

**Effect of rehabilitation on long-term outcomes after stroke:
Results from a population-based study**

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Abstract

Stroke is one of the leading causes of adult disability internationally and in New Zealand (NZ). The neurological sequelae commonly associated with stroke can severely impact long-term outcomes increasing reliance on others and reducing quality of life (QoL). While there is an abundance of research on physical outcomes from rehabilitation, little is known on the impact that inpatient and community rehabilitation has on long-term functional and QoL outcomes, especially within a NZ population. The purpose of this thesis was to determine the association between inpatient and community rehabilitation, and long-term functional and QoL outcomes in a cohort of four-year stroke survivors in Auckland, NZ.

This population-based follow-up study uses a quantitative approach and includes a sample drawn from the fourth Auckland Regional Stroke Outcomes Study (ARCOS- IV). Two hundred and forty-one stroke survivors completed outcome measures of functional independence (Barthel Index [BI]; and the Modified Rankin Scale [mRS]), anxiety and depression (Hospital Anxiety and Depression Scale [HADS]), cognitive functioning (Montreal Cognitive Assessment [MoCA]), fatigue (Fatigue Severity Scale [FSS]; and the Visual Analogue Fatigue Scale [VAFS]), self-reported health status (Medical Outcomes Study Short Form 36 [SF-36]), and health related QoL (EuroQol Quality of Life Scale [EQ-5D]) at baseline, and/or 1 month, 6, 12 (previously collected) and 48 months post-stroke onset. The data analysed within this study is data attained at 48 months (four years post-stroke). Data collected at baseline includes sociodemographic information, stroke-related characteristics, and medical history. Self-reported access to inpatient and community rehabilitation, taking into consideration hours, frequency, and also type of rehabilitation was attained also.

At four years post-stroke, the greatest proportion of the sample (83.4%) demonstrated below average cognitive functioning as assessed by the MoCA ($M=20.68$, $SD=4.7$), a large amount of participants (56.8%) presented with high levels of fatigue on the FSS ($M=5.22$, $SD=1.76$), with average scores on the VAFS representing debilitating levels of fatigue among the sample also ($M=54.61$, $SD=17.96$). At four years on the SF-36, stroke survivors exhibited below the mean of the NZ population in constructs involving physical functioning (51.9%, $M=60.44$, $SD=36.6$), role functioning physical (27%, $M=74.07$, $SD=41.16$), role functioning emotional (30.3%, $M=73.86$, $SD=42.1$), energy and fatigue (74.3%, $M=55.64$, $SD=22.7$), social functioning (22%, $M=83.61$, $SD=22.61$), general health (53.2%, $M=64.5$, $SD=27.31$), and health change (75.9%, $M=49.48$, $SD=21.22$).

In regards to inpatient rehabilitation it was established that 37.8% ($n=91$) of stroke survivors received inpatient rehabilitation involving physical, occupational and speech therapy as required. Stroke survivors that received inpatient rehabilitation did not present with significantly better outcomes in QoL and functional independence in comparison to those who did not receive inpatient rehabilitation. At four years stroke survivors who did receive inpatient rehabilitation were still significantly impaired in areas of self-care ($p=0.01$) and usual activities ($p=0.01$) according to the EQ-5D outcome measure,

demonstrating impairment in functional independence, which is understood to impact QoL post-stroke. In terms of community rehabilitation, 31.5% ($n=76$) of the participants received community rehabilitation involving physical, occupational and speech therapy. A relationship was found between negatively perceived health change on the SF-36 in 183 (75.9%) participants and those who did not receive community rehabilitation ($p=0.03$), potentially demonstrating more negative perceptions of health long-term post-stroke in those who did not have community rehabilitation support.

Findings from this study did not provide substantial evidence supporting positive outcomes from inpatient or community rehabilitation in long-term stroke survivors in Auckland, NZ. However, the findings have provided evidence that current inpatient and community rehabilitation being offered is not addressing the areas of persistent impairment, which stroke survivors are experiencing well after their stroke event. This includes disability in cognitive functioning, fatigue, emotional well-being (anxiety and depression), roles in physical and emotional functioning, social functioning and participation, general health and perceived health change. There was no evidence of cognitive or psychological interventions throughout inpatient and community rehabilitation services, which potentially could have contributed towards the impairment presented throughout this current sample at four years.

Current care as usual post-stroke in the inpatient and community rehabilitation setting in Auckland, NZ needs improvements in order to benefit stroke survivors' long-term outcomes in functional independence and QoL. Cognitive and psychological components incorporated into inpatient and community rehabilitation for stroke survivors could potentially improve long-term QoL and functional independence outcomes post-stroke.

Key Words: Stroke, Stroke Rehabilitation, Long-Term Outcomes, Functional Independence, Quality of Life.

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Ethical Approval

Ethical approval was obtained from the Northern X Regional Ethics Committee of the Health and Disability Ethics Committee (HDEC) and Auckland University of Technology Ethics Committee (AUTECH) for the studies encompassed in this thesis.

HDEC approval (ref: NTX/10/09/090/AM07) was received on 24th April, 2014 (see Appendix A). AUTECH (ref: 11/297) approval was received on 13th May, 2014 (see Appendix B).

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Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Signed:

Date: 29th November 2018

Chapter 1 Introduction

Stroke is a devastating condition which occurs when blood flow to the brain is disrupted, resulting in oxygen deprivation and leading to cellular loss (Kennedy, 2012). Every day, approximately 24 New Zealanders experience a stroke, and the neurological sequelae associated with stroke are understood to be the leading cause of serious adult disability nationally (Ministry of Health, 2016; Stroke Foundation of New Zealand, 2017b). In New Zealand (NZ) stroke is the second largest contributor to death, resulting in the loss of approximately 2,500 individuals annually (Stroke Foundation of New Zealand, 2017b). Stroke contributes towards 7.3% of overall health loss nationally, with 90% of stroke deaths occurring in people over the age of 65 years, and 10% occurring in those under the age of 65 (Stroke Foundation of New Zealand, 2017b).

According to the World Health Organisation (WHO), stroke is defined as a sudden onset with focal or global neurological deficits lasting more than 24 hours or leading to death (Aho et al., 1980b). Strokes are pathologically typed as either ischemic or haemorrhagic. An ischaemic stroke occurs when there is a blockage in an artery that provides blood to the brain, compared to a haemorrhage which is the result of a burst blood vessel causing bleeding in and around the brain (Kennedy, 2012). In 2017, it was estimated that there were approximately 60,000 stroke survivors in NZ, with only 30% independent in activities of daily living (Stroke Foundation of New Zealand, 2017b). This leaves majority of survivors disabled or with limited functioning, negatively impacting quality of life (QoL), and requiring daily support from others. With an increasing aging population in NZ, there will be a greater number of older adults living with the effects of stroke, who are discharged into the community from the hospital setting, with high levels of functional disability. This results in a substantial increase of stroke burden on the individual, families or caregivers, and the health care system in general (Dyall, Feigin, Brown, & Roberts, 2008; Stroke Foundation, 2017; Stroke Foundation of New Zealand, 2010).

In 2014, the economic burden of stroke in NZ was anticipated to cost the health sector \$700 million annually (V. Feigin, Krishnamurthi, Barber, & Arroll, 2014). Due to the negative impact and burden of stroke, effective rehabilitation processes are vital towards improving functionality and QoL for stroke survivors. However, there is currently a lack of data on stroke rehabilitation in NZ, which has examined the association between

frequency, duration and type of rehabilitation on long-term functional independence and QoL outcomes. This is surprising considering that there is a large amount of evidence-based research of stroke focused rehabilitation, specifically following the early stages of recovery, significantly improving outcomes post-stroke internationally (Australian Rehabilitation Centre, 2017; Kennedy, 2012; Outpatient Service Trialists, 2003). For example, a large 2003 study of 1617 stroke survivors, found those patients who received intensive rehabilitation (up to one year post-stroke) were shown to have more positive outcomes towards independency in functional tasks and higher levels of QoL in comparison to those who received no rehabilitation (Outpatient Service Trialists, 2003). Benefits of inpatient and on-going stroke rehabilitation have been well documented (Australian Rehabilitation Centre, 2017; De Wit et al., 2008; McNaughton, McRae, Green, Abernethy, & Gommans, 2014; Meyer et al., 2015; Shah et al., 2013). It is therefore imperative to obtain reliable evidence on the effect that inpatient and community rehabilitation has on long-term functional and QoL long-term outcomes for stroke survivors. This information will allow for understanding towards the impact stroke-focused rehabilitation has on long-term outcomes of stroke survivors.

Aim

This study will investigate the association of inpatient and community rehabilitation on long-term functional and QoL outcomes in an existing NZ cohort of four-year stroke survivors.

Chapter 2 Literature Review

2.1 Stroke Epidemiology

Stroke is the second leading cause of death and disability in developed countries (Johnston, Mendis, & Mathers, 2009; Stroke Foundation of New Zealand, 2010). Approximately 8,400 people in NZ have a new stroke annually (AROC, 2017), with mortality rates estimated at 2,500 people per year (Stroke Foundation of New Zealand, 2017b). While the majority of strokes are not fatal, outcomes usually result in chronic disability, significantly impacting functional independence and decreasing QoL for survivors (V. Feigin, Forouzanfar, et al., 2014).

An earlier systematic review conducted by Feigin and colleagues (2009) examining population-based studies on stroke incidence from 28 countries, found that incidence of stroke is increasing in lower-income and middle-income countries. In comparison, the past 40 years have showed a 42% decrease in stroke incidence in high-income countries. With the development of improved medical resources, mortality rates have decreased significantly in both low-income and middle-income (20%) and high income (37%) populations (V. Feigin, Forouzanfar, et al., 2014). The decline in average mortality rate in NZ for stroke over the past 20 years has remained stable, with a decline in stroke incident at 12% and the number of deaths by stroke per 100,000 proportionate to the aging population in NZ (Ministry of Health, 2016; Stroke Foundation of New Zealand, 2010). However, it is of concern that NZ's overall rate of decline is approximately four times slower than other developed countries, and stroke in Māori and Pacific populations are similar to those in developing low-income countries (V. Feigin, McPherson, Barker-Collo, & Krishnamurthi, 2014).

In the Global Burden of Disease (GBD) Study (2010), 31% of stroke incidence was estimated to be preventable in individuals under 65 years (V. Feigin, Forouzanfar, et al., 2014). In NZ, increased stroke prevalence in individuals younger than 65 years of age is evident, specifically in individuals of Māori and Pacific ethnicity, which is in concordance with results from the GBD Study (V. Feigin, Forouzanfar, et al., 2014). Māori and Pacific groups had the slowest degree of decline and experience stroke at a considerably younger age in comparison to NZ Europeans (60, 62 and 75 years respectively) (Dyall et al., 2008; V Feigin et al., 2015). For survivors aged under 65

years, there is a limited access to rehabilitation services and opportunities for rehabilitation post-stroke in NZ (Stroke Foundation, 2017).

2.2 Burden of Stroke

2.2.1 Symptoms

There is an array of symptoms following stroke, which vary between pathological types (ischaemic and haemorrhagic) and are dependent on the size of stroke, location and severity (Kennedy, 2012). Commonly reported symptoms involve: physical issues, such as paralysis (hemiplegia) or weakness of one side of the body (hemiparesis) (Carrasco & Cantalapiedra, 2016), problems with sitting balance, transferring to sitting to standing, standing balance, walking and gait issues, along with upper limb dysfunction; difficulties with communication, such as with reading, writing, receptive and expressive aphasia (unable to communicate clearly with words and sentences) (Armstrong, Hersh, Hayward, & Fraser, 2015); dysphagia, issues with swallowing (Carr & Wallis, 2016); visual disturbances (Petersen et al., 2016); fatigue (Maaijwee et al., 2014); incontinence (Tuong, Klausner, & Hampton, 2016); deficits in cognitive functioning, involving attention, memory, and executive functioning for example (Mahon, 2018); along with emotional and mood disturbances (Kim, 2017), namely anxiety and depression. Although some people who suffer from stroke make good recovery, a significant number experience permanent disability (Kennedy, 2012). Stroke outcomes will be discussed in more detail further on within this chapter.

Stroke has a deleterious effect on physical, emotional and cognitive outcomes for stroke survivors and families. These outcomes from stroke also highly impact communities and the health care systems. Reducing the burden of stroke in NZ and improving outcomes is important for enhancing independence within the community and for improvements in health service planning. Effective and efficient early intervention of rehabilitation can potentially encourage maximum recovery, along with increasing functional independence and QoL for survivors, with rehabilitation having the potential to reduce costly long-term complications and later strokes (Stroke Foundation of New Zealand, 2017b).

2.2.2 Disability Adjusted Life Years

Overall stroke burden, measured by disability-adjusted life years (DALYS), was reported to increase from 38 million to 113 million internationally (between 1990 to 2013 respectively)(V Feigin et al., 2015). DALYs have two components: years of life lost because of death, calculated by the age at death subtracted from the standard life expectancy for that cohort (Vos et al., 2012); and years lived with disability, representing healthy life years lost in survivors, calculated from the number of patients living with stroke sequelae, the amount of years living with disability caused by stroke, and the disability weight referring to the severity of the disease state (Vos et al., 2012). Years living with disability is calculated by stroke prevalence multiplied by disability weight (or severity) of the individuals (V. Feigin, Forouzanfar, et al., 2014). Due to this increase of stroke burden internationally, it is imperative that risk factors of stroke are understood and approached accordingly in order to reduce stroke occurrence and decrease people living with stroke sequelae.

2.3 Stroke Risk Factors

Stroke is a generally preventable medical condition with up to 75% of risk factors classed as modifiable (O'Donnell et al., 2016). The INTERSTROKE Study, comprised of 26,919 participants (cases of first acute stroke $n=13,447$; controls $n=13,472$) found that hypertension, lack of regular exercise, an unhealthy diet, being a current smoker, cardiac issues, alcohol consumption and diabetes mellitus were associated with risk factors for all stroke types (O'Donnell et al., 2016). The remaining 25% relates to non-modifiable factors caused by genetics (for example *cadasil*, most common hereditary stroke disorder, or ethnicity genotypes) and other factors such as age and gender. Risk factors are understood to be cumulative, the more risk factors present in an individual's life the poorer the person's health outcomes are likely to be (Ministry of Health, 2017). Over the past 30 years in NZ, decline in stroke incidence is 20% less than other countries over a similar time period (Feigin et al., 2015). Early recognition and control of risk factors, along with risk reduction strategies implemented throughout the community (such as the Stroke Riskometer Application develop by (AUT Enterprises Limited, 2014), can significantly lessen the potential of stroke occurring within the NZ population (Stroke Foundation of New Zealand, 2017b).

2.3.1 Modifiable Risk Factors

Blood Pressure

High blood pressure (hypertension) is the leading cause of stroke in NZ and internationally (O'Donnell et al., 2016; Stroke Foundation of New Zealand, 2017c). A person with high blood pressure is seven times more likely to have a stroke in comparison to someone with low to normal blood pressure (O'Donnell et al., 2016). Hypertension occurs in one in five New Zealanders, making preventable measures important (Stroke Foundation of New Zealand, 2017b). Feigin and colleagues (2015) reported a 15% increase in high blood pressure over a 30 year period, specifically in Māori men aged between 35-74 years (V Feigin et al., 2015).

Smoking

The chemicals in cigarette smoke speed up the development of fat, cholesterol and other matter (plaque), on the walls of blood vessels resulting in the narrowing of arteries, known as atherosclerosis, and increasing risk of stroke (O'Donnell et al., 2016; Stroke Foundation of New Zealand, 2017c). Moreover, chemicals from cigarettes thicken blood making it sticky, increasing the chances of clotting, whilst also tightening blood vessels which restricts the flow of blood and increases blood pressure (Stroke Foundation of New Zealand, 2017c). Encouragingly, a 11% decrease in the regularity of current smokers among stroke patients from 2002 to 2012 was evident in the NZ population (V Feigin et al., 2015). However, the prevalence of smoking in Māori (40.4%) and Pacific people (24.4%), compared to NZ Europeans (12.8%), was higher.

Atrial Fibrillation

Atrial fibrillation (AF) is a type of irregular heart rhythm that can cause poor blood flow to the body and is a risk factor for stroke (Heart Foundation, 2018; O'Donnell et al., 2016). 'Pooling' of the blood can occur in the heart and cause blood clots (Stroke Foundation of New Zealand, 2017c). Subsequently, clots can travel through the blood vessels to the brain and block an artery causing a stroke. According to Feigin and colleagues (2015), from 2002 – 2012 there has been an 7.2% increase in prevalence of AF in NZ European stroke patients. Comparatively, an increase in the incidence of AF in stroke patients was observed in another population-based study (Friberg et al., 2014), along with a global endemic of AF (Chugh et al., 2013) implying that this condition is becoming a leading risk factor in stroke.

Diabetes Type 2

Diabetes is a condition where the body does not create enough insulin, or a person becomes insulin resistant, and is unable to maintain an average range for blood glucose (sugar) levels, with high blood sugar resulting in the progression of atherosclerosis (narrowing of arteries), increasing the chance of stroke (Diabetes New Zealand, 2017; O'Donnell et al., 2016; Stroke Foundation of New Zealand, 2017c). Type 2 diabetes is usually diagnosed in people over the age of 30, is often associated with excess body weight, hypertension and high cholesterol levels (Diabetes New Zealand, 2017). In 2015, Feigin and colleagues found an increase of 12.5% in the prevalence of type 2 diabetes in stroke patients, with a larger incline for Māori (29.7%) and Pacific people (43.3%), compared to NZ Europeans (16.5%). Type 2 diabetes cannot be cured but blood sugar levels can often be maintained with an active and healthy lifestyle.

Diet, Weight and Exercise

Being overweight or having too much body fat can cause high blood pressure, high cholesterol and type 2 diabetes, which all contributes towards stroke risk (O'Donnell et al., 2016). Having a balanced diet and doing regular exercise will help an individual maintain a healthy body weight. The Ministry of Health's 2016 Annual Report (2017) suggests that dietary risk factors are one of the leading causes of overall health loss in NZ, contributing towards 9.4% of general health loss nationally. Fresh fruit and vegetables (contain antioxidants, vitamins and potassium, which are good for healthy arteries), grains, moderate amount of meat or low fat protein contributes to a healthy balanced diet. Fibre from cereals, beans, nuts and seeds help to reduce cholesterol whilst dairy products such as yogurt and protein help with growth and repairing cells within the body (Ministry of Health, 2017; National Stroke Foundation, 2017; Stroke Foundation of New Zealand, 2017c). Choosing foods which are low in saturated fat can reduce high cholesterol and reduce the chances of atherosclerosis (Saita, Kondo, & Momiyama, 2014). When a healthy diet and regular exercise is not maintained, the heart has to work harder to push the increased volume of blood through the blood vessels, creating strain on the arteries and increasing blood pressure (Stroke Foundation of New Zealand, 2017c). Alcohol intake should be limited also, with binge drinking at any age increasing stroke risk by five (Stroke Foundation of New Zealand, 2017c). Alcohol can increase blood pressure and result in brain haemorrhage (Kadlecová, Anđel, Mikulík, Handing, & Pedersen, 2015) 30 minutes of vigorous exercise a day can help maintain a healthy blood pressure and is estimated to reduce stroke risk by half. A recent report

from the Ministry of Health (2017) suggests physical activity is a protective factor against stroke. However, the same report found that only 47.7% of New Zealanders did regular physical activity.

2.3.2 Non-Modifiable Risk Factors

Age

Age is the most significant non-modifiable risk factor for all stroke types, with 90% of stroke deaths occurring in people over the age of 65 years in developed countries (O'Donnell et al., 2016; Stroke Foundation of New Zealand, 2017b). Ischaemic strokes are the most common subtype in older adults, whilst the most frequent subtype for younger populations is haemorrhages, with majority of subarachnoid haemorrhages appearing in those under 65 years (Chen, Balami, Esiri, Chen, & Buchan, 2010; Kelly-Hayes, 2011). It is theorised that certain lifestyle aspects of older age contribute to the higher risk of stroke, such as the likeliness of having a sedentary lifestyle (Boehme, 2017). Additionally, the longer an individual lives the more likely chronic health conditions (modifiable risk factors; diabetes mellitus, high blood pressure, and high cholesterol) will be acquired (Kelly-Hayes, 2011). On the other hand, it is suggested that the susceptibility of stroke in older age is due to age related alterations in the cerebral vessels that potentially reduce cerebrovascular reserves and increase potential for vascular insufficiency and ischemic injury (Boehme, 2017; Ueno, Tomimoto, Akiguchi, Wakita, & Sakamoto, 2002). The brain and nervous system also undergo an array of other changes during aging, such as: decrease in brain weight, especially in the cerebral cortex and hippocampal areas (Chen et al., 2010); decrease in brain volume; grey matter volume decreases; and capillary surface area decreases, while capillary diameter, volume and total length increase (Chen et al., 2010). However, these aspects are still not clearly understood in relation to stroke risk.

Sex

Sex is also an unmodifiable risk factor of stroke. Current NZ estimates predict that females account for 60% of stroke deaths internationally, are more probable to experience a recurrent stroke and are highly likely to have more severe strokes in comparison to males (Samai & Martin-Schild, 2015). Females have a higher life expectancy (81.94 years) in comparison to males (79.56 years); after 65 years of age life expectancy is 20.5 years for females and 17.90 for men (Kelly-Hayes, 2011; Samai & Martin-Schild, 2015). Appelros, Stegmayr, & Terent (2009) found that the mean age for

first-ever stroke is higher for females (72.9 years) in comparison to men (68.75 years) and perhaps due to the longer lifespan of woman there is more likelihood of reoccurring strokes during their lifetime (Samai & Martin-Schild, 2015). Though, it was also found in NZ that females were more likely to be economically inactive, to be living alone without a spouse or partner, experience lengthy hospital stays, more likely to have hypertension and AF, but were less likely to engage in behaviors such as smoking and drinking alcohol (Hung et al., 2018; Kelly-Hayes, 2011; Samai & Martin-Schild, 2015).

Several studies have shown that woman have poorer long-term outcomes after stroke in comparison to males, having inferior functional outcomes, limitations in activities of daily living and participation, and also a lower health related QoL (Gall, Tran, Martin, Blizzard, & Srikanth, 2012; Hung et al., 2018; Reeves et al., 2008). For example, results from a 2007 study ($n=373$) demonstrated that females were overall less likely to achieve independence in activities of daily living, had lower scores on a stroke specific QoL measure (across physical functioning, thinking, language and energy), and presented with lower mood and social function post-stroke (Gargano & Reeves, 2007). Sex specific modifiable risk factors and poor outcomes needs to be addressed in order to optimize stroke reduction and patient care (Hung et al., 2018).

Ethnicity and Genetics

In comparison to other high-income countries, the NZ population has had a significant increase in the prevalence of hypertension and diabetes mellitus among stroke patients (Stroke Foundation of New Zealand, 2017b). This is especially evident in Māori and Pacific groups (Feigin, 2015; Dyall et al., 2008; Fink, 2016). Increased burden of modifiable risk factors (such as high blood pressure, smoking, lack of physical activity, poor nutrition, diabetes, and high alcohol use) are apparent in non-European ethnicities and low socio-economic status (SES) populations (R Krishnamurthi et al., 2014). Additionally, lower SES groups are impacted by other modifiable risk factors such as lower educational achievement and having limited access to health services to manage such issues (Bay et al., 2015; R Krishnamurthi et al., 2014). For example, larger portions of Māori and Pacific peoples live in socially deprived areas of NZ and have greater incidence of non-communicable disease, such as stroke, and worse functional and QoL outcomes post-stroke (Ministry of Health, 2013).

Due to the large cultural diversity in NZ, and the differences of stroke risk factors between Māori, Pacific people and NZ Europeans, it is important that culturally appropriate stroke prevention strategies are implemented accordingly. To do this education of the risk factors and stroke outcomes, along with how they apply to different ethnicities within NZ, is essential.

2.4 Stages of Stroke Recovery: Acute, Sub-Acute and Chronic

2.4.1 Acute Stage

Unlike other chronic neurological conditions, stroke onset is sudden and often leaves the individual and family ill-prepared to deal with the neurological sequelae associated with stroke, affecting QoL for both survivors and their families (Kennedy, 2012; Sunnerhagen, 2014). As previously mentioned, outcomes from stroke vary between individuals dependent on the size, location of the damage caused by stroke and the severity of the event (Dyall et al., 2008; V. Feigin, Forouzanfar, et al., 2014). Although some symptoms can resolve in the early phases after stroke, many stroke survivors will continue to experience persistent impairment affecting physical, cognitive, psychological, and emotional and social functioning (V Feigin et al., 2015).

The acute phase post-stroke involves hospital admission to inpatient rehabilitation, or discharge into the community (McNaughton, Thompson, Stinear, Harwood, & McPherson, 2014). It involves the hours and days following stroke onset where emergency care, and inpatient stabilisation takes place (Hirshon et al., 2013). The acute phase is the most time-sensitive, is individually focused to reach diagnosis and involves curative actions with the main purpose attentive to improving health status (Hirshon et al., 2013). It is in this acute phase where there is evidence that admission to a stroke unit is in the stroke survivors' best interests, (Sunnerhagen, 2014).

2.4.2 Sub-Acute Stage

Regaining consciousness or awareness in the acute phase in a hospital setting is very traumatic. Especially so if a person becomes to the realisation that they are unable to communicate or have limited movement with no immediate understanding of why or how this has occurred (Kennedy, 2012). At this stage, patients are unaware of what stage they are at in recovery or how long recovery may take. Stroke survivors will commonly experience an array of emotions that fluctuate over time whilst in hospital.

Many fear the future and what effect the stroke has had on their physical and mental health, along with uncertainty of the impact that this medical event will have on their loved ones (Kennedy, 2012; Sunnerhagen, 2014).

The sub-acute stage (between 3 days <6 months) involves implementation of rehabilitation processes, usually in inpatient rehabilitation or through Early Supported Discharge (ESD), along with monitoring of the individual's health status (McNaughton, Thompson, et al., 2014). In this stage post-stroke, the rehabilitation process focuses on activity and participation of the stroke survivor along with pathology and impairment (McNaughton, Thompson, et al., 2014). It is reported that feelings of losing control and not having the same level of independence, as one had prior to a stroke, surfaces throughout the hospital process and being discharged. Patients often have anxiety about leaving the safety of the hospital, where there is medical assistance 24/7 (Kennedy, 2012; Sunnerhagen, 2014). Hospitalised patients often are not aware of the extent of their disabilities. Frequently patients have been reported to assume that when they are back in their normal home environment they will instinctively be able to independently function well again. In that, returning home after being discharged from hospital can often be a point of realisation for the patient (Kennedy, 2012). With ESD, explained in detail under 'Stroke Rehabilitation', this service allows for rehabilitation to occur in the survivors' home environment, which overcomes some of the previously mentioned difficulties. There is a strong relationship between the patient's evaluation of the stroke, coping behavior and the persons' resilience or adjustment to life post-stroke (Kennedy, 2009). For this reason, the significance of education around stroke and support for the patient, and their family, is seen to be essential towards recovery (Kennedy, 2012; Rochette, Desrosiers, Bravo, St-Cyr-Tribble, & Bourget, 2007). Throughout the sub-acute stage, the individuals recovery will be monitored to determine if functional independence and support through family and caregivers is at an adequate level to be within the community, or if they will need to be institutionalised for long-term care and management of chronic stroke symptomology and functional disability (Kennedy, 2012).

Approximately one-third of stroke survivors are dependent on others for basic needs of daily living, and up to 20% of stroke survivors have significant impairments requiring 24 hour care, and therefore are discharged from hospital to institutional care (Australian Rehabilitation Centre, 2017; McNaughton, McRae, et al., 2014). On the other hand, around 60% of stroke survivors are discharged from the hospital setting into the

community (Australian Rehabilitation Centre, 2017). Prior research has established that stroke survivors living in the community are considerably limited in participation relating to areas involving employment, study, along with cultural and community activities (V Feigin et al., 2010; McNaughton, Thompson, et al., 2014; Rochette et al., 2007).

Once a stroke survivor is discharged from hospital the majority of them return to their own homes, with or without stroke treatment, with home care often being provided by family members (Robinson-Smith, Johnston, & Allen, 2000; van Mierlo, van Heugten, Post, Hoekstra, & Visser-Meily, 2018). Having to care for a stroke survivor, can have a huge impact on the caregivers with increased feelings of responsibility, constant worrying, decline in caregivers' personal social activities, and feeling of isolation and loneliness is commonly reported (Hopman & Verner, 2003; W. J. Kruithof et al., 2016; Suenkeler et al., 2002). For example, a 2016 study on stroke caregiver burden ($n=183$) found that majority of the partners experienced very high burden, anxiety and depressive symptoms 2 months and 1 year post-stroke (W. J. Kruithof et al., 2016). Many stroke patients, and their families, report undesirable changes in emotional well-being once they return back home.

2.4.3 Chronic Stage

When symptoms do not subside and continue to persist past the sub-acute phase of recovery, individuals are understood to have chronic or long-term symptoms. The NZ Ministry of Health (2018) defines any chronic condition as any ongoing or reoccurring symptoms that have a substantial impact on an individual's life, usually for longer than six months. As mentioned previously, the majority of strokes do not result in death, and likely result in chronic long-term disability, significantly impacting functional independence and decreasing QoL for survivors while increasing the number of healthy years lost and DALYs (V. Feigin, Forouzanfar, et al., 2014). The frequency and intensity of care for those with chronic symptoms of stroke requires complex and sophisticated care from a variety of providers to manage survivors' conditions, maximise function, whilst maintaining independent living (Kennedy, 2012).

Chronic stroke sequelae negatively impacts survivors' participation in the community, involvement with cultural activities, along with presenting potential socioeconomic disadvantages if the survivor was previously working (Choi et al., 2017; Kennedy,

2012; Rochette et al., 2007). This further impacts individual's activities of daily living and functional status, along with overall QoL (Kennedy, 2012; Shimoda & Robinson, 1998). A mixed methods study conducted by Rochette and colleagues (2014), found that their 40 participants were highly impacted by stroke, with reduced participation levels within the community and within their own families 6 months post-stroke. Survivors of stroke have also been found to have a considerably reduced QoL in comparison to an age-matched control group (Saywell et al., 2012), with an Australian study ($n=225$) finding that 8% of stroke survivors rated their QoL as equal to or worse than death (Sturm et al., 2004). This could be due to the negative impact that chronic stroke sequelae has on self-identity, decreasing interest and attention levels, along with the loss of independence and functioning in a variety of physical, cognitive and psychological domains (Ellis-Hill and Horn, 2009).

2.5 Stroke Outcomes

2.5.1 Physical Impairment

Motor impairment is a common complication post-stroke, highly contributing towards an individual's ability to function independently, and is a strong indicator of long-term prognosis (Stinear, 2010). Physical impairments usually impact lower limb functioning (sitting balance, ability to transfer from sitting to standing and then to walking, standing balance, walking and gait issues), and upper limb functioning (use and control of arms, hands and fingers), all resulting in difficulties in everyday functioning post-stroke (Stroke Foundation, 2017). Walking difficulties are reported in 75% of patients on admission to hospital post-stroke, with walking capacity being an important factor towards determining potential for secondary ailments caused by falls (Stroke Foundation, 2017). In comparison, approximately 69% of stroke patients have upper limb impairment on admission to hospital, involving deficits in the movement of the shoulder, elbow, wrist, hand and fingers. These impairments are significantly important for activities of daily living, such as self-care (showering, toileting, dressing), eating and drinking, along with domestic and community tasks such as community access, transportation, and home maintenance (Stroke Foundation, 2017). Furthermore, these physical conditions commonly result in depression and anxiety (van Mierlo et al., 2018) and extreme fatigue (Mahon et al., 2018), highly impacting QoL for the stroke survivor and caregivers. For example, a 2017 study with 225 stroke survivors and caregiver dyads showed that improvements in the stroke survivors physical functioning over 12

months was strongly associated with an increase in both survivors' and caregivers' psychological and physical QoL (Pucciarelli et al., 2017). Standing balance in particular has proven to be a significant determining factor of an individual's ability to perform activities of daily living, and in turn a strong predictor of functional recovery and QoL (van Duijnhoven et al., 2016). Often stroke survivors regain standing balance, though not always to full capacity with chronic issues with postural sway, weight transference and maintaining balance commonly persisting (van Duijnhoven et al., 2016).

2.5.2 Cognitive Functioning

Stroke has a significantly destructive effect on cognition, impacting the extent of disability post-stroke. Cognitive impairment in the acute phase post-stroke is reported in up to 70% of stroke survivors (Melkas, Jokinen, Heitanen, & Erkinjuntti, 2014).

Cognitive impairments post-stroke include issues with: attention, process of selectively focusing on a distinct aspect of information whilst ignoring other information; memory, storing and retrieval of information; and executive function, involved with planning, initiation, organisation, problem-solving, monitoring and error correction, and inhibition (Mahon et al., 2017; Stroke Foundation, 2017). Many of these deficits may improve within the sub-acute phase post-stroke (weeks to months), though over 50% of stroke survivors experience ongoing long-term cognitive deficits, which can have a significant impact on everyday functioning and QoL (Jokinen et al., 2015). A 2017 study of 257 stroke survivors found that a significant proportion ($n=217$) demonstrated global cognitive deficits one year post-stroke (Mahon et al., 2017). Results also showed that cognition improved within the first year post-stroke, but then steadily declined thereafter. Sociodemographic factors, gender, marital status and employment were all significantly related to declining cognition post-stroke also (Mahon et al., 2017).

Cognitive decline due to stroke can significantly result in higher levels of social isolation (V Feigin et al., 2010) and poor QoL (Australian Rehabilitation Centre, 2017). Of equal importance, cognitive issues affect a survivors overall ability to participate or engage in rehabilitation, especially when patients have issues with memory and understanding new information (Galski, Bruno, Zorowitz & Walker, 1993; Robertson, Ridgeway, Greenfield & Parr, 1997). Approximately one-third of people with stroke suffer from some form of memory loss and learning new information, negatively impacting the length of hospital stays, functional independence, personal safety and distress of the stroke survivor and their family (Stroke Foundation, 2017). Memory impairments could also be impacted by

issues with attention and executive functioning (S. Barker-Collo, V. Feigin, V. Parag, C. Lawes, & H. Senior, 2010).

2.5.3 Sensorimotor Impairment

Approximately 40% of stroke survivors are diagnosed with sensory impairments (Stroke Foundation, 2017). These include deficits in: touch sensation; proprioception, ability to sense ones' self in own environment; kinaesthesia, the sensation by which bodily position, weight, muscle tension and movement are perceived; and visual loss (de Diego, Puig, & Navarro, 2013). These forms of sensory impairments negatively impact motor recovery, along with affecting the individual's safety, even if motor function is adequate (Doyle, Bennett, Fasoli, & McKenna, 2010). A qualitative study with stroke survivors ($n=15$) found that sensory impairments negatively impacted individuals' roles and participation in society, along with overall QoL (Doyle, Bennett, & Dudgeon, 2014). Visual field loss is diagnosed in approximately 20-57% of stroke survivors (Hazelton, Pollock, Taylor, & Brady, 2015; Pollock et al., 2011) usually impacting half of the field of vision in both eyes, known as homonymous hemianopia. Impairments with vision result in considerable functional complications, especially involving activities such as reading, writing, mobilising and driving (Stroke Foundation, 2017). A 2015 study with 328 ischemic stroke survivors found that vision problems were reported in up to 25% of participants post-stroke, and were directly associated with lower self-reported QoL on the EQ-5D and increased functional disability on the BI (Sand et al., 2016).

2.5.4 Communication

According to Australasian data, communication and speech problems occur in an estimated 60% of stroke survivors (Stroke Foundation, 2017). Research from the United Kingdom (UK) suggests that one-third of stroke survivors are left with communication deficits post-stroke (Bowen et al., 2012). Communication impairments usually occur in left hemisphere strokes, of individuals who are right handed (Stroke Foundation, 2017). Deficits include aspects such as how loud or fast a person speaks, tone of voice, facial expressions, body language along with the ability to construct words and sentences to convey feelings and meaning, and the ability to read and write (Armstrong et al., 2015; Stroke Foundation of New Zealand, 2017a). Specific communication deficits post-stroke include: aphasia, acquired loss of language system that impacts an individual's

ability to produce or comprehend speech along with the ability to read or write (Armstrong et al., 2015); dysarthria, impacting the output of speech due to impairment of speech muscles (lips, tongue, palate, larynx, respiration; (Bowen et al., 2012); apraxia, a deficit in temporal and spatial planning or programming of the movement for the production of speech (Ballard, Granier, & Robin, 2010); and dyspraxia, the inability to produce purposeful movement to create sound (Carr & Wallis, 2016). Other communication impairments such as flat melody of speech or issues with understanding other's emotion, turn-taking, comprehending nonliteral language and difficulties in producing discourse are often due to right hemisphere damage (Robert-Teasell & Hussein, 2016; Stroke Foundation, 2017).

Impairment in communication highly influences an individual's ability to live independently, their mood and overall QoL. For example, a 2011 study with 126 participants ($n=87$ were able to self-report) assessed the impact of aphasia 6 months post-stroke (Hilari, 2011). 32% were dependent on others for activities of daily living, 79% were limited in participation in their own family and community, 45% were assessed to have high psychological distress, and 54% had a significantly compromised QoL (Hilari, 2011). A 2008 qualitative study, involving 9 long-term stroke survivors and 6 caregivers, focused on the QoL post-stroke (Lynch et al., 2008). Many of the themes discussed involved negative changes in social relationships, along with social support systems whom survivors were functionally dependent on, due to difficulties with communication. A large degree of negative emotions were associated with communication impairments that resulted from stroke, which seemed to emotionally affect survivors much more than physical impairments, especially in the acute phase post-stroke (Lynch et al., 2008). This involved strong feelings of embarrassment, loss of self, frustration, loss of self-esteem, self-confidence, and independence having a significant impact on QoL and functional independence (Lynch et al., 2008).

2.5.5 Fatigue

Fatigue is commonly reported to be a debilitating symptom post-stroke (Choi-Kwon, Han, Kwon, & Kim, 2005; T. Cumming, Packer, Kramer, & English, 2016; Schepers, Visser-Meily, Ketelaar, & Lindeman, 2006), and is even highly prevalent in survivors of mild stroke who have little disability in physical and cognitive domains (Winward, Sackley, Metha, & Rothwell, 2009). Fatigue is classified as a subjective lack of physical or mental energy, or a combination of both, that impacts usual activities of daily living

(T. B. Cumming & Mead, 2017). Fatigue post-stroke is notably related to poor QoL (H. Naess, L. Lunde, J. Brogger, & U. Waje-Andreassen, 2012; Naess, Waje-Andreassen, Thomassen, Nyland, & Myhr, 2006). For example, a recent study ($n=371$) focusing on factors associated with fatigue at six months post-stroke, conducted by Hawkin and colleagues (2017), showed that 51% of participants reported fatigue and that new fatigue was reported in 38% of those who did not experience fatigue initially at baseline. At six months, fatigue was also independently associated with lower scores on the Nottingham Extended Activities of Daily Living measure, representing negatively impacted activities of daily living, and higher scores on the Becks Anxiety Inventory, demonstrating higher levels of anxiety (Hawkins et al., 2017). The presence of depression is also strongly associated with post-stroke fatigue (Wu, Barugh, Macleod, & Mead, 2014). This has a negative impact on social participation, employment, driving, reading and sleep patterns (White, Gray, & Magin, 2012) and overall long-term outcomes post-stroke (H. Naess et al., 2012).

Fatigue impacts activities of daily living and functional independence of stroke survivors, increasing dependence on significant others and/or institutions (Glader, Stegmayr, & Asplund, 2002). Fatigue also impacts the amount of participation one has within the home and the community, along with decreasing motivation and endurance towards rehabilitation potentially influencing therapy outcomes (de Groot, Phillips, & Eskes, 2003).

2.5.6 Emotional Well-being

It is normal for survivors and their families to experience a range of intense fluctuating emotions post-stroke. Depression and anxiety are understood to be a commonly reported symptom post-stroke, with approximately 30-50% of stroke patients suffering from depression in either acute or chronic stages of recovery (De Wit, Putman, Baert, Lincoln, Angst, Beyens et al., 2008; Gordan & Hibbard, 1997; Kennedy, 2012), and approximately 20-40% of patients presenting with anxiety (De Wit et al., 2008; Kennedy, 2012). For example, a 2017 population based study ($n=365$) found that 75% of stroke participants experienced depression or anxiety symptoms within one year post-stroke, with the greatest increase in depressive symptoms occurring from 6 months onwards post-stroke, and anxiety more prevalent within the first few months post-stroke (S Barker-Collo et al., 2017a). Furthermore, a 2015 stroke study with patients with first-ever minor ischemic stroke ($n=747$) found that 26.5% of participants were diagnosed

with post-stroke depression at one year follow up, being independently associated with higher levels of disability and poor physical and mental health (Shi et al., 2016).

Depression and anxiety usually presents due to the loss of many aspects of an individuals' healthy life prior to the stroke occurring, mainly functional independence and the reduction of QoL (Berg, Palomäki, Lehtihalmes, Lönnqvist, & Kaste, 2003; Shi et al., 2016; Singh et al., 2000).

Other general risk factors of emotive issues post-stroke include age, sex, the individuals living arrangement, lack of social support, and a family history of psychiatric disorders (Berg et al., 2003). Evidence suggests that stroke survivors who are suffering from depression are less likely to have a proactive attitude towards their personal rehabilitation and recovery, preventing the patient from engaging well with rehabilitation and therefore reducing the potential functional improvements that could be made (Schmid et al., 2011). For example, a 2015 study ($n=226$) found that 56% of their participants had depression post-stroke and these individuals also had poorer functional outcomes at discharge after rehabilitation interventions (Ahn, Lee, Jeong, Kim, & Park, 2015). Furthermore, Schmid and colleagues' 2011 study ($n=174$) reported that the severity of the individuals' depressive symptoms was negatively associated with the stroke survivors functional independence 12 weeks post-stroke. Stroke survivors suffering from depression and anxiety are more likely to have poorer psychosocial outcomes, are less likely to have a healthy balanced diet and good sleep routine, and are less likely to take their medication correctly (Berg et al., 2003; Kennedy, 2012). Therefore, addressing these issues in rehabilitation is imperative.

2.6 Stroke Rehabilitation

Stroke rehabilitation involves the process of restoring a person to optimum health by finding the best way for a person to return to everyday life and regain reasonable health after an event that led to disability (Kennedy, 2012; Sunnerhagen, 2014). The WHO (2018) defines rehabilitation as a process that assists people to attain and maintain their ideal physical, sensory, intellectual, psychological, emotional, and social levels of functioning, with the rehabilitation process starting from stroke onset and ending when the individual dies (Sunnerhagen, 2014). The quantity and quality of therapy is specifically important within the first 12 weeks post-stroke (McNaughton, Thompson, et al., 2014; Meyer et al., 2015; Stroke Foundation of New Zealand, 2017b), providing a recovery opportunity that is not present at later stages of the rehabilitation process. For

example, Horn and colleagues (2005) study ($n=830$) reported that better functional outcomes were associated with earlier initiation of rehabilitation, more time spent per day in higher-level rehabilitation activities targeting issues such as gait, upper-extremity control and problem solving (Horn et al., 2005).

During the acute period, neurobiological mechanisms that support natural recovery are stimulated (Murphy & Corbett, 2009; New Zealand Nurses Organisation, 2016). Such mechanisms incorporate: functional plasticity, with enhanced neuronal excitability and synaptic efficiency; use-dependent functional plasticity, regarding relearning abilities; and structural plasticity, in terms of cell genesis, axon and dendrite sprouting, and the development of synapses between neurons (Murphy & Corbett, 2009; Wieloch & Nikolich, 2006). Hence implementing rehabilitation in the acute phase of stroke is important for neural plasticity and brain recovery.

During the rehabilitation process, some stroke survivors recover a new sense of self and purpose within and beyond the restrictions of their disabilities as they learn to adapt to the world around them (Stroke Foundation of New Zealand, 2010). The goal of stroke rehabilitation is to support the stroke survivor to acquire knowledge and understanding of the stroke and its outcomes, to utilise their own coping strategies and to take responsibility of their life situation. Simultaneously, allowing survivors to become aware of their potential, considering the resources and limitations, in order to reach old and new life goals is imperative also (Sunnerhagen, 2014). Successful rehabilitation therefore provides stroke survivors with the tools they need to enhance self-determination and reach the highest level of functional independence possible (Kennedy, 2012).

Some research has suggested that a vital factor towards rehabilitation potential, and subsequent recovery from a stroke, is the patients' motivation (Burton, Horne, Woodward-Nutt, Bowen, & Tyrrell, 2015), with early initiation of rehabilitation proven to help strengthen a positive attitude towards recovery for both stroke survivors and their family (Ministry of Health, 2016; Shah et al., 2013). In the past 15 years there has been a significant improvement and growth in availability of stroke services in NZ through stroke units, inpatient rehabilitation, early discharge services, and community support (Stroke Foundation of New Zealand, 2010). Increased admission rates, to acute stroke units has resulted in better outcomes 28 days and 1-year post-stroke, with a

higher 1-year post-stroke survival rate of stroke patients too (Chróinín et al., 2011; V. L. Feigin, Lawes, Bennett, Barker-Collo, & Parag, 2009; Hannon et al., 2011; Palm et al., 2010).

2.6.1 Stroke Units: Acute Stroke Care

According to the Clinical Guidelines (Stroke Foundation, 2017), a successful stroke unit is a geographically-designated area where survivors of stroke are managed by a synchronised interdisciplinary team of health practitioners, with expertise in stroke and rehabilitation. Stroke units should be available, accessible and effective nationally, unrelatedly of where an individual lives, age bracket, ethnicity or gender (Stroke Foundation of New Zealand, 2010). In 2009, a study that assessed national acute stroke services found that only 39% of stroke patients were admitted to an appropriate stroke unit (Stroke Foundation, 2017), suggesting that many gaps still remain in acute stroke care. Due to the complexity of post-stroke impairment, guidelines for stroke rehabilitation both nationally and internationally recommend organised stroke care where expert stroke rehabilitation clinicians work together in a team (Davis, 2014). This is due to the variety of rehabilitation interventions needed within the hospital. It is therefore crucial to have different professionals working together as a multi-disciplinary team in order to lessen stroke sequelae and functional limitations. This will facilitate the stroke survivor with returning to active participation in the community, economic self-sufficiency post-stroke, higher independence and improved QoL (Cawood & Visagie, 2016; Sunnerhagen, 2014).

According to NZ Stroke Guidelines (Stroke Foundation, 2017), stroke patients should receive at least one hour of direct therapist-patient rehabilitation during the acute phase, five days a week. A survey was conducted in 2013 in NZ to assess whether District Health Boards (DHBs) were adhering to guidelines for stroke rehabilitation and organized stroke care (Davis, 2014). Out of the twenty DHBs nationally, a dedicated stroke unit with designated stroke beds was only represented in seven large DHBs (representing 62% of NZ population), with one large DHB not meeting the NZ Stroke Management (NZSM) Guidelines. However, this was an improvement from 2007, when seven DHBs meet NZSM Guidelines but only covered 49% of NZ population.

The National Acute Stroke Services Audit in 2008 ($n=832$), representing 1 in 5 stroke patients admitted to hospital in NZ over a 6 month period (Child et al., 2012), further

demonstrated NZ falling behind in stroke care. Results indicated that the implementation of best practice guidelines for stroke care was irregular, with substantial regional disparity across NZ, and much of the population not having access to a stroke care unit (Child et al., 2012). Out of the 832 stroke patients, only 28% were managed in a stroke unit. Even those patients admitted to one of eight DHBs with a specified stroke unit, only 52% received stroke-focussed care. Furthermore, stroke units are responsible for providing education about stroke to patients, caregivers, whanau and staff along with having protocols for the assessment and management of stroke related issues. Though, according to Davis (2014) stroke units delivered educational sessions on stroke to patients and careers (93%) more than to their own staff (32%) (Davis, 2014). Nursing staff that are caring for stroke survivors should be provided with adequate training and education in order for survivors to have the maximum benefit during recovery, especially in the acute stage.

On the other hand, evidence from the Audit in 2008 also suggests that those in large DHBs with stroke units were highly likely to receive physiotherapy, speech language and social work assessment within two days post-stroke, which is standard protocol. These patients were also less prone to suffering from complications associated to stroke progression than those managed outside of a stroke unit (Child et al., 2012). Data from the survey also established that all stroke units among the DHBs had multidisciplinary team meetings with 86% proving to have a formal process for goal setting and 53% having a written guidelines for goal setting with stroke survivors and family (Davis, 2014). Group therapy was implemented in 89% of the units, speech language therapy was used for 89% of the sample for dysphagia, but only 39% of units provided 'as much as can be tolerated' rehabilitation for communication difficulties. Notably, only 50% of the stroke units accomplished the recommended one hour, five days per week of direct therapist-client contact time 90% of the time (Australian Rehabilitation Centre, 2017; Davis, 2014; McNaughton, McRae, et al., 2014). Out of the 832 stroke patients, 120 (14%) died while in hospital, 224 (27%) were transferred from acute services to inpatient rehabilitation, 333 (40%) were discharged to their own or a family's home and 90 (11%) were discharged to residential care. Before being discharged, only 42% had a discharge care plan provided and recorded, 32% received patient education on stroke and 13% had a home visit performed (Child et al., 2012). Moreover a variation of 39% - 64% was found among DHBs conducting screening processes for communication, vision, cognition, perceptual deficits and nutrition issues. Surprisingly, 43% of units did

not screen for depression and anxiety, even though these are common psychological and emotional issues post-stroke.

The benefits of stroke unit care is extensively acknowledged but their still remains large reservations around what best practice is comprised of in terms of type of rehabilitation, length and dose. Access to stroke unit care persists to be insufficient for stroke patient management in NZ (Child et al., 2012; O'Rourke & Walsh, 2010; Stroke Unit Trialists Collaboration, 2013).

2.6.2 Inpatient Rehabilitation

Inpatient rehabilitation for stroke occurs within the hospital or inpatient rehabilitation setting (McNaughton, Thompson, et al., 2014). Processes that need to be implemented within stroke rehabilitation include medical, physical, cognitive, social, economic and vocational interventions focused and uniquely tailored to a stroke survivors functional impairments (Davis, 2014; Sunnerhagen, 2014). Stroke focused rehabilitation teams usually include the following members: physicians, nursing staff, occupational therapists, psychologists and social workers (Sunnerhagen, 2014). Consideration of the stroke survivor's needs, along with the team of professionals' specialised knowledge should be utilised (Sunnerhagen, 2014), with assessments and monitoring conducted by trained rehabilitation personnel (McNaughton, McRae, et al., 2014).

A low level of engagement and physical activity during the acute phase leads to a gradual physical deterioration and loss of function, which has a detrimental impacts on long-term activities of daily living and QoL (Aprile et al., 2006; Cramp et al., 2010; Outpatient Service Trialists, 2003; Rose et al., 2011; Saywell et al., 2012). For example, a randomised controlled trial of stroke survivors ($n=99$) reported that patients who were in the intervention group (receiving 36 sessions of stroke focused rehabilitation therapy over 12 weeks initiated from the acute phase post-stroke) had higher than average BI scores, in comparison to the usual care group immediately post-treatment (Studenski et al., 2005). Studenski et al., (2005) also reported that the intervention group had a higher QoL immediately post-treatment and at 12 week follow up, in comparison to those who received usual care. Another study found stroke survivors ($n=283$) who had regular rehabilitation, introduced in the acute inpatient phase, had higher BI scores, which correlated with significantly improved self-perceived health related QoL on EQ-5D 12 months post-stroke, in comparison to regular care (Hansson, Beckman, Wihlborg,

Persson, & Troein, 2013). More evidence is presented through a 1999 study ($n=220$) which examined the long-term outcomes of an acute rehabilitation unit in Norway, comparing outcomes of surviving patients at 10 years post-stroke (Indredavik, Bakke, Slørdahl, Rokseth, & Håheim, 1999). Evidence suggests that patients in the stroke unit who received stroke focused rehabilitation had higher independence, represented by higher BI scores and higher QoL scores at 10 years, in comparison to those in a general ward post-stroke (Indredavik et al., 1999). However, these studies were not population-based, outcome measurements were not taken at regular intervals and stroke patients used were not from a NZ population. Therefore, these studies have limited generalisability, whereas a population-based study is the gold-standard methodology for epidemiological research and allows for generalisation of results within the NZ population.

NZ's hospital facilities falling short of international and national guidelines is evident. In one large DHB and all the medium to small DHBs, stroke rehabilitation happened on general treatment and rehabilitation wards (Davis, 2014). On the whole, only 32% of primary rehabilitation units had designated beds for stroke and only 68% were able to accommodate all stroke patients needing inpatient stroke rehabilitation, with a further 29% able to accommodate stroke patients 75% of the time. A 2005 stroke study, with 1161 stroke survivors, compared stroke rehabilitation care in the United States of America (USA) and NZ, showing significantly better outcomes for those receiving more intensive rehabilitation (McNaughton, DeJong, Smout, Melvin, & Brandstater, 2005). The average length of stay in USA rehabilitation facilities was much shorter (18.6 days vs 30 days NZ), though physical and occupational therapy time per patient was much higher in the shorter amount of stay within the hospital in the USA. In fact, physiotherapist one on one time with patient was double the amount of minutes per day in the USA compared to NZ, and occupational therapist one on one time was more than triple amount of minutes per day. There were less survivors discharged to institutional care in the USA, and these stroke survivors had more significant improvements on a functional independence measure (McNaughton et al., 2005).

2.6.3 Community-Based Rehabilitation

In NZ, approximately 30% of stroke survivors are discharged from hospital to home but are dependent on others for activities of daily living, with the burden of an array of costs relating to ongoing rehabilitation, unemployment, carers reduced ability to work,

associated loss of social roles in the community and an incline in stress for all involved (Davis, 2014). Many community services that reduce hospital days have been developed for medical conditions such as diabetes, obstructive pulmonary disease and congestive heart failure in NZ (McNaughton, Thompson, et al., 2014). However, there is a lack of rehabilitation services within the community for those suffering from post-stroke difficulties, despite evidence towards such services reducing the amount of functional disability a stroke patient has long-term (Child et al., 2012; McNaughton, Thompson, et al., 2014; Saywell et al., 2012).

Several studies have established that stroke survivors living in the community are already considerably restricted in participation relating to areas involving employment, and loss of social roles and activities within the community (V Feigin et al., 2010; McNaughton, Thompson, et al., 2014). A 2017 study ($n=96$) assessed outcome levels of body function, activity and participation between two to three years post-stroke (Kapoor et al., 2017) and found that 52% of stroke survivors had community reintegration issues which highly impacted their overall QoL. Furthermore, White and colleagues found in their 2016 study ($n=134$) that one year post-stroke higher health related QoL scores were directly associated with greater community participation, demonstrating interventions aimed at addressing participation within the community post-stroke being important (White et al., 2016). Healthcare resources are restricted in NZ, and whether a stroke survivor obtains suitable and long-term stroke services is often related to non-stroke factors, such as resource availability, living location in NZ, age, and personal finances (Saywell et al., 2012).

Early Supported Discharge

ESD aims to reduce the length of hospital stay by connecting inpatient care with community services to deliver rehabilitation services within the stroke survivors' home environment (Stroke Foundation, 2017). The main purpose of ESD is to be an extension of stroke unit care in the individuals' home, as the goal of rehabilitation is to recover and establish skills of daily living within their home setting to increase functional independence and QoL (Stroke Foundation, 2017). The level and dosage of services post discharge from hospital can be restricted, with stroke survivors and families commonly reporting that they do not have sufficient information, access to support services and therapies available to assist with the rehabilitation process at home (Stroke Foundation, 2017). To be effective ESD must have comparable features to those of

organized multidisciplinary stroke teams. According to Sunnerhagen (2014), ESD has proven to be safe, financially economical for the health system, and reduced risk of death and dependency. Though there is a lack of information towards how ESD should be organised and implemented. According to the survey conducted on 20 DHBs in NZ in 2013, only 18% had an ESD service proficient in delivering a comparable service to inpatient care within 24 hours of discharge (Davis, 2014). The majority of units (82%) provided outpatient rehabilitation services through ESD, with an average delay of two weeks before receiving first therapist input, with the opening session usually being an assessment rather than the implementation of the rehabilitation program itself.

Taking the evidence that the intensity of rehabilitation input has a positive impact on outcomes, it seems inefficient to devote large amounts of time and money on inpatient acute stroke care and to not follow patients up with suitable ESD or community rehabilitation directly after hospital discharge. Similar outcomes achieved in inpatient care can be reached in the survivors own home also if rehabilitation dosage, at least once daily, is similar to that in the hospital. NZ community stroke services rarely provide rehabilitation more than 2 days a week (Davis, 2014), with only 18% of DHBs actually offering a community stroke focused service.

When comparing NZ stroke guidelines with the UK National Guidelines for Stroke (Royal College of Physicians, 2016), NZ standards are much lower in terms of community support and rehabilitation for survivors. UK National Guidelines for Stroke necessitates all patients to be contacted by the community rehabilitation team within 24 hours of discharge and assessed within 3 days. Treatment programs then must be instigated within 24 hours of assessment for those on ESD or within 7 days for other patients. Furthermore, it is expected that patients receive five sessions per week for the first two weeks or three sessions per week for the first four weeks including occupational therapy, physiotherapy and speech language therapy (Davis, 2014). In alignment with these guidelines, evidence is presented from a 2015 UK study ($n=293$) evaluating the benefits of ESD on activities of daily living, QoL and satisfaction with services for survivors of mild to moderate stroke (Fisher et al., 2016). Six weeks post discharge, stroke survivors receiving ESD ($n=135$) had less number of days in hospital, reported higher satisfaction towards services, expressed feelings that ESD had a large amount of practical and applicable help in their home environment, along with having more education towards reducing the risk of further stroke. EQ-5D index scores and BI

scores were much higher for the ESD group also, demonstrating that effectiveness of ESD if applied optimally (Fisher et al., 2016). Less evidence is available towards how services should be adapted towards different ethnicities (especially Māori and Pacific people in NZ) and different age groups (children, younger adult, middle aged adult, older adult). Though, evidence suggests that ongoing participation in physical activity and social engagement in the community setting prevents the decline in functional independence commonly seen in stroke survivors once acute rehabilitation has finished (Saywell et al., 2012).

Even though research suggests that hospital admissions of stroke has improved over a 30 year period in NZ (1981-2012), with more of the population having access to stroke focused medical care, along with more people being aware of stroke signs and therefore presenting to hospital sooner, there is still evidence of underutilisation of acute, inpatient and community rehabilitation facilities within NZ.

Chapter 3 Methodology

This study investigated the association between rehabilitation and long-term functional independence and QoL outcomes post-stroke in an existing NZ population-based cohort of four-year stroke survivors. This was done by comparing the type of stroke rehabilitation individuals received (inpatient and/or community rehabilitation) to functional independence measures (measuring an individual's level of daily functioning) and QoL measures four years post-stroke.

3.1 Participant Recruitment

The data for this project was derived from the four-year follow-up of sample ($n=255$) drawn from the fourth Auckland Stroke Regional Community Outcomes Population-based study (ARCOS-IV). The ARCOS-IV study is among a few in the world that have been carried out at a population level at regular intervals, making this study unique in stroke research both internationally and in NZ. The full methodology of the ARCOS-IV study has been described elsewhere (Krishnamurthi et al., 2014). In brief ARCOS-IV was an incidence and outcomes study of first-ever and recurrent stroke based in Auckland, between February 2011 until March 2012 (Krishnamurthi et al., 2014). There was four main inclusion criteria: 1) incident stroke between March 1, 2011 and February 29th, 2012; 2) resident of Auckland Region; 3) ≥ 16 years. Case ascertainment used various sources of information to acquire both hospitalised and non-hospitalised stroke cases. Stroke was defined using WHO standard diagnostic criteria, (Aho et al., 1980a) and divided into pathological types (ischaemic, intracerebral, subarachnoid, undetermined) according to standard clinical and CT (computed tomography)/MRI (magnetic resonance imaging)/necropsy findings (97% cases were identified according to this criteria). Medical and health-related risk factors were obtained via hospital medical records at the time of stroke and included information towards blood pressure, blood cholesterol levels, diabetes mellitus, coronary heart disease, and arrhythmia. Participants completed assessments at baseline (within two weeks of stroke event), and/or 1, 6, 12 and those who consented were followed up at four years post-stroke.

Originally there were 255 participants in the sample, though participants who had moderate to severe stroke, scoring ≥ 4 on the mRS, were removed ($n=14$) from the

analysis due to having very high functional disability and potentially skewing findings ($n=241$).

3.2 Procedure

The data for this project was previously collected during a four year follow-up of the ARCOS-IV study. A brief outline of the data collection is as follows. Participants who had provided consent at their 12 month follow-up assessment to be contacted about stroke research in the future were contacted and were invited to take part in the four-year follow-up study. Contact information for the previously consented participants was obtained via a password protected database. A participant information sheet and consent form was sent either through post or email. Written consent was obtained at the face-to-face assessment, which was completed at the participants' place of residence or an appropriate location for the participant, and took approximately 2 hours to complete. Participants were asked to answer general questions about their health, lifestyle factors and any other changes in living (marital and employment status) since their last assessment. Access to rehabilitation was recorded (taking into consideration hours per week and frequency of inpatient rehabilitation, and also type [physiotherapy, speech, occupational, outpatient program], hours per week and frequency of community rehabilitation)(see Appendix C) at the follow up appointment at four years post-stroke. QoL was assessed using the EuroQol Quality of Life Scale (EQ-5D; Appendix D), the Hospital Anxiety and Depression Scale (HADS; Appendix E), and the Medical Outcomes Study Short Form 36 (SF-36; Appendix F). Functional independence was assessed using the Barthel Index (BI; Appendix G), the Modified Rankin Scale (mRS; Appendix H), Fatigue Severity Scale (FSS; Appendix I) and the Fatigue Visual Analogue Scale (Appendix J), and the Montreal Cognitive Assessment (MoCA; Appendix K). All baseline demographic and clinical stroke characteristics were extracted from the ARCOS-IV database (see Table 1.).

3.3 Ethical Approval

Ethical approval was obtained from the NZ Northern Y Regional Ethics Committee (NTX/10/90/090/AM07) and the Auckland University of Technology Ethics Committee (AUTEK 11/297).

3.4 Demographic and Stroke Characteristics

Covariate factors measured at baseline, included demographics (age, gender, ethnicity, education level, marital status, employment); stroke characteristics (subtypes: vascular territory, lesion location, hemisphere); and vascular risk factors (hypertension, coronary artery disease, arrhythmia, hypercholesterolemia, and diabetes mellitus). Diagnostic criteria for these covariates are reported elsewhere (R Krishnamurthi et al., 2014).

3.5 Outcome Measures

Outcome measures implemented in this study focus on functional independence and QoL, also covering potential stroke sequelae understood to impact level of independence and life quality, namely cognitive functioning, fatigue, and emotional well-being.

3.5.1 Modified Rankin Scale

The Modified Rankin Scale (mRS; Appendix H) is the most universally used tool for measuring the grade of disability and functional independence in stroke patients (J. Rankin, 1957). The mRS is a 6-point ordinal scale which is rated from 0 (no residual symptoms at all) to 5 (bedridden) and 6 being deceased (J Rankin, 1957). For the purpose of this thesis mRS scores of ≤ 2 are graded as mild disability, and >2 is graded as severe disability. Administration only takes five minutes to complete and this measure has shown high sensitivity towards detecting clinical change subsequent to ischaemic and haemorrhagic stroke (Banks & Marotta, 2007; Cioncoloni et al., 2012; K. Lees et al., 2012; Nunn, Bath, & Gray, 2016; Olavarría et al., 2017). It has been demonstrated by a number of studies that the construct validity of the mRS is supported, signifying that lesion volume (Schiemanck et al., 2005), grade of injury caused by stroke (Derex et al., 2004), and stroke sub-type (Petty et al., 2000) are related with short and long-term disability.

3.5.2 The Barthel Index

The Barthel Index (BI; Appendix G) measures a person's daily functioning in terms of daily living and mobility (Collin, Wade, Davies, & Horne, 1988). This measure has commonly been used to measure activities of daily living in stroke patients, has high inter-rater and test-retest reliability, along with high correlations with other measures of

physical disability (O'Sullivan, O'Sullivan, & Schmitz, 2000). The BI is an ordinal scale and measures ten variables describing activities of daily living and mobility. Each performance item is rated and the sum of the patients' score for each item is added. Scores range from 0 – 20, with lower scores demonstrating increased disability (Collin et al., 1988). It is suggested by Collin and colleagues (1988) that a score of 14 indicates disability in functional independence that is compatible with the level of support found in the home setting, whereas a score ≤ 10 requires the stroke patient to have maximum support from family and careers or institutions (Collin et al., 1988). Therefore the cut off within this study will be ≤ 14 , representing disability in functional independence present.

The BI has been suggested to be a better predictor of functional outcomes in comparison to pathology of stroke (Donnelly, Power, Russell, & Fullerton, 2004; Shah, Vanclay, & Cooper, 1990; Sturm et al., 2004) and arguably one of the most popular activities of daily living measurements in clinical practice (Quinn, Langhorne, & Stott, 2011; Wade & Collin, 1988). The BI has been used in a range of research focusing on stroke rehabilitation functional outcomes (Dobkin, 2005; Quinn et al., 2011; Shah et al., 1990) and also functional outcomes in response to medication for stroke (Sulter, Steen, & De Keyser, 1999). The BI measures functional independence at one point in time and is reliable in measuring change over time.

3.5.3 Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale (HADS; Appendix E) (Zigmond & Snaith, 1983) is a self-administered psychometric tool used to measure mood and is well-validated for stroke populations (Ayerbe, Ayis, Crichton, Wolfe, & Rudd, 2014; S Barker-Collo et al., 2017b; R. Lees, Broomfield, & Quinn, 2014; Pedroso, Vieira, Brunoni, Lauterbach, & Teixeira, 2016). Scores range from 0 to 21, with 0 – 7 (representing normal mood), 8 – 10 (representing mild anxiety or depression), 11 – 14 (moderate anxiety or depression), and 15 – 21 (severe level of anxiety or depression) (Zigmond & Snaith, 1983). Therefore, the cut offs for this sample will be ≥ 8 , representing anxiety or depression present. There is the benefit of having separate anxiety and depression subscales, additional to the total HADS score, which will be utilised in this current study. HADS has shown a high level of internal consistency for both the anxiety and depression subscales (Cronbach alpha of .83 and .82) (Zigmond & Snaith, 1983). Though, several studies have commented on the anxiety subscale being

less sensitive to detect anxiety in older stroke populations in comparison to other anxiety measures (Bryant, Jackson, & Ames, 2009; Kneebone, Fife-Schaw, Lincoln, & Harder, 2016). A number of studies have used the HADS for measuring predictors of long-term cognitive impairment also (S Barker-Collo, V Feigin, V Parag, C Lawes, & H Senior, 2010; S Barker-Collo et al., 2016).

3.5.4 Montreal Cognitive Assessment

The Montreal Cognitive Assessment (MoCA; Appendix K) is a screening tool intended to distinguish global cognitive impairment across eight domains; conceptual thinking, calculation, attention, language, concentration, memory, orientation, visuo-constructional skills and orientation (Nasreddine et al., 2005). Responses are given points corresponding to specific criteria. With a maximum score of 30, higher scores signify higher cognitive function, with individuals scoring ≥ 26 considered as having no cognitive impairment (Nasreddine et al., 2005).

MoCA has been described as highly sensitive (0.88-92.3), (Dong et al., 2016; Trzepacz, Hochstetler, Wang, Walker, & Saykin, 2015; Tsai et al., 2016). Though the cut off score of ≤ 26 for the MoCA has been disputed throughout stroke research, with no clear agreement towards the best threshold (Chiti & Pantoni, 2014; R Stolwyk, 2016; R Stolwyk, O'Neill, McKay, & Wong, 2014), with a range of acceptable levels of sensitivity and specificity being testified at varying cut-off points (T Cumming, Churilov, Linden, & Bernhardt, 2013; Godefroy et al., 2011; Salvadori et al., 2013). For the purposes of this thesis stroke survivor participants who scored ≤ 26 on the total MoCA were considered as cognitively impaired in comparison to those with a cut-off score of ≥ 26 who were described as not impaired.

3.5.5 Fatigue Severity Scale

The Fatigue Severity Scale (FSS; Appendix I) is a 9-item self-report scale that assess the influence of fatigue on daily living, considering domains of motivation, social participation, sleep and activity (Krupp, LaRocca, Muir-Nash, & Steinberg, 1989). Every one of the 9-items are rated on a seven point scale, ranging from 1 signifying (no problem) to 7 (signifying severe problem), with scores of ≥ 4 signifying severe fatigue (Krupp et al., 1989). The FSS total score is attained by the average of the score of the 9-items. The FSS has been implemented extensively throughout stroke research and the

assessment of post-stroke fatigue (Learmonth et al., 2013; Lerdal & Gay, 2017; Lerdal & Kottorp, 2011; M Nadarajah & H Goh, 2015; H Naess, L Lunde, J Brogger, & U Waje-Andreassen, 2012). The FSS was found to have a very good test-retest reliability for stroke patients (demonstrated by intraclass correlation coefficient = 0.93) (Nadarajah, Mazlan, Abdul-Latif, & Goh, 2016), outstanding internal consistency (Nadarajah et al., 2016), and good internal consistency (Cronbach's alpha >.90). The FSS was also found to have good concurrent validity with the Visual Analogue Fatigue Scale measure (determined by spearman correlation coefficient $r > .60$) (Tseng, Gajewski, & Kluding, 2010).

3.5.6 Visual Analogue Fatigue Scale

The Visual Analogue Fatigue Scale (VAFS; Appendix J) measures the subjective experience of fatigue by marking their perceived level of fatigue on a vertical 10cm line (Tseng et al., 2010). Potential scores range from 0 (indicating no fatigue present) to 100 (severe levels of fatigue present) (Lee, Hicks, & Nino-Murcia, 1991; Shahid, Wilkinson, Marcu, & Shapiro, 2012; Tate, 2010; Tseng et al., 2010). Because of the vertical presentation of the measure, it removes complications for stroke survivors who may have issues with visuospatial deficits and/or visual neglect (Tseng et al., 2010). The VAFS has also shown good reliability and validity as a measure for fatigue within stroke populations (Benjamin, Byron, & Patricia, 2010; Kruithof, Van Cleef, Rasquin, & Bovend'Eerdt, 2016; Lerdal et al., 2009; M Nadarajah & H Goh, 2015; Tsoi, Chan, Hirai, Wong, & Kwok, 2015).

3.5.7 Medical Outcomes Study Short Form 36

The Medical Outcomes Study Short Form 36 (SF-36; Appendix F) is a generic health measure of self-reported health status (Scott, Tobias, Sarfati, & Haslett, 1999). The questionnaire comprises of 36 items, grouped into eight scales measuring varying aspects of health. This includes: physical functioning; role functioning physical, involving the impact of physical health on daily performance roles; role functioning emotional, involving the impact of emotional health on daily performance roles; social functioning; emotional well-being; energy and fatigue; general health; and perceived health change (Rand Health, 2018; Scott et al., 1999). Each item is scored on 0 (lowest) to 100 (highest) range, with higher scores associated with higher health status (Rand Health, 2018).

Cut offs for this current sample will be distinguished as below the mean for each of the eight subscales, differentiated by NZ normative data (Scott et al., 1999). The SF-36 has demonstrated good internal consistency within the NZ population (Cronbach's alpha >0.70 for all eight scales). Construct validity was also above acceptable, proving to measure the health concepts in focus, and demonstrated higher psychometric performance in the NZ population in comparison to other national surveys (Scott et al., 1999).

3.5.8 EuroQol Quality of Life Scale

The EuroQol Quality of Life Scale (EQ-5D; Appendix D) consists of five questions with three response categories. The EQ-5D takes approximately 2 – 3 min to complete and provides a profile indicating the extent of problems experienced on each of five dimensions by the stroke patient, a population-weighted health index and a self-rated assessment of current perceived health (Salter et al., 2005). The EQ-5D is a self-administered questionnaire. The first part contains a simple descriptive profile of health in five dimensions (mobility, self-care, usual activities, pain/discomfort and anxiety/depression). The respondent chooses the statement within each dimension that is most applicable to themselves at the time of assessment. Each dimension statement selected receives a numerical rating of 1 (some or no problem), 2 (moderate problems) or 3 (extreme problems) (EuroQol Group, 1990). The scores of the five dimensions can be converted into a summary index number, with 243 such representations possible, which can be compared to other health profiles (Salter et al., 2005). By the application of scores from standard value sets each of these dimensions of health can be transformed into a utility value ranging from 0 (worst possible) to 1 (best possible). Standard values have been produced for a variety of countries, including NZ, and cut-offs for each of the five dimensions have been derived from population data (EuroQol Group, 1990).

The EQ-5D is simple to administer and imposes minimal burden on the respondent (EuroQol Group, 1990), considering the range of functional disabilities that one may have post-stroke. The EQ-5D considers the patient's emotional, social and physical well-being by providing a profile indicating the extent of problems experienced on each of five dimensions (Dyer, Goldsmith, Sharples, & Buxton, 2010). The EQ-5D is a useful measurement tool to assess health related QoL outcomes for patients impacted by stroke, and to compare QoL outcomes between those who received rehabilitation and those who did not.

3.6 Statistical Analysis

Profile analyses has been used for descriptive statistics to summarise the demographic, socio-demographic, stroke-related characteristics, and stroke related risk factors of the sample. Data has been reported as number and percentages for categorical variables, and means and standard deviations for continuous variables.

To assess representativeness of those who received inpatient rehabilitation compared to those who did not, and for those who received community rehabilitation compared to those that did not, chi square analyses was used to compare categorical predictors. Bivariate correlation (Spearman's) was employed to explore the association of rehabilitation with demographic, sociodemographic stroke related characteristics, stroke related risk factors, and outcome measures of functional independence, QoL, emotional well-being, fatigue, and cognition. Independent Samples T-test was used to compare parametric outcome measures and the Mann-Whitney U test to compare non-parametric outcome measures. The significance level will be set to $p < 0.05$ to signify statistical significance. Multivariate regression analysis was not conducted because none of the covariates were considered significant.

Chapter 4 Results

Descriptive information is presented in Table 1 for demographic and stroke characteristics of the sample. In brief, the average time since stroke was 3.29 years \pm 0.23 (ranging from 2.52 to 4.34 years). The mean age of the sample at four years was $m=71.07 \pm 13.62$ (ranging from 28.6 to 95.44 years). At the time of stroke, NZ Europeans were older ($M=69.58$, $SD=12.66$) by an average of 17 years, compared to Pacific people ($M=52.17$, $SD=10.06$), and 16 years compared to Māori ($M=53.43$, $SD=12.15$). Female participants ($n=113$, 46.9%) were very similar in age at stroke onset ($M=67.89$, $SD=15.46$) in comparison to male participants' ($n=128$, 53.1%) age at stroke onset ($M=67.68$, $SD=11.89$). The majority of the sample were NZ European ($n=195$, 80.9%) and had ISC strokes ($n=209$, 86.7%). 202 (83.8%) experienced their first ever stroke, compared to 29 (16.2%) who had a recurrent stroke. Lesions occurred for the most part in subcortical areas (60.2%) compared to cortical areas (27%). Baseline vascular risk factors included high cholesterol ($n=125$, 51.9%), hypertension ($n=157$, 65.1%), diabetes mellitus ($n=47$, 19.5%), coronary heart disease ($n=50$, 20.7%), and arrhythmia ($n=63$, 26.1%).

91 (37.8%) out of the 241 participants received inpatient rehabilitation and 76 (31.5%) had community rehabilitation. Within the sample, 49 (20.3%) received both inpatient and community rehabilitation, leaving 74 (30.7%) participants who did not receive any form of rehabilitation post-stroke. All 241 participants completed the mRS, the BI, the HADS, the FSS, the VAFS, EQ-5D, the SF-36, at four year follow up.

Table 1. Demographic and Clinical Features of Sample

Descriptive	<i>n</i>	<i>%</i>
Age Groups		
< 50	32	13.3
51- 64	54	22.4
65-74	75	31.1
75+	80	33.2
Gender		
Female	113	46.9
Male	128	53.1
Ethnicity		
Māori	12	5
Samoan	2	0.8
Tongan	2	0.8

Asian or Other	29	12
Niuean	1	0.4
NZ European	195	80.9
Marital Status		
Married	151	62.7
Never married/separated, divorced, or widowed	90	37.3
Employment		
Employed	47	19.5
Unemployed	22	9.1
Retired	160	66.4
Not specified	12	5
Education		
Did not complete school	64	26.6
Completed school	48	19.9
Post-school qualification	125	51.8
Missing	4	1.7
Recurrent Stroke		
Yes	39	16.2
No	202	83.8
Stroke Type		
IS	209	86.7
ICH	14	5.8
SAH	18	7.5
Stroke Subtype		
PACI	73	30.3
TACI	18	7.5
LACI	69	28.6
POCI	63	26.1
Unknown	18	7.5
Hemisphere of Lesion		
Left	106	44
Right	113	46.9
Brainstem	8	3.3
Both	13	5.4
Uncertain	1	0.4
Stroke Vascular Territory		
MCA	130	53.9
PCA	49	20.3
PICA	31	12.9
ACA	9	3.7
SCA	2	0.8
Unknown	20	8.4
Location of Lesions		

Cortical	65	27.0
Subcortical	145	60.2
Unknown	31	12.8
Vascular Risk Factors		
High cholesterol	125	51.9
Hypertension	157	65.1
Diabetes	47	19.5
Coronary heart disease	50	20.7
Arrhythmia present	63	26.1
Inpatient Rehabilitation		
Yes	91	37.8
No	148	61.4
Missing	2	0.8
Community Rehabilitation		
Yes	76	31.5
No	163	67.6
Missing	2	0.8
Inpatient and Community Rehabilitation Received		
	49	20.3
Age Years, mean, (SD)	67.78	13.65
Time Since Stroke, mean, (SD)	3.29	0.23

Note: ISC, ischemic stroke; ICH, intracerebral haemorrhage; SAH, subarachnoid haemorrhage; PACI, partial anterior circulation infarct; TACI, total anterior circulation infarct; LACI, lacunar infarct; POCI, posterior circulation infarct; MCA, middle cerebral artery; PCA, posterior cerebral artery; PICA, posterior inferior cerebral artery; ACA, anterior cerebral artery; SCA, superior cerebellar artery.

4.1 Outcomes at Four Years

Table 2 shows the mean outcome scores at 4 years post-stroke. Scores represent mean scores (M) and standard deviations (SD) for the outcome measures of the sample. The mRS on average ($M=1.03$, $SD=1.11$) showed the sample to have minimal disability, though mRS >3 was excluded from analysis. Functional independence also represented minimal disability, measured by the BI ($M=19.16$, $SD=2.56$), scores range from 0 – 20, with lower scores demonstrating increased disability. Furthermore, HADS anxiety ($M=3.58$, $SD=3.38$) and depression ($M=4.11$, $SD=2.82$) were also representative of a normal mood four years post-stroke within this sample, with scores ≤ 7 representing normal mood. The EQ-5D utility score at four years was also within a suitable range ($M=0.75$, $SD=0.23$), with a utility value ranging from 0 (worst possible) to 1 (best possible). On the EQ-5D constructs a smaller proportion of participants reported moderate to severe problems in mobility ($n=90$, 37.3%), self-care ($n=52$, 21.6%), usual activities ($n=84$, 34.9%), pain and discomfort ($n=83$, 34.4%), and anxiety and depression ($n=50$, 20.7%).

When examining the remaining outcome measures, impairment was evident at four years. For example; 201 (83.4%) of participants had cognitive impairment, as indicated by a mean MoCA score of <26 ($M=20.80$, $SD=4.61$). Additionally, a high level of fatigue was present in 137 (56.8%) of the participants on the FSS ($M=5.22$, $SD=1.76$), with a score of ≥ 4 signifying severe fatigue. The VAFS ($M=54.61$, $SD=17.96$) also demonstrated self-reported fatigue present on average, with a score of 0 representing no fatigue present and a score of 100 representing severe levels of fatigue present. At four years on the SF-36, the sample demonstrated to be below the mean of the NZ population in constructs involving physical functioning ($M=60.44$, $SD=36.6$), role functioning physical ($M=74.07$, $SD=41.16$), role functioning emotional ($M=73.86$, $SD=42.1$), energy and fatigue ($M=55.64$, $SD=22.7$), social functioning ($M=83.61$, $SD=22.61$), general health ($M=64.5$, $SD=27.31$), and health change ($M=49.48$, $SD=21.22$).

Table 2. Outcomes at Four Years of Sample

Outcome Measures	<i>M</i>	<i>SD</i>
MRS	1.03	1.11
BI	19.16	2.56
HADS		
Anxiety	3.58	3.38
Depression	4.11	2.82
MoCA	20.80	4.61
FSS	5.22	1.76
VAFS	54.61	17.96
SF-36		
Physical Functioning	60.44	36.6
Role Functioning Physical	74.07	41.16
Role Functioning Emotional	73.86	42.1
Energy and Fatigue	55.64	22.7
Mental Health	78.71	15.59
Social Functioning	83.61	22.61
General Health	64.5	27.31
Health Change	49.48	21.22
EQ-5D		
Mobility	1.39	0.51
Self-Care	1.24	0.48
Usual Activities	1.39	0.57
Pain and Discomfort	1.39	0.58
Anxiety and Depression	1.22	0.43
EQ-5D Utility Score	0.75	0.23

* Scores represent mean total scores (*M*) and standard deviations (*SD*) for the outcome measures at four years.

Note: mRS, Modified Rankin Scale; BI, Barthel Index; HADS, Hospital Anxiety and Depression Scale; MoCA, Montreal Cognitive Assessment; FSS, Fatigue Severity Scale; VAFS, Visual Analogue Fatigue Scale; SF-36, Medical Outcomes Study Short Form 36; EQ-5D, EuroQol Quality of Life Scale.

Spearman's correlation was conducted to identify relationships between inpatient or community rehabilitation and outcomes at four years (Table 3). Significant correlation was found between Inpatient Patient Rehabilitation and the BI ($p=0.004$), and within the EQ-5D Self-Care ($p=0.001$) and Usual Activities constructs ($p=0.005$). A relationship was also found between Community Rehabilitation and the SF-36 Health Change construct ($p=0.025$).

Table 3. Spearman's Correlation: Inpatient Rehabilitation versus Community Rehabilitation and Outcome Measures at Four Years Post-Stroke

Outcome Measures	Inpatient Rehabilitation <i>p</i>-value	Community Rehabilitation <i>p</i>-value
Inpatient Rehabilitation	.	0
Community Rehabilitation	0	.
mRS	0	0
BI	0.004	0.506
HADS Anxiety	0.738	0.637
HADS Depression	0.324	0.633
MoCA	0.251	0.79
FSS	0.958	0.17
VAFS	0.958	0.17
SF-36 Physical Functioning	0.088	0.602
SF-36 Role Functioning Physical	0.94	0.84
SF-36 Role Functioning Emotion	0.605	0.739
SF-36 Energy and Fatigue	0.905	0.136
SF-36 Mental Health	0.247	0.732
SF-36 Social Functioning	0.561	0.134

SF-36 General Health	0.785	0.625
SF-36 Health Change	0.066	0.025
EQ-5D Mobility	0.065	0.29
EQ-5D Self-Care	0.001	0.792
EQ-5D Usual Activities	0.005	0.054
EQ-5D Pain and Discomfort	0.656	0.641
EQ-5D Anxiety	0.494	0.117
EQ-5D Utility Score	0.076	0.362

**P-values represent significance at <0.05.*

Note: mRS, Modified Rankin Scale; BI, Barthel Index; HADS, Hospital Anxiety and Depression Scale; MoCA, Montreal Cognitive Assessment; FSS, Fatigue Severity Scale; VAFS, Visual Analogue Fatigue Scale; SF-36, Medical Outcomes Study Short Form 36; EQ-5D, EuroQol Quality of Life Scale.

4.2 Inpatient Rehabilitation

The average amount of time the 91 participants spent in inpatient rehabilitation was 6 weeks \pm 5.72 (ranging from 2 days to 38 weeks). The locations of inpatient rehabilitation varied among the sample and included; North Shore Hospital, Acquired Brain Injury (ABI) Rehabilitation, Rehab Plus, Laura Fergusson Rehabilitation Greenlane, Auckland Hospital, Waitakere Hospital, and Assessment, Treatment and Rehabilitation (AT&R) Services (geriatric rehabilitation service). At least 9 participants received inpatient care from multiple services, 3 of these were due to other complications such as broken hip and pulmonary embolism.

Table 4 compares means of demographic information between those participants who received inpatient rehabilitation against those who did not receive inpatient rehabilitation. In terms of representativeness of those who received inpatient rehabilitation and those who did not within the stroke sample, there was no significant differences between most characteristics, with the exception of stroke sub-type.

Table 4. Characteristics of Sample: Inpatient Rehabilitation versus No Inpatient Rehabilitation

Descriptive	Inpatient Rehabilitation		No Inpatient Rehabilitation		Test of Difference Value
	<i>n</i>	%	<i>n</i>	%	
Age Group					
< 50	11	12.1	21	14.2	$X^2 = 2.67, p=0.45$
51- 64	25	27.5	29	19.6	
65-74	29	31.9	45	30.4	
75+	26	28.6	53	35.8	
Gender					
Female	46	50.5	66	44.6	$X^2= 0.8, p=0.37$
Male	45	49.5	82	55.4	
Ethnicity					
European	74	81.3	119	80.4	$X^2= 1.87, p=0.17$
Non-European	17	18.7	29	19.6	
Marital Status					
Married	56	61.5	95	64.2	$X^2=0.17, p=0.68$
Never married/separated, divorced, or widowed	35	38.5	53	35.8	
Employment					
Employed	14	15.4	32	21.6	$X^2 = 1.99, p=0.57$
Unemployed	9	9.9	13	8.8	
Retired	62	68.1	97	65.5	
Not specified	6	6.6	6	4.1	
Recurrent Stroke					
Yes	10	11	29	19.6	$X^2= 3.06, p=0.08$
No	81	89	119	80.4	
Stroke Type					
IS	74	81.3	133	89.9	$X^2 = 3.34, p=0.19$
ICH	9	9.9	5	3.4	
SAH	8	8.8	10	6.8	
Stroke Sub-Type					
PACI	28	30.8	43	29.1	$X^2=10.93, p=0.03$
TACI	12	13.2	6	4.1	
LACI	27	29.7	42	28.4	
POCI	16	17.6	47	31.8	
Unknown	8	8.8	10	6.8	
Hemisphere of Lesion					
Left	45	49.5	59	39.9	$X^2= 4.68, p=0.19$
Right	42	46.2	71	48	

Brainstem	1	1.1	7	4.7	
Both	3	3.3	10	6.8	
Vascular Risk Factors					
<i>High Cholesterol</i>					
Yes	40	44	84	56.8	$X^2= 3.83, p=0.05$
No	50	54.9	62	41.9	
<i>Hypertension</i>					
Yes	57	62.6	99	66.9	$X^2= 0.45, p=0.5$
No	34	37.4	49	33.1	
<i>Diabetes</i>					
Yes	19	20.9	28	18.9	$X^2= 0.14, p=0.71$
No	72	79.1	120	81.1	
<i>Coronary Heart Disease</i>					
Yes	20	22	30	20.3	$X^2=0.08, p=0.77$
No	71	78	117	79.1	
<i>Arrhythmia</i>					
Yes	27	29.7	36	24.3	$X^2=0.81, p=0.37$
No	63	69.2	110	74.3	

* A chi-square test was performed and a value of $p<0.05$ represents statistical significance.

Note: ISC, ischemic stroke; ICH, intracerebral haemorrhage; SAH, subarachnoid haemorrhage; PACI, partial anterior circulation infarct; TACI, total anterior circulation infarct; LACI, lacunar infarct; POCI, posterior circulation infarct; MCA, middle cerebral artery; PCA, posterior cerebral artery; PICA, posterior inferior cerebral artery; ACA, anterior cerebral artery; SCA, superior cerebellar artery.

Table 5 shows outcome measures at four years of stroke survivors that received inpatient rehabilitation in comparison to those who did not receive inpatient rehabilitation. Significance was found for EQ-5D Self-Care and Usual Activities constructs. Independent Samples t-test demonstrates that those who received inpatient rehabilitation were still significantly disabled in areas of self-care ($p=0.01$) and usual activities ($p=0.01$) 4 years post-stroke. Significance was also found for the mRS measure and inpatient rehabilitation, indicating that those who did not receive inpatient rehabilitation were more likely to have lower scores on the mRS ($p=0.001$), representing lower functional disability. It was also found that those who did not receive inpatient rehabilitation were more likely to have higher BI scores at four years ($p=0.004$).

Table 5. Outcome Measures at Four Years: Inpatient Rehabilitation versus No Inpatient Rehabilitation

Outcome Measures	Inpatient Rehabilitation		No Inpatient Rehabilitation		<i>t</i> -value	<i>p</i> -value
	n	%	n	%		
mRS						
Mild Disability	71	78	141	95.3	4.22	0.001
Severe Disability	20	22	7	4.7		
BI						
No Disability	81	89%	145	98	u=7,698.500	0.004
Disability Present	10	11	3	2		
HADS Anxiety						
Normal Range	76	83.5	126	85.1	0.34	0.738
Present	15	16.5	22	14.9		
HADS Depression						
Normal Range	81	89	125	84.5	-0.99	0.32
Present	10	11	23	15.5		
MoCA						
Disability Present	77	84.6	123	83.1	0.34	0.73
No Disability	14	15.4	25	16.9		
FSS						
No Fatigue	13	14.3	14	9.5	-0.678	-0.5
Problematic Fatigue	45	49.5	65	43.9		
SF-36						
<i>Physical Functioning</i>						
No Disability	37	40.7	77	52	-1.71	0.89

Disability Present	54	59.3	71	48		
<i>Role Function Physical</i>						
No Disability	66	72.5	108	73		
Disability Present	25	27.5	40	27	-0.08	0.94
<i>Role Function Emotional</i>						
No Disability	65	71.4	108	73		
Disability Present	26	28.6	47	31.8	0.52	0.61
<i>Energy and Fatigue</i>						
No Disability	24	26.4	38	25.7		
Disability Present	67	73.6	110	74.3	0.12	0.91
<i>Mental Health</i>						
No Disability	58	63.7	105	70.9		
Disability Present	33	36.3	43	29.1	-1.16	0.25
<i>Social Functioning</i>						
No Disability	69	75.8	117	79.1		
Disability Present	22	24.2	31	30.9	-0.58	0.56
<i>General Health</i>						
No Disability	43	47.3	68	4.9		
Disability Present	47	51.6	80	54.1	0.27	0.79
<i>Health Change</i>						
No Disability	28	30.8	30	20.3		
Disability Present	63	69.2	118	79.7	1.78	0.07
<hr/>						
EQ-5D						
<i>Mobility</i>						
No Problems	50	54.9	99	66.9	1.86	0.065

Moderate to Severe Problems	41	45.1	49	33.1		
<i>Self-Care</i>						
No Problems	61	67	126	85.1		
Moderate to Severe Problems	30	33	22	14.9	3.14	0.01
<i>Usual Activities</i>						
No Problems	49	53.8	106	71.6		
Moderate to Severe Problems	42	46.2	42	28.4	2.76	0.01
<i>Pain and Discomfort</i>						
No Problems	61	67	95	64.2		
Moderate to Severe Problems	30	33	53	35.8	-0.45	0.66
<i>Anxiety and Depression</i>						
No Problems	69	75.8	119	80.4		
Moderate to Severe Problems	21	23.1	29	19.6	0.68	0.49

** an independent samples t-test was performed for normally distributed measures and a value of $p < 0.05$ represents statistical significance. Mann-Whitney U test was performed for non-parametric measures and a value of $p < 0.05$ represents statistical significance.

Note: ISC, ischemic stroke; ICH, intracerebral haemorrhage; SAH, subarachnoid haemorrhage; mRS, Modified Rankin Scale; BI, Barthel Index; HADS, Hospital Anxiety and Depression Scale; MoCA, Montreal Cognitive Assessment; FSS, Fatigue Severity Scale; VAFS, Visual Analogue Fatigue Scale; SF-36, Medical Outcomes Study Short Form 36; EQ-5D, EuroQol Quality of Life Scale.

4.3 Community Rehabilitation

76 patients from the sample received community rehabilitation at any point post-stroke, with 49 (20.3%) receiving inpatient rehabilitation also. 31 (40%) received community rehabilitation services once per week, 6 (7.9%) once per fortnight, 5 (6.6%) once per month, and 4 (5.3%) once every 6 months. Information towards frequency of community rehabilitation was missing from 30 (39.5%) of these participants. The types of community rehabilitation services these participants received involved; physiotherapy, occupational therapy, speech language therapy, visits from community based rehabilitation teams, and outpatient appointments with Waitakere Hospital, Rehab Plus, Laura Fergusson Rehabilitation and Mount Albert Rehabilitation Centre. At least 2 participants privately paid for extra rehabilitation support.

Table 6 compares means of demographic characteristics and outcome measures between those participants who received community rehabilitation against those who did not. In terms of representativeness of those who received community rehabilitation and those who did not within the stroke sample, there was no significant differences between most characteristics, with the exception hypertension.

Table 6. Characteristics of Sample: Community Rehabilitation versus No Community Rehabilitation

Descriptive	Community Rehabilitation		No Community Rehabilitation		Test of Difference Value
	<i>n</i>	%	<i>n</i>	%	
Age Groups					
< 50	12	15.8	20	12.3	$X^2 = 2.91, p = 0.41$
51- 64	20	26.3	34	20.9	
65-74	24	31.6	49	30.1	
75+	20	26.3	60	36.8	
Gender					
Female	38	50	74	45.4	$X^2 = 0.44, p = 0.51$
Male	38	50	89	54.6	
Ethnicity					
European	61	80.3	132	81	$X^2 = 0.02, p = 0.89$
Non-European	15	19.7	31	19	
Marital Status					
Married	54	71.1	95	58.3	$X^2 = 3.61, p = 0.06$
Never married/separated, divorced, or widowed	22	28.9	68	41.7	
Employment					

Employed	15	19.7	31	19.6	$X^2 = 1.99, p=0.58$
Unemployed	7	9.2	15	9.2	
Retired	48	63.2	110	67.5	
Not specified	6	7.9	6	3.7	
Recurrent stroke					
Yes	12	15.8	27	16.6	$X^2 = 0.02, p=0.88$
No	64	84.2	136	83.4	
Stroke type					
IS	64	84.2	143	87.7	$X^2 = 1.47, p=0.48$
ICH	4	5.3	10	6.1	
SAH	8	10.5	10	6.1	
Stroke subtype					
PACI	22	28.9	51	31.3	$X^2 = 3.25, p=0.52$
TACI	8	10.5	10	6.1	
LACI	19	25	49	30.1	
POCI	19	25	43	26.4	
Unknown	8	10.5	10	6.1	
Hemisphere of Lesion					
Left	33	43.4	73	44.8	$X^2 = 2.97, p=0.39$
Right	37	48.7	74	45.4	
Brainstem	4	5.3	4	2.5	
Both	2	2.6	11	6.7	
Vascular Risk Factors					
<i>High Cholesterol</i>					
Yes	34	44.7	89	54.6	$X^2 = 2.03, p=0.15$
No	41	53.9	72	44.2	
<i>Hypertension</i>					
Yes	42	55.3	113	69.3	$X^2 = 4.49, p=0.03$
No	34	44.7	50	30.7	
<i>Diabetes</i>					
Yes	12	15.8	35	21.5	$X^2 = 1.06, p=0.3$
No	64	84.2	128	78.5	
<i>Coronary Heart Disease</i>					
Yes	15	19.7	33	20.2	$X^2 = 0.01, p=0.91$
No	61	80.3	129	79.1	
<i>Arrhythmia Present</i>					
Yes	18	23.7	44	27	$X^2 = 0.38, p=0.53$
No	58	76.3	116	71.2	

* A chi-square test was performed and a value of $p < 0.05$ represents statistical significance.

Note: ISC, ischemic stroke; ICH, intracerebral haemorrhage; SAH, subarachnoid haemorrhage; PACI, partial anterior circulation infarct; TACI, total anterior circulation infarct; LACI, lacunar infarct; POCI, posterior circulation infarct; MCA, middle cerebral artery; PCA, posterior cerebral artery; PICA, posterior inferior cerebral artery; ACA, anterior cerebral artery; SCA, superior cerebellar artery.

Table 7 shows outcome measures for those stroke survivors that received community rehabilitation in comparison to those who did not. Independent samples t-test demonstrated that those who did not receive community rehabilitation presented with negative change ($p=0.03$) within the health change construct of the EQ-5D.

Table 7. Outcome Measures at Four Years: Community Rehabilitation versus No Community Rehabilitation

Outcome Measure	Community Rehabilitation		No Community Rehabilitation		<i>t</i> -value	<i>p</i> -value
	n	%	n	%		
mRS						
Mild Disability	64	84.2	149	91.4	1.69	0.97
Severe Disability	12	15.8	14	8.6		
BI						
No Disability	69	90.8	158	96.9	u=6,407.500	0.51
Disability Present	7	9.2	5	3.1		
HADS Anxiety						
Normal Range	63	82.9	139	85.3	0.47	0.64
Present	13	17.1	24	14.7		
HADS Depression						
Normal Range	67	88.2	140	85.9	-0.48	0.63
Present	9	11.8	23	14.1		
MoCA						
Disability Present	68	89.5	132	81	0.4	0.69
No Disability	8	10.5	31	19		
FSS						
No Fatigue	9	11.8	18	11	0.79	0.43
Problematic Fatigue	45	5.2	63	38.7		
SF-36						
<i>Physical Functioning</i>						
No Disability	35	46.1	81	49.7	-0.52	0.6
Disability Present	41	53.9	82	50.3		
<i>Role Function Physical</i>						
No Disability	55	72.4	120	73.6	-0.2	0.84

Disability Present	21	27.6	43	26.4		
<i>Role Function Emotional</i>						
No Disability	52	68.4	115	70.6	-0.33	0.74
Disability Present	24	31.6	48	29.4		
<i>Energy and Fatigue</i>						
No Disability	15	19.7	47	28.8	-1.5	0.14
Disability Present	61	80.3	116	71.2		
<i>Mental Health</i>						
No Disability	51	67.1	113	69.3	-0.34	0.73
Disability Present	25	32.9	50	30.7		
<i>Social Functioning</i>						
No Disability	55	72.4	132	8	-1.5	0.13
Disability Present	21	27.6	31	19		
<i>General Health</i>						
No Disability	55	72.4	78	47.9	-0.49	0.63
Disability Present	42	55.3	84	51.5		
<i>Health Change</i>						
No Disability	25	32.9	32	19.6	2.12	0.03
Disability Present	51	67.1	131	80.4		
<hr/>						
EQ-5D						
<i>Mobility</i>						
No Problems	44	57.9	106	65	1.06	0.29
Moderate to Severe Problems	32	42.1	57	35		
<i>Self-Care</i>						
No Problems	59	77.6	129	79.1	0.26	0.79
Moderate to Severe Problems	17	22.4	34	20.9		
<i>Usual Activities</i>						
No Problems	43	56.6	113	69.3	1.93	0.54

Moderate to Severe Problems	33	43.3	50	30.7		
<i>Pain and Discomfort</i>						
No Problems	48	63.2	108	66.3	0.46	0.64
Moderate to Severe Problems	28	36.8	55	33.7		
<i>Anxiety and Depression</i>						
No Problems	55	72.4	134	82.2	1.58	0.12
Moderate to Severe Problems	20	26.3	29	17.8		

** an independent samples t-test was performed for normally distributed measures and a value of $p < 0.05$ represents statistical significance.

Man Whitney U test was performed for non-parametric measures and a value of $p < 0.05$ represents statistical significance.

Note: ISC, ischemic stroke; ICH, intracerebral haemorrhage; SAH, subarachnoid haemorrhage; mRS, Modified Rankin Scale; BI, Barthel Index; HADS, Hospital Anxiety and Depression Scale; MoCA, Montreal Cognitive Assessment; FSS, Fatigue Severity Scale; VAFS, Visual Analogue Fatigue Scale; SF-36, Medical Outcomes Study Short Form 36; EQ-5D, EuroQol Quality of Life Scale.

Chapter 5 Discussion

This chapter discusses the findings from the analysis. The aim of this study was to investigate the association between inpatient or community-based rehabilitation and long-term functional and QoL outcomes in an existing NZ cohort of four-year stroke survivors.

5.1 Rehabilitation and Long-Term Outcomes

This study examined the relationship between those who received rehabilitation compared with those who did not and functional independence and QoL at four year post-stroke. In this study, 91 (37.76%) of participants received inpatient rehabilitation, and 76 (31.5%) of the sample received community rehabilitation, with 148 (61.4%) receiving no inpatient rehabilitation and 163 (67.6%) receiving no community rehabilitation. Leaving 74 (30.7%) participants who did not receive any form of rehabilitation post-stroke. The most commonly reported types of rehabilitation services provided to stroke patients included physiotherapy, occupational therapy and speech therapy, through a number of hospitals and outpatient facilities. There was no evidence to suggest other forms of rehabilitation, such as psychological and cognitive interventions, were implemented.

At four years stroke survivors demonstrated below average in constructs of the SF-36 (Scott et al., 1999), including; physical functioning, role functioning physical, role functioning emotional, energy and fatigue, social functioning, general health and health change. A large portion of the sample ($n=137$, 56.8%) also experienced severe fatigue on average at four-years, determined by a score of ≥ 4 on the FSS. Furthermore, 201 (83.4%) of participants had cognitive impairment at four years, as indicated by a mean MoCA score of <26 , irrespective of whether the participant received inpatient or community rehabilitation or not. Surprisingly, participants at four years post-stroke demonstrated, on average, within normal range for anxiety and depression on the HADS, showed good functional independence on the BI and good QoL according to the EQ-5D utility score and the mobility, self-care, usual activities, pain and discomfort, and anxiety and depression constructs at four years. Majority of the sample ($n=214$, 88.8%) presented with mild disability in functional independence on the mRS (<2), with only 27 (11.2%) participants presenting with severe functional disability. However, this could have also been impacted by the removal of the 14 cases from the sample with

scores ≥ 4 on the mRS, who represented with higher disability and functional dependence at baseline.

In terms of inpatient rehabilitation, only 91 (37.8%) participants received inpatient rehabilitation, while 148 (61.4%) stroke survivors from the sample did not. This is comparable with findings from the Stroke Foundation of NZ (2009) audit, which reported 39% of patients were receiving rehabilitation after stroke. Similar findings were reported by Child and colleagues (2012), which found only 28% of stroke patients received inpatient rehabilitation in a stroke unit. The average amount of time the 91 participants spent in inpatient rehabilitation in this sample was 6 weeks \pm 5.72 (ranging from 2 days to 38 weeks). Information collected towards type and frequency was not consistent throughout the sample, though participants received inpatient rehabilitation at a variety of locations and services within Auckland. Nevertheless, according to NZ Stroke Guidelines (Stroke Foundation of New Zealand, 2010), stroke patients should receive at least one hour of direct therapist-patient rehabilitation during the acute phase, five days a week. From the information attained from this study it is not clear if the NZ Stroke Guidelines were being met in terms of rehabilitation dosage.

In regards to self-reported health status, it was found that those participants who received inpatient rehabilitation were still significantly disabled in areas of self-care ($p=0.01$) and usual activities ($p=0.01$) at four years, indicated by a score >1 within each of these constructs on the EQ-5D outcome measure. These findings are consistent with other research which has shown stroke survivors having problems with functional independence in usual activities and self-care impacting health related QoL long-term. For example a 2004 study, with 266 stroke survivors, found that a substantial proportion of survivors had very poor health-related QoL and functional independence in activities of daily living, including self-care, at two years post-stroke (Sturm et al., 2004). Rehabilitation interventions which focus more towards rehabilitation for mood and activities of daily living was suggested in order to improve QoL and functional independence (Sturm et al., 2004). Other studies have shown that inpatient rehabilitation improves long-term outcomes in stroke survivors. A study conducted by Hansson and colleagues (2013), found stroke survivors ($n=283$) who had regular rehabilitation, introduced in the acute inpatient phase, had significantly improved self-perceived health related QoL, on the EQ-5D 12 months post-stroke, including

improvements in the self-care and usual activities constructs, in comparison to regular care. This was not represented within this current sample.

It should be noted that significance was also found for the mRS measure and inpatient rehabilitation ($p=0.001$), indicating that those who did not receive inpatient rehabilitation were more likely to have lower scores on the mRS, representing lower functional disability. It was also found that those who did not receive inpatient rehabilitation were more likely to have higher BI scores at four years ($p=0.004$), also representing higher functional independence. This potentially could represent that patients with less functional dependence at baseline were less likely to receive inpatient rehabilitation due to functional independence being at a suitable level. However, 14 cases of moderate to severe stroke, as determined by a score of ≥ 4 on the mRS, were removed due to impacting the distribution of stroke severity within the sample. This potentially could have impacted long-term outcomes of the sample at four years post-stroke.

It is evident from international studies that NZ is falling behind in terms of inpatient stroke rehabilitation. A study conducted in 2005 ($n=1161$), comparing inpatient stroke rehabilitation care in NZ to the United States of America (USA), demonstrated significantly better outcomes for those receiving more intensive inpatient rehabilitation in the USA (McNaughton et al., 2005). The average length of stay in USA rehabilitation facilities was shorter (18.6 days versus 30 days NZ), though physical and occupational therapy time per patient was higher within the shorter amount of stay in the USA. There was less survivors discharged to institutional care in the USA inpatient facilities, and these stroke survivors had significant improvements on a functional independence measure (McNaughton et al., 2005). To the authors knowledge, none of the aforementioned studies provided cognitive or psychological interventions during the inpatient rehabilitation process as focus was predominantly on physical functional independence and health-related QoL. Therefore, long-term outcomes of cognitive and psychological inpatient rehabilitation interventions are unknown.

In terms of community rehabilitation, a third of the sample ($n=76$, 31.5%) received community rehabilitation compared with 163 (67.6%) not receiving inpatient rehabilitation. This is lower than the 86% of stroke survivors having access to community-based rehabilitation provided in the home-setting according to the National

Stroke Audit of Rehabilitation Services in Australia reported in 2016 (Stroke Foundation, 2016). Previous research has recognised that stroke survivors having access to community rehabilitation services is often related to non-stroke factors, such as resource availability, living location in NZ, age, and personal finances (Saywell et al., 2012). Being based in Auckland, NZ's largest city, it is of concern that such a large portion of the stroke survivors did not receive rehabilitation once being discharged into the community. However, from the information attained from this current study it is not clear if a health-related follow up took place within the community setting to determine the need for on-going care for the stroke survivor.

A relationship was found between negatively perceived health change on the SF-36 in 183 (75.9%) participants and those who did not receive community rehabilitation ($p=0.03$), as determined by a score of <59.14 on the health change construct (Rand Health, 2018). Furthermore, at four years 128 (53.2%) of the whole sample reported disability in general health, and 185 (75.9%) of participants were experiencing negative health change on the SF-36, irrespective of receiving inpatient or community rehabilitation or not. This study is consistent with other research which also found self-reported negative health change post-stroke. Walsh and colleagues (2015) conducted a national survey ($n=196$) in Ireland to assess self-reported need in relation to stroke recovery and community reintegration five years post-stroke. It was found that over 75% of participants reported negative health change experiencing mobility, emotional, fatigue, concentration and general health difficulties post-stroke in the community (Walsh, Galvin, Loughnane, Macey, & Horgan, 2015). Furthermore, emotional and fatigue issues were reported to be the highest unmet needs, with 52% highly dependent on their families for personal care, 42% of relationships deteriorating post-stroke, and 60% of respondents reported negative financial change (Walsh et al., 2015).

The relationship between stroke survivors who did not receive community rehabilitation and negative health change on the EQ-5D, perhaps shows potential towards community rehabilitation improving perceptions of health post-stroke. Research specifically focusing on long-term health change perspectives of stroke survivors who received community rehabilitation is limited. However, other studies have demonstrated community rehabilitation improving long-term QoL outcomes post-stroke. One study ($n=91$) demonstrates that community focused treatment, provided to 84.6% of the patients, showed a significant increase in median BI scores ($p=0.01$), representing

higher functional independence, and an improvement in depressive symptoms and self-perceived QoL (Aziz et al., 2013). The pilot study looked at stroke risk factors, self-reported depressive symptoms and level of independence one year post community rehabilitation for stroke. The clinic was held weekly and focused on secondary risk prevention, screening for stroke-related issues, facilitating further rehabilitation, especially in areas of activities of daily living, and aiding with reintegration into the community through support services (Aziz et al., 2013). This highlights the importance of community based stroke rehabilitation services focused not only on physical aspects of rehabilitation, but also on mood.

From the information attained from the study it is not clear what differentiated between those who were offered community rehabilitation and those who were not. Frequency of rehabilitation within the community differed also, with 31 (40%) receiving community rehabilitation services once per week, 6 (7.9%) once per fortnight, 5 (6.6%) once per month, and 4 (5.3%) once every 6 months. There is no evidence that psychological and cognitive rehabilitation at a community level was implemented for this study sample. This is in alignment with a recent study examining the interventions of a community stroke rehabilitation team in Auckland, NZ finding that there were more interventions for body function and structure than for activities of daily living and participation (Evans, Hocking, & Kersten, 2017). Furthermore, there was no interventions provided for emotional functioning and limited interventions for community, social and domestic life (Evans et al., 2017), as also found within this population based study in Auckland. A recently published report by the Stroke Foundation of NZ (2017), suggested that stroke survivors and families are not being provided with adequate information about stroke along with having limited access to support services and therapies to assist with the rehabilitation process at home. It was stated in 2014 by Davis, that only 18% of DHBs in NZ were offering a community service for stroke survivors. Furthermore, only 18% had ESD service satisfactory to delivering a comparable service to inpatient care within 24 hours of discharge. 82% of the hospital units offered outpatient community rehabilitation with a delay of at least two weeks (Davis, 2014). This perhaps represents the lack of post-stroke rehabilitation facilities within the community, even though there is a wealth of research demonstrating such services decreasing the amount of functional disability and increasing QoL long-term (Child et al., 2012; McNaughton, Thompson, et al., 2014; Saywell et al., 2012). With the abundance of evidence towards input of community rehabilitation having positive outcomes long-term, it seems unproductive to

dedicate large amount of time to inpatient rehabilitation to not follow up with sufficient community rehabilitation post discharge. Furthermore, community rehabilitation needs to be implemented for those stroke survivors and families who did not receive extensive inpatient rehabilitation and for those needing more support. These findings highlight a potential gap in rehabilitation services in Auckland, NZ and a need for specific rehabilitation interventions within the community.

Another finding in the current study involved physical functioning. Those who did not received inpatient rehabilitation reported higher physical functioning at four years according to the SF-36. A potential explanation is that those at baseline with higher physical functioning did not require physical inpatient rehabilitation due to having minimal physical disability impacting level of functional independence at baseline. However, 125 (51.9%) of the sample self-reported issues on the physical functioning construct of the SF-36 at four years post-stroke, along with 65 (27%) reporting stroke sequelae impacting their role functioning in physical domains. This is consistent with other research demonstrating that stroke survivors are highly impacted in physical domains of functioning, having an impact on functional independence and QoL. The Stroke Foundation (2017) reports that 75% of patients on admission to hospital present with walking difficulties, being a strong predictor of secondary physical ailments usually caused by falls, and 69% of participants present with upper limb impairment, involving deficits in the movement of the shoulder, elbow, wrist, hand and fingers. These physical impairments, which are a consequent of the stroke event, impact functional independence, in areas such as self-care (showering, toileting, dressing), eating and drinking, along with participation within the home and community settings.

There is an abundance of evidence towards focused physical rehabilitation in the acute and sub-acute phases post-stroke positively impacting long-term functional independence. For example, a Cochrane systematic review ($n=10401$, 96 studies) conducted by Pollock and colleagues (2014) found physical rehabilitation to have a beneficial effect on functional recovery post-stroke in comparison to no treatment. This effect was also reported to last long-term beyond the intervention period (Pollock et al., 2014). A significant difference was presented based on dose of the intervention, indicating 30 to 60 minutes per day administered five to seven days a week being the most effective physical rehabilitation interventions for significant improvements in functional independence (Pollock et al., 2014). Furthermore, there was evidence that

greater improvements were made in functional independence when physical rehabilitation was administered within a shorter time since stroke (Pollock et al., 2014). From the information attained from this study it is not clear on when physical rehabilitation commenced and how frequently it was administered amongst this sample. Therefore it is not clear whether these factors had a significant impact on outcomes.

This study also found that age of stroke onset for Māori and Pacific people was 16 to 17 years younger (53 and 52 years), respectively compared with Europeans (69 years). This is consistent with existing national statistics reporting Māori and Pacific groups experiencing stroke at a significantly younger age in comparison to Europeans (Ministry of Health, 2017). At present there is limited available data on long-term outcomes of inpatient and outpatient rehabilitation on functional independence and QoL within the ethnically diverse NZ population. While the amount of studies internationally looking at the functional and QoL outcomes from inpatient and community rehabilitation in survivors of stroke is abundant, less is understood towards outcomes from rehabilitation and predictors between different ethnic populations, especially in NZ. Although the sample size for both Māori ($n=12$) and Pacific people ($n=5$) was smaller, consent rates were proportional to previous ARCOS studies (Feigin et al., 2015). Considering there are substantial ethnic differences in incidence, in regards to age at onset and associated risk factors (V Feigin et al., 2015; Ministry of Health, 2017), this relationship requires further exploration with a larger sample size.

5.2 Other Rehabilitation Considerations

Even though the findings from this study did not provide evidence to support inpatient and community rehabilitation in Auckland, NZ having better outcomes at four years post-stroke, this diverse population-based study has identified gaps in stroke rehabilitation in terms of availability, frequency and type of rehabilitation offered within NZ. A potential explanation for the long-term outcome results in this study is that rehabilitation was only offered for physiotherapy, occupational therapy and speech language therapy where appropriate. A large number of this sample experienced high levels of cognitive impairment ($n=201$; 83.4%), and fatigue ($n=137$, 56.8%) at four years, irrespective of whether the participant received inpatient or community rehabilitation or not. There is also evidence at four years that some participants had negatively impacted social functioning ($n=53$, 22%). These impairments could have

influenced long-term outcomes especially in terms of independence in usual activities at four years, along with self-perceived physical and emotional functioning, role physical and emotional functioning, general health and perception of health change also.

However, it is recognised in the literature that anxiety and depression are a common occurrence for stroke survivors. It should be considered for standard practice to have interventions throughout rehabilitation that address mental health and emotional well-being, as evidence from the literature suggests (M. L. Hackett, Anderson, House, & Halteh, 2008). Though this sample did not present with high levels of anxiety and depression at four years post-stroke.

5.2.1 Cognition

Over 50% of stroke survivors experience long-term cognitive deficits (Crichton, Bray, McKeivitt, Rudd, & Wolfe, 2016; Delavaran et al., 2017; Levine et al., 2015), which has been shown to directly predict health related QoL, functional independence on usual activities, levels of disability and emotional well-being (S. Barker-Collo et al., 2010; Bieńkiewicz, Brandi, Hughes, Voithl, & Hermsdörfer, 2015; V Feigin et al., 2010).

Several studies have shown an association between cognitive impairment, poor activities of daily living and QoL. For example, a 2016 population based study ($n=2625$) in South London looked at long-term outcomes at 15 years focusing on cognitive impairment, disability, activity, QoL, and depression and anxiety (Crichton et al., 2016). At 15 years, it was found that poor cognitive functioning, functional independence and psychological outcomes were impacting a large proportion of the long-term stroke survivors, with 30% of participants being cognitively impaired (Crichton et al., 2016). Another study, conducted by Kapoor and colleagues (2017), examined functional outcomes two to three years post-stroke ($n=270$). 43 (54%) of the participants were cognitively impaired, 47 (52%) had restrictions with reintegration into the community, and 30 (32%) suffered from clinical depression. They concluded that over half of the stroke survivors who had excellent functional recovery continued to have cognitive impairment, which determined restrictions in participation in daily activities, along with depression levels two to three years post-stroke (Kapoor et al., 2017). Another population based study ($n=645$) had similar findings, showing cognitive impairment at four years post-stroke was associated with poor long-term outcomes, including greater disability and morbidity (Patel, Coshall, Rudd, & Wolfe, 2002). The impact of stroke on cognition at four years within this sample has been explored extensively elsewhere (Mahon, 2018).

Within this study, 201 (83.4%) of participants had cognitive impairment at four years, as indicated by a mean MoCA score of <26, irrespective of whether the participant received inpatient or community rehabilitation, or not. Findings from this study are in accordance with previous research conducted in Auckland, NZ where a considerable proportion of the five year stroke survivors ($n=307$) experienced cognitive deficits, mainly in information processing speed and executive functioning (S. Barker-Collo et al., 2010). It was further found that visuoperceptual/construction abilities, visual memory, and information processing speed were highly associated with functional dependence and health related QoL (S. Barker-Collo et al., 2010). Moreover, cognitive impairment was independently associated with functional dependence outcomes. Within this current study there was no relationship between higher cognitive functioning and the stroke survivor receiving inpatient rehabilitation or community rehabilitation. This represents a gap in rehabilitation services in Auckland as there was no evidence of cognitive rehabilitation being offered within this stroke population as focus is mainly on physical aspects of functional independence.

Rehabilitation interventions for cognition focus on therapy which is aimed to restore function and/or compensate for deficits in functioning, in order to minimise functional dependence for survivors of stroke and increase QoL (Cicerone et al., 2008; Goverover, Chiaravalloti, O'Brien, & DeLuca, 2018). Approaches to cognitive rehabilitation conventionally focus on interventions that either restore function or compensate for the loss of function of the stroke survivor, to promote adaptation and assist independence (Sunnerhagen, 2014). Currently, there is insufficient evidence to support or disprove the benefits of cognitive rehabilitation for stroke survivors (Cicerone et al., 2008; Mahon, 2018), due to a main focus on the recovery of physical and motor function and less attention on cognitive recovery.

A number of Cochrane reviews have been conducted focusing on cognitive rehabilitation for memory deficits (das Nair, Cogger, Worthington, E., & Lincoln, 2017), spatial neglect (Bowen, Hazelton, Pollock, & Lincoln, 2013), deficits in executive functioning (Chung, Pollock, Campbell, Durward, & Hagen, 2013), and deficits in attention (Loetscher & Lincoln, 2013). However, each has concluded that the effectiveness of cognitive rehabilitation is yet to be established. For example, Das Nair and colleagues (2017) focused on determining whether participants who received

tailored cognitive rehabilitation for memory impairments following stroke have better memory, functional independence, emotional well-being and QoL outcomes in comparison to those who did not receive cognitive rehabilitation ($n=514$). Benefits from rehabilitation on subjective memory was represented in the short term, four weeks. However, the effect was not demonstrated at four months, showing limited evidence for memory rehabilitation on long-term cognitive outcomes. In comparison, Loetscher and Lincoln (2013) wanted to determine whether people receiving cognitive treatment for attention show better outcomes for attention functioning in comparison to those who did not received focused rehabilitation, and whether this impacted functional recovery in relation to mood, activities of daily living and QoL (6 randomised controlled trials, 223 participants). No statistically significant effect of cognitive rehabilitation on global measures of attention, standardised attention assessments, or functional outcomes was evident (Loetscher & Lincoln, 2013). Limited evidence towards cognitive rehabilitation improving aspects of attention in the short term was presented, though there was insufficient evidence to support or refute the effects of cognitive rehabilitation on attention, or on functional outcomes, in both the short and long-term. This demonstrates the need for more research on cognitive rehabilitation post-stroke to determine whether this form of rehabilitation has a positive impact long-term on functional independence and QoL.

The lack of knowledge of cognitive rehabilitation post-stroke and the inattention to cognitive deficits has been noted in other stroke rehabilitation studies also (Gillespie et al., 2015; McNaughton, McRae, et al., 2014; Weistein et al., 2016). In a meta-analysis conducted by Sunnerhagen (2014), it was established that most of the interventions within the studies were aimed to minimise functional disability by improving activities of daily living, rather than focusing on cognitive interventions. The Stroke Foundation Clinical Guidelines for Stroke Management (Stroke Foundation, 2017) in NZ and Australia have acknowledged the importance of both assessment and treatment of cognitive impairments needing to take precedence in research (Mahon, 2018). However, evidence from this study demonstrates a gap in stroke rehabilitation processes in NZ still remains and needs to be addressed.

5.2.2 Fatigue

Fatigue is commonly reported post-stroke, and has frequently been described as being one of the most debilitating symptom post-stroke also (Choi-Kwon et al., 2005; T.

Cumming et al., 2016; Schepers et al., 2006). Fatigue is notably related to poor QoL and functional independence in activities of daily living and physical functioning also (H. Naess et al., 2012; Naess et al., 2006), having a negative impact on social participation, employment, driving, reading, sleep patterns (White et al., 2012), and long-term outcomes post-stroke (H. Naess et al., 2012). This further impacts the amount of participation one has within the home and the community, along with decreasing motivation and endurance towards rehabilitation (de Groot et al., 2003) whilst increasing dependence on significant others and/or institutions (Glader et al., 2002).

In terms of long-term outcomes of this current sample, participants were experiencing debilitating fatigue, as indicated by a mean score of ≥ 4 on the FSS. This provides evidence towards fatigue being a disabling factor four years post-stroke and highlights the need for cognitive or psychological rehabilitation focused on fatigue management. However, there is a lack of evidence supporting the efficacy of fatigue management or rehabilitation post-stroke improving long-term functional and QoL outcomes. Fatigue management has only been mentioned in the NZ guidelines for stroke management (National Stroke Foundation, 2017) in terms of importance of intervention studies being urgently needed to address this potentially treatable sequela. Approaches that incorporate aspects of psychoeducation, improvement of nutrition, a good exercise program, sleep interventions, relaxation and meditation training, psychoeducation towards biofeedback, music therapy and recreational therapy have demonstrated some potential value (S. Barker-Collo, Feigin, & Dudley, 2007; Michael, 2002).

Other recommendations from the Australian clinical stroke guidelines suggest that therapy for stroke survivors should be implemented during parts of the day in which the individual is most alert, and stroke survivors and their caregivers should be given education towards fatigue, involving potential management strategies (National Stroke Foundation, 2017). Recommendations from the American Heart Association and the American Stroke Association suggest that post-stroke fatigue may be worsen from a sedentary lifestyle, and physical activity is encouraged (Billinger et al., 2014).

In the current study there was no evidence to suggest stroke survivors received psychological or cognitive rehabilitation that focused on minimising or controlling for the impact of fatigue. With fatigue being highly prevalent throughout stroke populations, this highlights a gap in the stroke rehabilitation services offered in

Auckland, NZ (T. Cumming et al., 2016; M. Nadarajah & H. Goh, 2015; Staub & Bogousslavsky, 2001). Fatigue management incorporated into stroke rehabilitation could potentially have a positive impact long-term on functional independence and QoL outcomes (H. Naess et al., 2012; Naess et al., 2006).

5.2.3 Social Functioning and Participation

Another interesting finding at four years was that 53 (22%) of participants reported health issues impacting social functioning, 65 (25%) were also impacted in areas of role functioning physical and 73 (30.3%) of participants were impacted in role functioning emotional. This demonstrates stroke sequelae limiting participation within the home and community. It has been noted throughout literature that survivors of stroke often face restrictions in participation in all aspects of life post-stroke including; returning to work, social roles, community activities (V Feigin et al., 2010; McNaughton, Thompson, et al., 2014), and involvement with rehabilitation, which simultaneously impacts long-term functional independence and overall QoL (Kennedy, 2012; Shimoda & Robinson, 1998). For example a 2017 study ($n=96$) focused on the outcome levels of activity and participation between two and three years post-stroke, finding that 52% of stroke survivors had problems with reintegrating into the community due to social functioning and participation issues (Kapoor et al., 2017). Furthermore, Chau and colleagues (2009) found in their study in Hong Kong ($n=188$), functional ability, depressive symptoms, low state of self-esteem and living in a residential care facility were the largest predictors of the level of participation for stroke survivors at one year post-stroke (Chau, Thompson, Twinn, Chang, & Woo, 2009).

There is evidence from previous research suggesting that early initiation of rehabilitation establishes a positive attitude and enhances participation for stroke survivors. For example, in a quasi-experimental study, stroke survivors ($n=50,000$) were either in a community-based rehabilitation intervention program, which included a two year rehabilitation education program and a three month community-based rehabilitation technique, and a control group (Xiaojuan et al., 2017). Within the intervention group the stroke survivors' social functioning and BI scores (functional independence) significantly improved in comparison to the controls (Xiaojuan et al., 2017). Another study ($n=361$) evaluated the impact on participation and QoL one year post-stroke of an Accelerated Skills Acquisition Program (which included capacity building, skill acquisition, motivation enhancement and autonomy support), to a usual

occupational therapy intervention and care as usual groups (Lewthwaite et al., 2018). At one year post-stroke, the Accelerated Skills Acquisition Program intervention group demonstrated greater improvements in participation, perceived health, community reintegration and QoL outcomes post-intervention, and greater gains in participation and QoL in comparison to the other interventions (Lewthwaite et al., 2018). This demonstrates the need for not only physical and occupational rehabilitation, but a focus on psychosocial aspects through psychological rehabilitation too. Psychologically focused rehabilitation has proven to improve participation levels and long-term functional and QoL outcomes post-stroke, however evidence of psychological interventions being implemented throughout inpatient and community rehabilitation in Auckland, NZ is not clear.

5.2.4 Anxiety and Depression

Within this current sample, 73 (30.3%) of participants indicated the impact of emotional health on daily performance roles to be below average. 76 (31.5%) of the sample also reported to have disability in terms of anxiety and depression on the EQ-5D, as indicated by NZ normative data (Scott et al., 1999). Even though there is a lack of representation in this current sample, anxiety and depression are frequently reported issues of emotional well-being post-stroke. It has been reported in other international research that approximately 20-40% of survivors present with anxiety (De Wit et al., 2008; Kennedy, 2012), and 30-50-% of stroke survivors suffer from depression in either the acute or chronic phase post-stroke (De Wit, Putman, Baert, Lincoln, Angst, Beyens et al., 2008; Gordan & Hibbard, 1997; Kennedy, 2012).

Hackett and colleagues (2000) also reported similar findings. They examined QoL and emotional well-being in six year stroke survivors from the Auckland Stroke Study, 1991-1992 cohort, in comparison to the general population. Out of the 1761 participants, 639 were alive at 6 year follow up. It was reported that health related QoL and mood was relatively good for most of the stroke survivors at 6-years post-stroke, indicated by the SF-36, despite ongoing physical disability (Maree L Hackett, Duncan, Anderson, Broad, & Bonita, 2000). Presenting with issues in emotional functioning is common in other research looking at long-term mood outcomes post-stroke, and it has been well reported that depression and anxiety remains prevalent years after stroke.

The positive benefit of psychological intervention for the prevention of post-stroke depression potentially endorses the use of more structured methods for delivering psychoeducation and emotional support focusing on emotional adaptation and recovery, along with adjustment to stroke sequelae (M. L. Hackett, Anderson, House, & Halteh, 2008). Nevertheless, there is limited evidence to support the regular use of psychological interventions in stroke rehabilitation along with the generalisability to all stroke populations. Within this current study sample there was no significant difference in anxiety and depression levels between those who received inpatient rehabilitation or not, or received community rehabilitation or not. This represents a gap in the evidence of stroke rehabilitation in Auckland, NZ, having a positive effect on long-term emotional outcomes. There is also no evidence of psychological therapy either at an inpatient level or within the community setting. Conducting RCT's in Auckland implementing a structured psychological rehabilitation intervention and a control group (care as usual) could help determine the efficacy of specified and tailored rehabilitation methods on long-term emotional functioning outcomes.

Differences between many of the aforementioned studies and the present study involve the implementation of a focused rehabilitation program, whereas this population-based study investigated long-term outcomes of care as usual post-stroke with no intervention. The previously mentioned studies also included patients from all stroke severity whereas this study removed 14 cases of moderate to severe stroke. However, the majority of these studies were not population-based, outcome measurements were taken at different time points and not necessarily taken at regular intervals, and majority of the studies, with an exception of a few, did not have a stroke sample from a NZ population. Therefore, these studies have limited generalizability, whereas a population-based study is the gold-standard methodology for epidemiological research and allows for generalization of results to the NZ population.

5.3 Limitations

Limitations from the study include the use of self-report data for rehabilitation information, lack of an intervention and control group, removal of participants with high mRS scores, the lack of comparison between baseline and four-year outcome measures and the small number of Māori and Pacific people within the sample.

5.3.1 Self-Report Data

Information towards rehabilitation was attained through self-report from the four-year stroke survivors. With the quantity and quality of rehabilitation being specifically important within the first 12 weeks post-stroke (McNaughton, Thompson, et al., 2014; Meyer et al., 2015; Stroke Foundation of New Zealand, 2017b), more detailed information regarding when rehabilitation commenced, the type of rehabilitation received, and the amount received per day and week would have been useful. Location, type of rehabilitation, and approximation of length of inpatient and community rehabilitation was acquired within this study through self-report from the stroke survivor. However, self-report from stroke survivors with possible cognitive impairment, could be a limitation. This is due to the impact that stroke potentially has on the survivors cognitive functioning, especially memory recall (das Nair et al., 2017). Furthermore, asking the stroke survivor whether or not they received inpatient or community rehabilitation, along with the length and type is not a standardised measure.

5.3.2 Lack of Intervention and Control Group

Inclusion of an inpatient and community rehabilitation intervention group and a control group (receiving care as usual) would have strengthened the study's findings. A matched control sample to an intervention group would have allowed comparisons to be made between stroke survivors who received inpatient and community rehabilitation, and those who received care as usual, in aspects of QoL and functional independence. This should be considered for future research also in order to measure the efficacy and impact on long-term outcomes of stroke rehabilitation, and perhaps efficacy of psychological and cognitive rehabilitation techniques.

5.3.3 Participants and mRS Scores

Originally there was 255 participants within this sample. However, 14 cases of moderate to severe stroke, as determined by a score of ≥ 4 on the mRS, were removed due to impacting the distribution of stroke severity within the sample. This potentially could have impacted the results at four-years. Including participants who had higher mRS scores at baseline could have impacted the sample's presentation of functional independence and QoL outcome measures at four year.

5.3.4 Comparison Between Baseline and Four-Year Outcome Measures

Improvements made at four years could have been clearer if compared to baseline outcome measures. This would have allowed to see the improvements or declines made overall of stroke survivors and perhaps would have been a better indicator of differences between those who received inpatient rehabilitation and those who did not, and those who received community rehabilitation and those who did not. This should be considered for future research, and the inclusion of all stroke severity, according to the mRS, would be more suitable.

5.3.5 Lack of Māori and Pacific People within Sample

Another limitation of this study was that majority of the participants were European. Within the study there was: Māori ($n=12$); Samoan ($n=2$); Tongan ($n=2$); Niuean ($n=1$); Asian or Other ($n=29$); and European ($n=195$). With Māori and Pacific groups on average experiencing stroke at a considerably younger age in comparison to NZ Europeans (60, 62 and 75 years respectively) (Dyall et al., 2008; V Feigin et al., 2015), it would be beneficial to have recruited more Māori and Pacific people. However, consent rates were proportional to previous ARCOS studies (Feigin et al., 2015). Having a larger number of Māori and Pacific people within the sample would have allowed for separate demographic categories for analysis also, rather than ‘European’ and ‘Non-European’ demographic categories. Further analysis could have focused on the association between ethnicity and long-term outcomes of rehabilitation and other potential relationships perhaps would have surfaced.

5.3.6 Missing Data

Another limitation was the amount of missing data, specifically for the FSS. Out of the 241 participants, 104 (43.27%) of the sample did not complete the FSS at four years post-stroke. Therefore the findings of this research may have underestimated the relationship between rehabilitation and long-term fatigue outcomes, or fatigue could have been under or over represented within this sample.

5.4 Strengths

5.4.1 Population Based Design

The population-based design of the ARCOS-IV study was a strength. Auckland city has four large public hospitals and a clearly defined geographical area and an ethnically diverse population. Population-based research is fundamental for accurately attaining

information towards stroke incidence and burden to inform healthcare planning, allocation of resources, along with evaluating the efficacy of preventable approaches in the population (R. Krishnamurthi et al., 2014). Studies based within a hospital alone are unable to collect cases within the community, that are not seen in the hospital setting, other study designs consequently are unable to attain an accurate incidence of stroke within a population (R. Krishnamurthi et al., 2014). Three population-based studies on stroke incidence and outcomes in Auckland, NZ have been conducted in the past, which covered a 30 year time frame (Anderson et al., 2005; Bonita, Broad, & Beaglehole, 1993; V. Feigin et al., 2006; V Feigin et al., 2015), and various population-based studies internationally (V. Feigin et al., 1996; V. L. Feigin et al., 2009; Lavados et al., 2005; Minelli, Fu Fen, & Camara Minelli, 2007; Rothwell et al., 2004; Thrift, Dewey, Macdonell, McNeil, & Donnan, 2000), which have contributed towards the understanding of trends in stroke prevalence, incidence and burden.

Population-based information on long-term outcomes of stroke is imperative for a number of reasons. This includes: allowing unbiased estimates of long-term outcomes of stroke survivors, which informs planning of the future for healthcare systems, providers, families and the survivor themselves; this method of research allows understanding of predictive factors to inform evidence based inpatient and community rehabilitation along with educational programs for stroke survivors and their families at different points in time post-stroke; data attained from the population based study can function as a baseline for preventative and/or therapeutic interventions; and population-based research is critical for accurate health-care planning, along with the delivery of effective interventions at inpatient and community levels. Information attained from this population-based study also can provide vital understandings towards predictors of, and the relationship between, a variety of long-term outcomes of stroke survivors. This shapes the foundations for advancing preventative and rehabilitative strategies needing to be in focus for future research, with the aim of improving long-term outcomes of stroke especially within the NZ population.

ARCOS-IV study has been conducted with the same methodology previously used in other ARCOS studies, with further components added to expand the range of information collected on stroke incidence and its burden (R. Krishnamurthi et al., 2014). The ARCOS-IV study includes outcomes assessments at one and six months, twelve months and 48 months (four years) post-stroke.

5.4.2 Sample Size and Characteristics

Other strengths of this study include a reasonable sample size ($n=241$), extensive range of baseline covariates, which have not been included or considered in previous population-based studies (Levine et al., 2015), and long-term follow up. This allows for understanding towards the nature of long-term functional independence and QoL post-stroke and the potential impact of inpatient and community rehabilitation.

5.5 Implications for Future Research

It is evident from this study that rehabilitation throughout the inpatient and community rehabilitation setting is not meeting current NZ Stroke Guidelines (Stroke Foundation, 2017). Further population-based research into whether or not NZ stroke rehabilitation has improved over the past 5 years is needed.

Future research examining what is being offered in terms of rehabilitation services that focuses on the management of cognitive functioning, fatigue, participation, along with depression and anxiety, would help inform better rehabilitation practice in Auckland. In that, research focusing on the impact of cognitive and psychological rehabilitation on long-term functional independence and QoL outcomes, being administered in the inpatient and community rehabilitation setting, would be beneficial.

It has been recognised that fatigue management post-stroke is a highly neglected issue and research focusing on the management of post-stroke fatigue is very limited throughout the literature. Future research should focus on the efficacy of fatigue management programs being administered in Auckland during both inpatient and community rehabilitation settings by comparing baseline and long-term outcomes measures. A randomised control trial focusing on the effectiveness of a fatigue after stroke educational recovery program (FASTER), conducted by Jones and colleagues, within the Waikato and Auckland region will initiate in March 2019 (Auckland University of Technology, 2018).

Future research focusing on the efficacy of cognitive rehabilitation as part of the stroke rehabilitation process for deficits in different cognitive domains, with survivors who are under the cut off, < 26 on the MoCA, would be beneficial. Specifically focusing on memory, attention, executive functioning, spatial neglect and attention, along with looking at the effectiveness of rehabilitation tailored to these deficits. Furthermore,

looking into how cognitive rehabilitation could be adapted for Māori and Pacific populations to be more productive within these populations would be beneficial too, considering these populations' earlier stroke onset and higher stroke representation.

Future research could focus on those stroke survivors who are above the clinical cut offs for depression and anxiety on the HADS and look at how psychological and/or cognitive rehabilitation impacts mental health, along with developing a more positive sense of self beyond the restrictions of individuals' disabilities acquired from the stroke event. Examining the impact that rehabilitation focused on emotional well-being alongside physiotherapy and occupational therapy, on long-term QoL and functional outcomes would be beneficial. This is significant as evidence from previous research suggests that those suffering from depression and anxiety are less likely to be motivated towards personal rehabilitation and recovery (Schmid et al., 2011).

It would be interesting to look further into what differentiates those who have the option to access community rehabilitation and those who do not. It would also be of interest to determine whether the self-perceived lack of change in health and disability on the self-care and usual activity constructs of the EQ-5D were reported due to the cumulative frustration with their health problems, or due to insufficient rehabilitation services. Additionally, determining if self-perceived functional dependence decreases and QoL increases over time due to the stroke survivor adjusting to their disabilities and deficits could be something to consider.

Having a control group who receive care as usual throughout the rehabilitation process and having an intervention group would be beneficial for future research. With the intervention group receiving stroke rehabilitation as usual with additional psychological and cognitive rehabilitation would help establish or refute the potential benefits that this rehabilitation has towards functional and QoL long-term outcomes.

Research towards how inpatient and community rehabilitation should be adapted towards different ethnicities, specifically Māori and Pacific people in NZ, would be valuable. Specifically focusing on the recruitment of Māori and Pacific people in future research would allow for more information towards the rehabilitation processes available to these populations to monitor if such Westernised methods are effective and appropriate, and how they can be adapted to be more suitable for these populations.

Furthermore, understanding why Māori and Pacific people are perhaps not wanting to be involved in research would be beneficial going forwards.

ARCOS-IV had the option for the stroke survivor to nominate a caregiver (who was considered to be their main caregiver post-stroke) who could be approached to take part in the study also. This was to assess the impact and burden of stroke on caregivers and outcome measures were completed at 28 days, six months and one year post-stroke. This data was not included in this study due to the focus being on the stroke survivors' long-term QoL and functional independence. However, future research could include the caregivers perspective towards functional independence, QoL, and emotional well-being of the stroke survivor also over the same time frame and longer, to complement the stroke survivors self-report, in order to attain a more informed depiction.

5.6 Implications for Practice

As demonstrated from this current study, there was no significant association between better outcomes at four years and those who received inpatient rehabilitation or not, and those who received community rehabilitation or not. It is therefore evident that rehabilitation practice in Auckland, NZ potentially needs improvements, perhaps in terms of being tailored towards addressing persistent long-term symptoms such as cognition, fatigue, social functioning and participation, and emotional well-being.

There is a small amount evidence for the benefits of cognitive rehabilitation, as the primary focus of past rehabilitation and research in this area has been on the recovery of motor and physical functioning, with much less attention towards cognitive rehabilitation (Shigaki, Frey, & Barrett, 2014). Therefore, the degree in which cognitive recovery post-stroke transpires or how recovery can occur with cognitive focused rehabilitation, remains uncertain (Mahon, 2018). However, interventions that are aimed at either restoring function or compensating for the loss of cognitive function, has shown evidence towards promoting adaptation and assisting functional independence for survivors, consequently improving long-term QoL outcomes (Sunnerhagen, 2014). Some form of rehabilitation for cognitive impairments should therefore be implemented throughout inpatient and/or community rehabilitation in NZ. Access to cognitive rehabilitation should be available to all stroke survivors to implement restorative or compensatory approaches to aid their everyday functioning, and to monitor change in cognitive functioning. Neglecting cognitive rehabilitation, as it has been in the past

within research and practice, could have a detrimental impact on QoL, functional independence, emotional well-being, engagement in rehabilitation and overall long-term outcomes post-stroke. The practical implications of implementing such services needs to be considered, especially in terms of training staff, establishing evidence-based therapies, long-term monitoring and the associated costs.

The implementation of cognitive or psychological rehabilitation in practice would also create a platform to focus on fatigue management and allow stroke survivors and families to receive more guidance and education towards controlling and managing debilitating fatigue. There is an abundance of evidence towards fatigue being a long-term burden post-stroke, impacting functional independence and QoL, yet, to the authors knowledge, there is no evidence within this sample or other research in NZ that fatigue management or psychoeducation for fatigue is being received in inpatient or community rehabilitation. Fatigue management on other populations has shown success (chronic fatigue syndrome), which provides potential for fatigue focused rehabilitation to be tailored for stroke populations.

Psychological interventions, especially for those who present with anxiety and depression post-stroke, should be implemented in the rehabilitation process too. Even though depression and anxiety was not significantly present within this sample, it has been reported from previous research that approximately 20-40% of stroke survivors present with anxiety and 30-50% suffer from depression (De Wit et al., 2008; Kennedy, 2012). Stroke has a major impact on an individual's sense of self, QoL and functional independence influencing the level of participation one has within the home and community. Implementing psychological rehabilitation and support for stroke survivors could increase a stroke-survivors' motivation and involvement in rehabilitation (Aziz et al., 2013), in turn improving long-term outcomes. The emotional well-being of the stroke-survivor could therefore be monitored throughout the rehabilitation process also and adapted accordingly.

Due to there being a large amount of stroke survivors not receiving inpatient ($n=148$, 61.4%) or community ($n=163$, 67.3%) rehabilitation post-stroke, it is questionable to why this is occurring. It could be due to the lack of resources, minimal disability, or purely the stroke survivor's choice. It is therefore recommended for clinical practice that stroke patients should be triaged for rehabilitation using a standardised approach

across NZ. By implementing this, those stroke survivors and families who are in need of specific rehabilitation interventions can be graded and provided with adequate care and support accordingly in a timely manner.

5.7 Conclusion

This study investigated the association between inpatient and community stroke rehabilitation and long-term functional independence and QoL outcomes in an existing NZ cohort of four-year stroke survivors. Findings from this sample did not provide substantial evidence towards stroke survivors who received inpatient or community rehabilitation, in Auckland, having superior long-term outcomes. However, the findings have provided evidence that current inpatient and community rehabilitation being offered in Auckland, NZ is not addressing the areas of persistent impairment which stroke survivors are experiencing well after their stroke event.

Within this sample ($n=241$) rehabilitation that was received included physiotherapy, occupation therapy and speech therapy as required. There was no evidence of cognitive or psychological interventions throughout inpatient and community rehabilitation services. This could have explained the lack of significance on four year outcomes between those who received inpatient rehabilitation and those who did not, and those who received community rehabilitation and those who did not. The lack of cognitive and psychological rehabilitation potentially could have explained the poor outcomes at four years for the sample overall, especially in areas including: cognitive functioning (MoCA); fatigue (FSS;VAFS); and physical functioning, role functioning physical, role functioning emotional, energy and fatigue, social functioning, general health and perceived health change (SF-36). With the understanding throughout stroke research of the high prevalence of cognitive functioning issues, debilitating fatigue, problems in emotional well-being, deficits in social functioning, community reintegration and participation, along with negatively perceived health in stroke survivors, it is imperative for these issues to be addressed accordingly in order to have effective and adaptive rehabilitation practices.

Only 91 (37.8%) out of the 241 participants had inpatient rehabilitation, and 76 (31.5%) out of the 241 participants had community rehabilitation, leaving 74 (30.7%) participants who did not receive any form of rehabilitation post-stroke. However, those stroke survivors that did receive inpatient rehabilitation did not present with better scores in QoL and functional independence outcome measures at four years in comparison to those who did not receive inpatient rehabilitation. At four years those stroke survivors who received inpatient rehabilitation were still significantly impaired in areas of self-care and usual activities according to the EQ-5D outcome measure,

demonstrating impairment in functional independence in areas that are understood to impact QoL post-stroke. In comparison, those stroke survivors who did not receive community rehabilitation presented with self-perceived negative change within the health change construct of the EQ-5D. This perhaps shows potential towards community rehabilitation improving perceptions of health post-stroke within this sample, which has been demonstrated in other research also (Aziz et al., 2013; Langstaff et al., 2014). However, significance in other functional independence and QoL outcome measures was not presented.

Throughout the sample there was no evidence of psychological or cognitive rehabilitation being implemented throughout the inpatient or community setting. More evidence is needed towards cognitive rehabilitation and how this can be best implemented within the NZ stroke populations to improve long-term functional independence and QoL outcomes, with attaining an understanding towards how such rehabilitation should be provided and adapted to different ethnic populations also. With a large amount of the sample still being cognitively impaired at four years it is imperative to address the gaps in both inpatient and community rehabilitation services to help improve long-term cognitive functioning in stroke survivors. Moreover, evidence is also needed towards fatigue management and how this can be effectively employed throughout rehabilitation for improved long-term outcomes for stroke populations. Other populations, such as those with chronic fatigue syndrome, have demonstrated improvements in reported fatigue after differing fatigue interventions. In that, establishing successful fatigue management in stroke rehabilitation will help address debilitating fatigue and potentially improve long-term outcomes in functional independence and QoL, along with participation, cognitive functioning, and social and emotional well-being.

In terms of emotional well-being it is clear that depression and anxiety is highly prevalent in stroke populations years post-stroke, although this was not represented within the current sample. Some studies have demonstrated success in declining long-term prevalence of depression and anxiety (M. L. Hackett, Anderson, House, & Xia, 2008; Kootker et al., 2017). Rehabilitation in the inpatient and community settings has the potential to incorporate psychological rehabilitation in order to prevent depression and anxiety post-stroke. This further could allow a space for issues in social functioning and relationships, physical and emotional roles, participation in the community and

motivation within rehabilitation to be addressed. Within this current sample there is no evidence of any psychological interventions throughout the rehabilitation setting being implemented and demonstrates a gap in rehabilitation services in Auckland, NZ which potentially have an impact on long-term QoL and functional independence outcomes.

With Māori and Pacific people demonstrating earlier onset of stroke in comparison to European populations, it is vital to attain an understanding towards how rehabilitation can be tailored to benefit long-term outcomes of these populations. Especially due to the age of stroke onset for Māori and Pacific people likely to be within their working years and having a family who is still financially reliant on them. Considering a more collectivist approach to stroke rehabilitation, where involving the QoL and the impact of functional dependence of the stroke survivor and their family or caregivers too, has the potential to benefit not only Māori and Pacific populations, but European populations also. This is important to consider for future research and practice within NZ.

It is obvious that rehabilitation services and resources are either insufficient and/or underutilised in Auckland, NZ. A standardised measure should be utilised throughout NZ, where stroke survivors are triaged for rehabilitation. This would allow for stroke survivors and families to be provided with the appropriate level of support and have the inpatient and community rehabilitation interventions they specifically need within a certain time frame. This has potential towards attaining a better understanding of what survivors of stroke are receiving at the inpatient and community rehabilitation levels, along with what services they are being referred too, when they are referred, and why.

Within this current sample there was no evidence of inpatient or community rehabilitation being associated with more favourable outcomes in functional independence and QoL at four years. This represents a gap in the rehabilitation services provided to stroke populations in Auckland, NZ. It was evident that those who did receive inpatient rehabilitation were still significantly disabled in areas of self-care and usual activities on the EQ-5D measure at four years, indicating that there is a gap in stroke rehabilitation in Auckland. There was a relationship between those who did not receive community rehabilitation and negatively perceived health change on the EQ-5D outcome measure, indicating that not receiving community rehabilitation potentially impacted self-reported health change perspectives. At four years, the sample on average showed deficits in a range of outcome measures, including: cognitive functioning

(MoCA); fatigue (FSS, VAFS); usual activities and self-care (EQ-5D); physical functioning, role functioning physical and emotional, energy and fatigue, social functioning, general health and health change (SF-36). Current care as usual post-stroke in the inpatient and community rehabilitation setting in Auckland, NZ needs improvements in order to benefit stroke survivors' long-term outcomes.

Improvements in rehabilitation care are needed in NZ in order to reach national and international Clinical Stroke Guidelines and to ensure that survivors are attaining and maintaining their ideal physical, sensory, cognitive, psychological, emotional, and social levels of functioning post-stroke. Further population-based research into psychological and cognitive components incorporated into stroke rehabilitation, and the influence this has on long-term functional independence and QoL outcomes, could inform future Stroke Clinical Guidelines and practice. Participants in this current research present with disability in a range of functional independence and QoL outcome measures at four years, irrespective of receiving inpatient rehabilitation or not, or community rehabilitation or not. It is therefore evident that there are gaps in rehabilitation services in Auckland, NZ, as care as usual is not addressing areas of persistent disability (namely cognitive functioning, fatigue, emotional well-being, social functioning and participation), that are prevalent throughout stroke populations globally. Addressing these issues has the ability to minimise adult disability caused by stroke sequelae and to enhance potential for higher functional independence and improved QoL for stroke survivors, along with family and caregivers impacted by stroke also.

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Appendices

Appendix A: Letter of Ethical Approval Health and Disability Ethics Committee (HDEC)



Health and Disability Ethics Committees
Ministry of Health
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24 April 2014

Professor Valery L. Feigin
National Institute for Stroke and Applied Neurosciences
90 Akoranga Drive
AUT University
Northcote 0627
Auckland 0627

Dear Professor Feigin

Re:	Ethics ref:	NTX/10/09/090/AM07
	Study title:	Auckland Regional Community Stroke Study: Measuring and reducing stroke in New Zealand

I am pleased to advise that this amendment has been approved by the Northern A Health and Disability Ethics Committee. This decision was made through the HDEC Expedited Review pathway.

Please don't hesitate to contact the HDEC secretariat for further information. We wish you all the best for your study.

Yours sincerely,

Dr Brian Fergus
Chairperson
Northern A Health and Disability Ethics Committee

Encl: appendix A: documents submitted
appendix B: statement of compliance and list of members

Appendix B: Letter of Ethical Approval AUT University Ethics Committee (AUTEC)



13 May 2014

Valery Feigin
Faculty of Health and Environmental Sciences

Dear Valery

Re: Ethics Application: **11/297 Auckland Regional Community Stroke Study (ARCOS IV). Measuring and reducing the stroke burden in New Zealand. Part 1: ARCOS IV incidence and outcomes study (2010-2013)**

Thank you for your request for approval of an amendment to your ethics application.

I have approved a minor amendment to your ethics application allowing a 3 year follow up with participants who had previously agreed to be approached.

I remind you that as part of the ethics approval process, you are required to submit the following to the Auckland University of Technology Ethics Committee (AUTEC):

- A brief annual progress report using form EA2, which is available online through <http://www.aut.ac.nz/researchethics>. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 31 October 2014;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/researchethics>. This report is to be submitted either when the approval expires on 31 October 2014 or on completion of the project.

It is a condition of approval that AUTEC is notified of any adverse events or if the research does not commence. AUTEC approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

AUTEC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to obtain this. If your research is undertaken within a jurisdiction outside New Zealand, you will need to make the arrangements necessary to meet the legal and ethical requirements that apply there.

To enable us to provide you with efficient service, please use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at ethics@aut.ac.nz.

All the very best with your research,

Kate O'Connor
Executive Secretary
Auckland University of Technology Ethics Committee

CC: Rita Krishnamurthi; Kathryn McPherson; Max Abbot; Sue Mahon

A u c k l a n d U n i v e r s i t y o f T e c h n o l o g y E t h i c s C o m m i t t e e

WA505F Level 5 WA Building City Campus

Private Bag 92006 Auckland 1142 Ph: +64-9-921-9999 ext 8316 email ethics@aut.ac.nz

Appendix C: Rehabilitation Questionnaire


 100% KORO ARO O TE KONE O TAHAKI HAKAUPAU WHAKAI
ARCOS IV ARCOS - IV 3 Year Follow - Up:Stroke
 Auckland Regional Community Outcome Stroke

Registration Number	Participant Initials	Date Of Birth
<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <small>Day Month Year</small>

7.0 Rehabilitation

7.1 Did you receive inpatient rehabilitation following your stroke?
 Yes No

7.1.1 If yes, specify length of stay

7.2 Did you receive community rehabilitation following your stroke?
 Yes No

7.2.1 If yes, which service?

7.2.2 How often did you receive community rehabilitation?
 Once per week Once per month Other:
 Once per fortnight Once per 6 months

Appendix D: : EuroQol Quality of Life Scale



ARCOS IV

Auckland Regional Community Outcome Stroke

ARCOS - IV 3 Year Follow - Up:Stroke

Registration Number

Participant Initials

Date Of Birth

Day	Month	Year	Year

10.0 Health related Quality of life

Instructions: By placing one tick only in each question, please indicate which statements best describe your health today.

10.1 Mobility (tick one only)

I have no problems walking about

I have some problems walking about

I am confined to bed

10.2 Self-Care (tick one only)

I have no problems with self-care

I have some problems washing or dressing myself

I am unable to wash or dress myself

10.3 Usual Activities (e.g. work, study, housework, family or leisure activities) (tick 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

10.4 Pain/Discomfort (tick one only)

I have no pain or discomfort

I have moderate pain or discomfort

I have extreme pain or discomfort

10.5 Anxiety/Depression (tick one only)

I am not anxious or depressed

I am moderately anxious or depressed

I am extremely anxious or depressed

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 100 and the worst state you can imagine is marked 0.

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 drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.

10.6 Health state score:

Your own health state today

Best Imaginable Health State

100

90

80

70

60

50

40

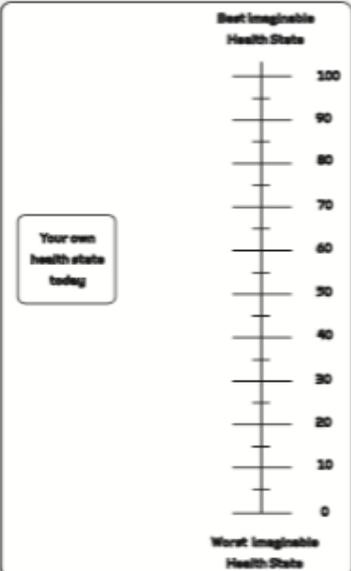
30

20

10

0

Worst Imaginable Health State



Appendix E: Hospital Anxiety and Depression Scale


ARCOS IV Auckland Regional Community Outcome Stroke
ARCOS - IV 3 Year Follow - Up:Stroke

Registration Number
Participant Initials
Date Of Birth

Complete remaining sections in Part A at ALL assessments (ALL Participants)

15.0 Hospital Anxiety and Depression Scale (HADS)

Please indicate which of the following options best describes how you have been feeling during the last week.

15.1 I feel tense or wound up (tick one only)

- 3 - Most of the time
- 2 - A lot of the time
- 1 - From time to time, occasionally
- 0 - Not at all

15.2 I still enjoy the things I used to enjoy (tick one only)

- 0 - Definitely as much
- 1 - Not quite as much
- 2 - Only a little
- 3 - Hardly at all

15.3 I get a sort of frightened feeling as if something awful is about to happen (tick one only)

- 3 - Very definitely and quite badly
- 2 - Yes, but not too badly
- 1 - A little, but it doesn't worry me
- 0 - Not at all

15.4 I can laugh and see the funny side of things (tick one only)

- 0 - As much as I always could
- 1 - Not quite so much now
- 2 - Definitely not as much now
- 3 - Not at all

15.5 Worrying thoughts go through my mind (tick one only)

- 3 - A great deal of the time
- 2 - A lot of the time
- 1 - From time to time, but not too often
- 0 - Only occasionally



Registration Number

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Participant Initials

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Date Of Birth

Day	Month	Year	

- 15.6** I feel cheerful (tick one only)
- 3 - Not at all
 - 2 - Not often
 - 1 - Sometimes
 - 0 - Most of the time
- 15.7** I can sit at ease and feel relaxed (tick one only)
- 0 - Definitely
 - 1 - Usually
 - 2 - Not often
 - 3 - Not at all
- 15.8** I feel as if I am slowed down (tick one only)
- 3 - Nearly all the time
 - 2 - Very often
 - 1 - Sometimes
 - 0 - Not at all
- 15.9** I get a sort of frightened feeling like 'butterflies' in the stomach (tick one only)
- 0 - Not at all
 - 1 - Occasionally
 - 2 - Quite often
 - 3 - Very Often
- 15.10** I have lost interest in my appearance (tick one only)
- 3 - Definitely
 - 2 - I don't take as much care as I should
 - 1 - I may not take quite as much care
 - 0 - I take just as much care as ever
- 15.11** I feel restless as if I have to be on the move (tick one only)
- 3 - Very much indeed
 - 2 - Quite a lot
 - 1 - Not very much
 - 0 - Not at all
- 15.12** I look forward with enjoyment to things (tick one only)
- 0 - As much as I ever did
 - 1 - Rather less than I used to
 - 2 - Definitely less than I used to
 - 3 - Hardly at all



ARCOS IV
Auckland Regional Community Outcome Stroke

ARCOS - IV 3 Year Follow - Up:Stroke

Registration Number

Participant Initials

Date Of Birth

Day Month Year

15.13 I get sudden feelings of panic (tick one only)

- 3 - Very often indeed
 2 - Quite often
 1 - Not very often
 0 - Not at all

15.14 I can enjoy a good book or TV programme (tick one only)

- 0 - Often
 1 - Sometimes
 2 - Not often
 3 - Very seldom

Anxiety Subscore

Depression Subscore

15.15 **Total HADS Score**

Appendix F: The Medical Outcomes Study Short Form 36

14.0 MOS 36-Item Short Form Survey Instrument (SF-36) (Australia/New Zealand, Version 1.0)

This questionnaire asks for your views about your health, how you feel and how well you are able to do your usual activities. Answer every question. If you are unsure about how to answer a question, please give the best answer you can.

14.1 In general, would you say your **health** is
(tick one only)

- Excellent
- Very good
- Good
- Fair
- Poor

14.2 Compared to one year ago, how would you rate your health in general now?
(tick one only)

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



Registration Number

Participant Initials

Date Of Birth

Day Month Year

14.3 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? (tick one circle on each line)

ACTIVITIES	Yes, limited a lot	Yes, limited a little	No, not limited at all
14.3.1 Vigorous activities , such as running, lifting heavy objects, participating in strenuous sports	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14.3.2 Moderate activities , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14.3.3 Lifting or carrying groceries	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14.3.4 Climbing several flights of stairs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14.3.5 Climbing one flight of stairs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14.3.6 Bending, kneeling or stooping	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14.3.7 Walking more than one kilometre	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14.3.8 Walking half a kilometre	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14.3.9 Walking 100 metres	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14.3.10 Bathing or dressing yourself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

14.4 During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities as a result of your **physical health**? (tick one circle on each line)

	Yes	No	
14.4.1	<input type="radio"/>	<input type="radio"/>	Cut down on the amount of time you spent on work or other activities
14.4.2	<input type="radio"/>	<input type="radio"/>	Accomplished less than you would like
14.4.3	<input type="radio"/>	<input type="radio"/>	Were limited in the kind of work or other activities
14.4.4	<input type="radio"/>	<input type="radio"/>	Had difficulty performing the work or other activities (for example, it took extra effort)



Registration Number

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Participant Initials

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Date Of Birth

Day	Month	Year			

14.5 During the **past 4 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)?

(tick one circle on each line)

- | | Yes | No | |
|--------|-----------------------|-----------------------|---|
| 14.5.1 | <input type="radio"/> | <input type="radio"/> | Cut down on the amount of time you spent on work or other activities |
| 14.5.2 | <input type="radio"/> | <input type="radio"/> | Accomplished less than you would like |
| 14.5.3 | <input type="radio"/> | <input type="radio"/> | Didn't do work or other activities as carefully as usual |

14.6 During the **past 4 weeks**, to what extent has your **physical health** or **emotional problems** interfered with your **normal** social activities with family, friends, neighbours, or groups? (tick one only)

- Extremely
- Quite a bit
- Moderately
- Slightly
- Not at all

14.7 How much **bodily pain** have you had during the **past 4 weeks**? (tick one only)

- Very severe
- Severe
- Moderate
- Mild
- Very mild
- No bodily pain

14.8 During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)? (tick one only)

- Extremely
- Quite a bit
- Moderately
- A little bit
- Not at all



Registration Number

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Participant Initials

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Date Of Birth

Day	Month	Year	

14.9 These questions are about how you feel and how things have been with you during the **past 4 weeks**. 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 4 weeks**...

(tick one circle on each line)

ACTIVITIES	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
14.9.1 Did you feel full of life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14.9.2 Have you been a very nervous person?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14.9.3 Have you felt so down in the dumps that nothing could cheer you up?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14.9.4 Have you felt calm and peaceful?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14.9.5 Did you have a lot of energy?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14.9.6 Have you felt down?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14.9.7 Did you feel worn out?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14.9.8 Have you been a happy person?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14.9.9 Did you feel tired?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

14.10 During the **past 4 weeks**, how much of the time has your **physical health** or **emotional problems** interfered with your **social activities** (like visiting with friends, relatives, etc.)? (tick one only)

- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time

Appendix G: Barthel Index

8.0 Barthel Index

Guidelines for Completion

- a. *The index should be used as a record of what a participant does, not as a record of what a participant, could do.*
- b. *The main aim is to establish the degree of independence from any help, physical or verbal, however minor or for whatever reason.*
- c. *The need for supervision renders the participant not independent.*
- d. *A participant's performance should be established using the best available evidence. Asking the participant, friends/relatives and nurses are the usual sources, but direct observation and common sense are also important. However, direct testing is not needed.*
- e. *Usually the participant's performance over the proceeding 24-48 hours is important, but occasionally longer periods will be relevant.*
- f. *Middle categories imply that the patient supplies over 50 percent of the effort.*
- g. *Use of aids to be independent is allowed.*

Choose the scoring point for the statement that most closely corresponds to the patient's current level of ability for each of the following 10 items. Record actual, not potential, functioning. Information can be obtained from the patient's self-report, from a separate party who is familiar with the patient's abilities (such as a relative), or from observation.

Refer to the Guidelines section for detailed information on scoring and interpretation.

8.1 Feeding (tick one only)

- 2 Independent: Able to use any necessary device; feeds in a reasonable time; able to cut up food, use condiments, spread butter etc. on his/her own. Food may be placed within reach.
- 1 Needs help: e.g. with cutting or spreading butter.
- 0 Dependent: Needs to be fed.

Appendix H: Modified Rankin Scale

9.0 Modified Rankin Scale

How would you describe your current symptoms or disability?

SCORE	DESCRIPTION
<input type="radio"/> 0	No symptoms at all
<input type="radio"/> 1	No significant disability despite symptoms; able to carry out all usual duties and activities
<input type="radio"/> 2	Slight disability; unable to carry out all previous activities but able to look after own affairs without assistance
<input type="radio"/> 3	Moderate disability; requiring some help, but able to walk without assistance
<input type="radio"/> 4	Moderately severe disability; unable to walk without assistance and unable to attend to own bodily needs without assistance
<input type="radio"/> 5	Severe disability; bedridden, incontinent and requiring constant nursing care and attention
<input type="radio"/> 6	Dead

9.1 MRS Score

Appendix I: Fatigue Severity Scale

12.0 Fatigue Severity Scale

Please circle the number between 1 and 7 which you feel best fits the following statements. This refers to your usual way of life within the last week. 1 indicates "strongly disagree" and 7 indicates "strongly agree."

Read and circle a number.	Strongly disagree	→					Strongly agree
1. My motivation is lower when I am fatigued.	1	2	3	4	5	6	7
2. Exercise brings on my fatigue.	1	2	3	4	5	6	7
3. I am easily fatigued.	1	2	3	4	5	6	7
4. Fatigue interferes with my physical functioning.	1	2	3	4	5	6	7
5. Fatigue causes frequent problems for me.	1	2	3	4	5	6	7
6. My fatigue prevents sustained physical functioning.	1	2	3	4	5	6	7
7. Fatigue interferes with carrying out certain duties and responsibilities.	1	2	3	4	5	6	7
8. Fatigue is among my most disabling symptoms.	1	2	3	4	5	6	7
9. Fatigue interferes with my work, family, or social life.	1	2	3	4	5	6	7

12.1
Total
fatigue
score:



ARCOS IV
Auckland Regional Community Outcome Stroke

ARCOS - IV 3 Year Follow - Up:Stroke

Registration Number

Participant Initials

Date Of Birth

Day

Month

Year

13.0 International classification of sleep disorders

- Yes No
- 13.1 Do you have trouble staying awake during the day
(e.g. falling asleep in waiting rooms, lectures, when a passenger in a car)?
- 13.2 Do you need to have naps during the day?
- 13.3 Do you experience frequent episodes of breathing pauses (or gasping for air) during sleep or has someone told you that you "stop breathing" while you are asleep?
- 13.4 Don't know Do you snore very loudly?
- 13.5 Do you get morning headaches?
- 13.6 Do you have a dry mouth upon awakening?

Appendix J: Fatigue Visual Analogue Scale

 **ARCOS IV** Auckland Regional Community Outcome Stroke **ARCOS - IV 3 Year Follow - Up:Stroke**

Registration Number:

Participant Initials:

Date Of Birth: / /

11.0 Fatigue Visual Analogue Scale

On a scale of 0 to 100, with 100 representing maximum fatigue and 0 representing no fatigue, how much fatigue have you experienced since your stroke?

Worst imaginable fatigue

100
90
80
70
60
50
40
30
20
10
0
No fatigue

Please put a line on the scale that represents how much fatigue you have experienced.

(Office Use only)

11.1 Fatigue score

If zero, go to 13.0



Registration Number

Participant Initials

Date Of Birth

MOCA Test Scores

(Instructions for RA: please use the information and sub-scores above to complete the following section)

18.1 MOCA (tick one only)

(Instruction: If Not Done, go to section 10)

Full test

Short test, reason:

Not done, reason:

18.2 : Start Time
hh mm

18.3 : Finish Time
hh mm

18.4 Visuospatial/executive

18.5 Naming

18.6 Attention

18.7 Language

18.8 Abstraction

18.9 Delayed recall

18.10 Orientation

18.11 Total MOCA Score

Please record the following additional information from the MoCA during testing:

18.12 Verbal fluency

Number of words beginning with f generated in the first 15 seconds

18.13 Delayed recall (category cue)

Number of words recalled with category cue (if patient does not spontaneously recall all the words)

18.14 Delayed recall (multichoice cue)

Number of words recalled with a multichoice cue (if patient fails to recall the words with a category cue)