
x	Fruit or vegetable juice	☐	☐	☐
y	Potatoes cooked without fat	☐	☐	☐
z	Tomato sauce, tomato paste or dried tomatoes	☐	☐	☐
aa	Fresh or tinned tomatoes	☐	☐	☐
bb	Peppers (capsicum)	☐	☐	☐
cc	Lettuce, endive or other salad greens	☐	☐	☐
dd	Cucumber	☐	☐	☐
ee	Celery	☐	☐	☐
ff	Beetroot	☐	☐	☐
gg	Carrots	☐	☐	☐
hh	Cabbage or brussels sprouts	☐	☐	☐
ii	Cauliflower	☐	☐	☐
jj	Broccoli	☐	☐	☐
kk	Silverbeet or spinach	☐	☐	☐
ll	Peas	☐	☐	☐
mm	Green beans	☐	☐	☐

		Never	Less than once a week	Once a week or more
nn	Bean sprouts or alfalfa sprouts	☐	☐	☐
oo	Baked beans	☐	☐	☐
pp	Soya beans, soy bean curd or tofu	☐	☐	☐
qq	Other beans (*include chick peas, lentils etc*)	☐	☐	☐
rr	Pumpkin	☐	☐	☐
ss	Onions or leeks	☐	☐	☐
tt	Garlic (*not garlic tablets*)	☐	☐	☐
uu	Mushrooms	☐	☐	☐
vv	Zucchini	☐	☐	☐

Q74b **Over the LAST 12 MONTHS, on average, how often did you eat the following foods?**
(Mark one on each line)

		Never	Less than once a week	Once a week	2-4 times per week	5 or more times per week
a	Cheese	☐	☐	☐	☐	☐
b	Ice cream	☐	☐	☐	☐	☐
c	Yoghurt	☐	☐	☐	☐	☐
d	Beef	☐	☐	☐	☐	☐
e	Veal	☐	☐	☐	☐	☐
f	Chicken	☐	☐	☐	☐	☐
g	Lamb	☐	☐	☐	☐	☐
h	Pork	☐	☐	☐	☐	☐
i	Fish, steamed, grilled or baked	☐	☐	☐	☐	☐
j	Fish, tinned (*salmon, tuna, sardines etc*)	☐	☐	☐	☐	☐

Q75 **How often do you currently smoke cigarettes or any tobacco products?**
(Mark one only)

- Daily ☐ → Go to Q76
- At least weekly (but not daily) ☐ → Go to Q77
- Less often than weekly ☐
- Not at all ☐ → Go to Q78

Q76 **If you smoke daily, on average how many cigarettes do you smoke EACH DAY?**
PRINT the number in the box

☐☐☐ cigarettes per day → Go to Q80

Q77 **If you smoke, but not daily, on average how many cigarettes do you smoke PER WEEK?**
PRINT the number in the box

☐☐☐ cigarettes per week

Q78 **Have you ever smoked DAILY?**
(Mark one only)

- Yes ☐
- No ☐ → If No, go to Q80

Q79 **At what age did you finally stop smoking DAILY?**
PRINT age in the box

☐☐ years old

Think about all of the time you spend sitting during EACH DAY while at home, at work, while getting from place to place or during your spare time.

Q80 **How many hours EACH DAY do you typically spend sitting down while doing things like visiting friends, driving, reading, watching television or working at a desk or computer?**

a On a usual **WEEK DAY** ☐☐ hours

b On a usual **WEEKEND DAY** ☐☐ hours

The next two questions are about the amount of physical activity you did LAST WEEK.

Q81 **How many *times* did you do each type of activity LAST WEEK?**
*Only count the number of times when the activity lasted for 10 minutes or more. (If you did **not** do an activity, please write "0" in the box)*

a **Walking briskly** *(for recreation or exercise, or to get from place to place)* ☐☐ times

b **Moderate leisure activity** *(like social tennis, moderate exercise classes, recreational swimming, dancing)* ☐☐ times

c **Vigorous leisure activity** *(that makes you breathe harder or puff and pant like aerobics, competitive sport, vigorous cycling, running, swimming)* ☐☐ times

d **Vigorous household or garden chores** *(that make you breathe harder or puff and pant)* ☐☐ times

Q82 **If you add up all the times you spent in each activity LAST WEEK, how much time did you spend ALTOGETHER doing each type of activity?**
*(If you did **not** do an activity, please write "0" in the box)*

a **Walking briskly** *(for recreation or exercise, or to get from place to place)* ☐☐ hours ☐☐ minutes

b **Moderate leisure activity** *(like social tennis, moderate exercise classes, recreational swimming, dancing)* ☐☐ hours ☐☐ minutes

c **Vigorous leisure activity** *(that makes you breathe harder or puff and pant like aerobics, competitive sport, vigorous cycling, running, swimming)* ☐☐ hours ☐☐ minutes

d **Vigorous household or garden chores** *(that make you breathe harder or puff and pant)* ☐☐ hours ☐☐ minutes

Q83 **This question asks about your physical activity in your MAIN job (this could be paid work, unpaid work, caring etc - whatever you spend most of your "working day" doing). On a usual working day, how often do you do each of the following while you are at work?** *(Mark one on each line)*

		All of the time	Most of the time	Some of the time	A little of the time	None of the time
a	Sitting	☐	☐	☐	☐	☐
b	Standing	☐	☐	☐	☐	☐
c	Walking	☐	☐	☐	☐	☐
d	Heavy labour or physically demanding work	☐	☐	☐	☐	☐

women's health is about how you spend your time

Q84 **What is your date of birth?**

☐☐ Day ☐☐ Month 19 ☐☐ Year

Q85 **In a USUAL WEEK, how much time in total do you spend doing the following things?**
(Mark one on each line)

		I don't do this activity	1-15 hours	16-24 hours	25-34 hours	35-40 hours	41-48 hours	49 hours or more
a	Full time paid work	☐	☐	☐	☐	☐	☐	☐
b	Part-time paid work	☐	☐	☐	☐	☐	☐	☐
c	Casual paid work	☐	☐	☐	☐	☐	☐	☐
d	Home duties *(own / family home)*	☐	☐	☐	☐	☐	☐	☐
e	Work without pay *(eg family business)*	☐	☐	☐	☐	☐	☐	☐
f	Looking for work	☐	☐	☐	☐	☐	☐	☐
g	Unpaid voluntary work	☐	☐	☐	☐	☐	☐	☐
h	Active leisure *(eg walking, exercise, sport)*	☐	☐	☐	☐	☐	☐	☐
i	Passive leisure *(eg TV, music, reading, relaxing)*	☐	☐	☐	☐	☐	☐	☐
j	Studying	☐	☐	☐	☐	☐	☐	☐

Q86 **Managing time is often difficult. How often do you feel:**
(Mark one on each line)

		Every day	A few times a week	About once a week	About once a month	Never
a	That you are rushed, pressured, too busy?	☐	☐	☐	☐	☐
b	That you have time on your hands that you don't know what to with?	☐	☐	☐	☐	☐

Q87 **Are you happy with your share of the following tasks and activities?**
(Mark one on each line)

		Happy the way it is	Would like other household members to do more	Would prefer another arrangement	Not applicable (don't do this)
a	Domestic work *(shopping, cooking, cleaning etc)*	☐	☐	☐	☐
b	Childcare	☐	☐	☐	☐
c	Caring for another adult *(who is elderly / disabled / sick)*	☐	☐	☐	☐
d	Other household work *(gardening, home / car maintenance)*	☐	☐	☐	☐

Q88 **Do you regularly provide (unpaid) care for grandchildren or other people's children?**
(Mark one only)

- Yes, daily ☐
- Yes, weekly ☐
- Yes, occasionally ☐
- No, never ☐

Q89 **Do you regularly provide care or assistance *(eg personal care, transport)* to any other person because of their long-term illness, disability or frailty?**
(Mark one on each line)

		Yes	No	
a	For someone who lives with you	☐	☐	If No to both, go to Q93
b	For someone who lives elsewhere	☐	☐	

Q90 **How many people with long-term illness, disability or frailty do you regularly provide care for?**
(Mark one only)

- One person ☐
- Two people ☐
- More than two people ☐

Q91 **How often in total do you provide this care or assistance?**
(Mark one only)

- Every day ☐
- Several times a week ☐
- Once a week ☐
- Once every few weeks ☐
- Less often ☐

Q92 **How much time do you usually spend providing such care or assistance on each occasion?**
(Mark one only)

- All day and night ☐
- All day ☐
- All night ☐
- Several hours ☐
- About an hour ☐

women's health *is about the kinds of work you do and your plans for the future*

Q93 **Do you normally do any of the following kinds of paid work?**
(Mark all that apply)

		Yes
a	Paid shift work	☐
b	Paid work at night	☐
c	Paid work from home	☐
d	Self employment	☐
e	Paid work in more than one job	☐
f	Casual paid work	☐
g	Paid work involving none of the above	☐
h	I don't do any paid work	☐

Q94 **We would like to know YOUR and YOUR PARTNER'S main occupation NOW:**
(Mark one in each column)

	A self	B partner
Manager or administrator *(eg magistrate, farm manager, media producer, school principal)*	☐	☐
Professional *(eg registered nurse, allied health professional, teacher, artist)*	☐	☐
Associate professional *(eg office manager, branch manager, shop manager, retail buyer, youth worker, police officer)*	☐	☐
Tradesperson or related worker *(eg cook, dressmaker, hairdresser, gardener, florist)*	☐	☐
Advanced clerical or service worker *(eg credit officer, radio despatcher, personal assistant, flight attendant, law clerk)*	☐	☐
Intermediate clerical, sales or service worker *(eg accounts clerk, checkout supervisor, data entry operator, child care worker, nursing assistant, hospitality worker)*	☐	☐
Intermediate production or transport worker *(eg machine operator, bus driver)*	☐	☐
Elementary clerical, sales or service worker *(eg filing / mail clerk, parking inspector, sales assistant, telemarketer, housekeeper)*	☐	☐
Labourer or related worker *(eg cleaner, factory worker, kitchen hand, fast food cook)*	☐	☐
No paid job	☐	☐
Don't know or **no partner**		☐

Q95 **How do you manage on the income you have available?**
(Mark one only)

- It is impossible ☐
- It is difficult all the time ☐
- It is difficult some of the time ☐
- It is not too bad ☐
- It is easy ☐

Q96 **Are there people who do NOT live with you who are dependent on your household income?**
(Mark one only)

- No ☐
- Yes, one ☐
- Yes, more than one ☐

Q97 **Women's employment patterns have changed a lot over recent years. We are keen to learn how women see retirement in their own lives. Please indicate the following description that best fits your life now. If you want to add more please write this on page 30.**
(Mark one only)

- I am not retired at all ☐
- I am partially retired ☐
- I am completely retired from paid work ☐
- I gave up paid work over 20 years ago ☐
- I have never been in paid work ☐

Q98 **When did you retire or give up work completely?**

(Print year in the box) ☐☐☐☐ Not applicable ☐

Q99 **At what age do you expect to retire (completely) from the paid workforce?**

(Print age, in whole years, in the box) ☐☐

- Do not expect to ever retire ☐
- Have already retired ☐
- Don't know ☐

Q100 **You have said when you expect to retire, but if you had the choice, at what age would you like to retire (completely) from the paid workforce?**

(Print age, in whole years, in the box) ☐☐

- Do not expect to ever retire ☐
- Have already retired ☐
- Don't know ☐

Q101a **What are your CURRENT sources of income?**
(Mark all that apply)

		Yes
a	Age pension / Service pension / Widow's pension / War Widow's pension	☐
b	Other government pension or allowance	☐
c	Lump sum superannuation payout	☐
d	A pension or annuity purchased with superannuation or some other funds	☐
e	Income from savings and investments *(such as shares and property)*	☐
f	Income from a business	☐
g	Income or pension from your spouse / partner	☐
h	Financial support from family	☐
i	Spouse / partner's superannuation	☐
j	Wage or salary	☐
k	Other sources	☐

Q101b **When you are OVER 65 what will be your sources of income?**
(Mark all that apply)

		Yes
a	Age pension / Service pension / Widow's pension / War Widow's pension	☐
b	Other government pension or allowance	☐
c	Lump sum superannuation payout	☐
d	A pension or annuity purchased with superannuation or some other funds	☐
e	Income from savings and investments *(such as shares and property)*	☐
f	Income from a business	☐
g	Income or pension from your spouse / partner	☐
h	Financial support from family	☐
i	Spouse / partner's superannuation	☐
j	Wage or salary	☐
k	Other sources	☐

Q102 **Have you begun to think about your life in retirement? In particular, have you made any plans for the following aspects of your life?**
(Mark one on each line)

		Not at all	Thought about it	Made some plans	Have firm plans
a	To be socially active with friends or family or the community	☐	☐	☐	☐
b	To be mentally active *(eg join a group, do word or number puzzles)*	☐	☐	☐	☐
c	To be physically active	☐	☐	☐	☐
d	To be financially secure	☐	☐	☐	☐
e	To be in some kind of paid, unpaid or voluntary work	☐	☐	☐	☐
f	To be in housing that meets your needs	☐	☐	☐	☐

Q103 **When you are 65 how do you expect to manage on your available income?**
(Mark one only)

- It will be impossible ☐
- It will be difficult all of the time ☐
- It will be difficult some of the time ☐
- It will not be too bad ☐
- It will be easy ☐

Q104 **These questions are about getting on with other people:**
(Mark one on each line)

		Yes	No
a	Are you sad or lonely often?	☐	☐
b	Do you feel uncomfortable with anyone in your family?	☐	☐
c	Can you take your own medication and get around by yourself?	☐	☐
d	Do you feel that nobody wants you around?	☐	☐
e	Does someone in your family make you stay in bed or tell you you're sick when you know you are not?	☐	☐
f	Has anyone forced you to do things you didn't want to do?	☐	☐
g	Has anyone taken things that belong to you without your OK?	☐	☐
h	Do you trust most of the people in your family?	☐	☐
i	Do you have enough privacy at home?	☐	☐
j	Has anyone close to you tried to hurt or harm you recently?	☐	☐
k	Has anyone close to you called you names or put you down or made you feel bad recently?	☐	☐
l	Are you afraid of anyone in your family?	☐	☐
m	Does anyone in your family drink a lot of alcohol?	☐	☐
n	Have you ever been in a violent relationship with a partner / spouse?	☐	☐

Q105 **If you have ever lived with a violent partner or spouse, in which years did you experience violence?**
(Mark all that apply)

a	I have never lived with a violent partner or spouse	☐
b	Before 1996	☐
c	1996-1998	☐
d	1999-2001	☐
e	2002-2004	☐
f	2005-now	☐

Q106 **What is your present marital status?**
(Mark one only)

Married *(registered)*	☐
De facto relationship *(opposite sex)*	☐
De facto relationship *(same sex)*	☐
Separated	☐
Divorced	☐
Widowed	☐
Never married	☐

■

Q107 **How many people live with you now?**
(Mark all that apply)

a	No one, I live alone	☐			
		One	Two	Three or more	
b	Partner or spouse	☐			
c	Children under 16 years	☐	☐	☐	
d	Children 16-18 years	☐	☐	☐	
e	Children over 18 years	☐	☐	☐	
f	Your parents or in-laws	☐	☐	☐	
g	Other adult relatives	☐	☐	☐	
h	Other adults *(not family members)*	☐	☐	☐	

Q108 **People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it?**
(Mark one on each line)

		None of the time	A little of the time	Some of the time	Most of the time	All of the time
a	Someone to help you if you are confined to bed	☐	☐	☐	☐	☐
b	Someone you can count on to listen to you when you need to talk	☐	☐	☐	☐	☐
c	Someone to give you good advice about a crisis	☐	☐	☐	☐	☐
d	Someone to take you to the doctor if you need it	☐	☐	☐	☐	☐
e	Someone who shows you love and affection	☐	☐	☐	☐	☐
f	Someone to have a good time with	☐	☐	☐	☐	☐
g	Someone to give you information to help you understand a situation	☐	☐	☐	☐	☐
h	Someone to confide in or talk to about yourself or your problems	☐	☐	☐	☐	☐
i	Someone who hugs you	☐	☐	☐	☐	☐
j	Someone to get together with for relaxation	☐	☐	☐	☐	☐
k	Someone to prepare your meals if you are unable to do it yourself	☐	☐	☐	☐	☐
l	Someone whose advice you really want	☐	☐	☐	☐	☐
m	Someone to do things with to help you get your mind off things	☐	☐	☐	☐	☐
n	Someone to help with daily chores if you are sick	☐	☐	☐	☐	☐
o	Someone to share your most private worries and fears with	☐	☐	☐	☐	☐
p	Someone to turn to for suggestions about how to deal with a personal problem	☐	☐	☐	☐	☐
q	Someone to do something enjoyable with	☐	☐	☐	☐	☐
r	Someone who understands your problems	☐	☐	☐	☐	☐
s	Someone to love and make you feel wanted	☐	☐	☐	☐	☐

Q109 **Are you a twin?**
(Mark one only)

- Yes - identical ☐
- Yes - not identical *(fraternal)* ☐
- No ☐

Q110 **In general, are you satisfied with what you have achieved in your life so far in the areas of:**
(Mark one on each line)

		Very satisfied	Satisfied	Dissatisfied	Very dissatisfied
a	Work	☐	☐	☐	☐
b	Career	☐	☐	☐	☐
c	Study	☐	☐	☐	☐
d	Family relationships	☐	☐	☐	☐
e	Partner / closest personal relationship	☐	☐	☐	☐
f	Friendships	☐	☐	☐	☐
g	Social activities	☐	☐	☐	☐

If you filled in this survey for the participant, please answer the next three questions.

Q111 **Your relationship to participant:** *(Mark one only)*

- Family member ☐
- Professional health worker *(eg nurse)* ☐
- Other *(eg friend)* ☐

Q112 **When you filled in this survey for the participant, which of the following applied?**
(Mark one only)

- The participant told me what answers she wanted ☐
- The participant was unable to tell me what answers she wanted and I used my own judgement ☐

Q113 **What was the MAIN reason why the participant did not fill in the survey herself?**
(Please describe)

Have we missed anything?

If there is ANYTHING else you would like to tell us about changes in your health (especially in the last three years) please write on the lines below.

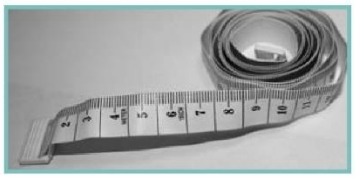
Consent

Mid 5 2007

I consent to the researchers 'matching' the information provided in this survey with that provided in previous surveys so that any changes in my health can be noted.

Signature: _____ Date: _____

What is your maiden name? _____



Have you remembered to measure your waist?
Page 17 Question 56

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Help us keep in touch!

Sometimes we lose touch with our participants. It would be helpful if you could give us your mobile phone number and email address.

Mobile

Email

It would also be helpful if you could give us details of a relative or friend who will be able to help us find you.

Name

Address

P'Code

Phone (home) ( )

Relationship to you

Name

Address

P'Code

Phone (home) ( )

Relationship to you

Thank you for taking the time to complete this survey.

If you have any questions you can contact us by telephoning

1800 068 081 (freecall).

Don't forget to sign the consent and post this back to us!

women's health australia

Fifth survey for mid - age women March 2007

Australian Longitudinal Study on Women's Health
The University of Newcastle, Callaghan NSW 2308
Phone 02 4923 6872 email: whasec@newcastle.edu.au
Web: http://www.alswh.org.au

Appendix 11: UTS HREC Approval Letter

From: Research.Ethics@uts.edu.au
To: Jon Adams; David Sibbritt; Wenbo Peng; Research Ethics
Subject: UTS HREC Approval - ETH19-3442
Date: Monday, 25 March 2019 1:17:57 PM

Dear Applicant

The UTS Human Research Ethics Committee reviewed your application titled, "Health services utilisation amongst older Australian adults with hypertension or stroke", and agreed that this application now meets the requirements of the National Statement on Ethical Conduct in Human Research (2007) and has been approved on that basis. You are therefore authorised to commence activities as outlined in your application, subject to any conditions detailed in this document.

You are reminded that this letter constitutes ethics approval only. This research project must also be undertaken in accordance with all UTS policies and guidelines including the Research Management Policy (http://www.gsu.uts.edu.au/policies/research-management-policy.html).

Your approval number is UTS HREC REF NO. ETH19-3442.

Approval will be for a period of five (5) years from the date of this correspondence subject to the submission of annual progress reports.

The following standard conditions apply to your approval:

- Your approval number must be included in all participant material and advertisements. Any advertisements on Staff Connect without an approval number will be removed.

- The Principal Investigator will immediately report anything that might warrant review of ethical approval of the project to the Ethics Secretariat (Research.Ethics@uts.edu.au).

- The Principal Investigator will notify the UTS HREC of any event that requires a modification to the protocol or other project documents, and submit any required amendments prior to implementation. Instructions can be found at https://staff.uts.edu.au/topichub/Pages/Researching/Research%20Ethics%20and%20Integrity/Human%20research%20ethics/Post-approval/post-approval.aspx#tab2.

- The Principal Investigator will promptly report adverse events to the Ethics Secretariat (Research.Ethics@uts.edu.au). An adverse event is any event (anticipated or otherwise) that has a negative impact on participants, researchers or the reputation of the University. Adverse events can also include privacy breaches, loss of data and damage to property.

- The Principal Investigator will report to the UTS HREC annually and notify the HREC when the project is completed at all sites. The Principal Investigator will notify the UTS HREC of any plan to extend the duration of the project past the approval period listed above through the progress report.

- The Principal Investigator will obtain any additional approvals or authorisations as required (e.g. from other ethics committees, collaborating institutions, supporting organisations).

- The Principal Investigator will notify the UTS HREC of his or her inability to continue as Principal Investigator including the name of and contact information for a replacement.

I also refer you to the AVCC guidelines relating to the storage of data, which require that data be kept for a minimum of 5 years after publication of research. However, in NSW, longer retention requirements are required for research on human subjects with potential long-term effects, research with long-term environmental effects, or research considered of national or international significance, importance, or controversy. If the data from this research project falls into one of these categories, contact University Records for advice on long-term retention.

You should consider this your official letter of approval. If you require a hardcopy please contact Research.Ethics@uts.edu.au.

If you have any queries about your ethics approval, or require any amendments to your research in the future, please do not hesitate to contact Research.Ethics@uts.edu.au.

Yours sincerely,

A/Prof Beata Bajorek
Chairperson
UTS Human Research Ethics Committee
C/- Research & Innovation Office
University of Technology Sydney
E: Research.Ethics@uts.edu.au