

**Community Integration in Long-Term Stroke Survivors**

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**Master of Health Science in Psychology**

# **Community Integration in Long-Term Stroke Survivors**

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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 acknowledgments), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institutions of higher learning.

Signed:

Date: 10/11/18

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## Abstract

The aim of the current study is to examine the level of community integration in a cohort of long-term four-year stroke survivors with the objective of understanding what factors at baseline can affect low levels of community integration. Stroke, an acute neurological deficit lasting more than 24 hours, is one of the most preventable diseases globally, with around 85% of strokes able to be prevented each year. It causes around six million deaths per year and in New Zealand, has the highest stroke prevalence rate than any other high-income country. Rehabilitation post stroke is extremely important to ensure an individual has the best chance of recovery, as around 40 percent of individuals experience some form of disability. Community integration is an important area of rehabilitation to ensure it is possible for individuals to integrate back into the community as well as possible. Community integration can be a struggle for individuals who have suffered from a stroke as there are major changes within their lives that they must navigate. There are different factors that current research has found to affect community integration levels such as good levels of social support, mobility levels and confidence yet there is still a limited number of studies that look at the long term impact of community integration on stroke and what baseline factors are related to levels of community integration.

This quantitative study used previously collected data from a follow-up of participants who consented into the fourth Auckland Regional Community Outcomes Stroke study. It analysed data from 255 participants over 16 years of age living in Auckland, New Zealand. The data were collected using questionnaires at baseline and /or within two weeks after stroke and then again four years later. The community integration questionnaire, a psychometric tool used to measure community integration, was used to examine the level of community integration and was used with the baseline factors to understand which factors can predict levels of community integration. A descriptive analysis and multiple logistic regression were used to analyse the data. This analysis found that community integration was a problem for many individuals within this study, based on the cut off scores for low community integration being <14.

The data analysed, using a multiple regression analysis, found there were many factors that were significant in predicting community integration. The main findings from this study were that age, employment status and education levels at baseline were found to significantly predict community integration levels four years post stroke. Several previous studies have backed up these findings, particularly the findings with age but more research is necessary to make assumptions about how well these factors can predict the likelihood of having low community integration levels.

This unique New Zealand study investigated factors which influence community integration in long term stroke survivors. It highlights the importance of rehabilitation post stroke as it has

shown there are many issues that individuals may struggle with post stroke that can be improved by utilising rehabilitation as soon as possible post stroke. It also highlights the lack of research in this area. To ensure these results are useful in the rehabilitation community, future research should focus more on the baseline factors that were found to be significant, which was age, education and employment status as these were shown to have a relationship with community integration levels four years post stroke.

## *Table of Contents*

<b>Attestation of Authorship .....</b>	<b>3</b>
<b>Acknowledgements.....</b>	<b>4</b>
<b>Abstract.....</b>	<b>5</b>
<b>Table of Contents .....</b>	<b>6</b>
<b>Chapter One: Introduction .....</b>	<b>8</b>
<b>Chapter Two: Literature review of stroke and community integration.....</b>	<b>12</b>
Overview of stroke /defining stroke .....	12
Prevalence .....	13
Risk factors .....	16
Ethnic disparities .....	19
Burden in relation to outcomes in stroke .....	21
Community integration .....	26
Community integration and stroke .....	29
<b>Chapter Three: Methodology.....</b>	<b>34</b>
Design.....	34
Research Aim.....	34
Participants.....	34
Procedure .....	34
Predictor Variables (baseline factors) .....	35
Outcome Variables.....	35
Ethical Considerations.....	36
Data Collection .....	37
Statistical Analysis .....	37
<b>Chapter Four: Results section.....</b>	<b>38</b>
Demographic Characteristics .....	38
Table 1: Demographic and Clinical Features of Participants.....	39
Table 2: Multiple Logistic Regression of all Baseline Factors.....	41
Table 3: Multiple logistic regression of significance for variables affecting community integration within the ARCOS-IV samples.....	43
<b>Chapter Five: Discussion of results .....</b>	<b>44</b>
Brief summary of results .....	44
The results and other studies.....	44

Age.....	47
Employment status .....	49
Education.....	50
<b>Implications .....</b>	<b>54</b>
<b>Strengths and Limitations .....</b>	<b>55</b>
<b>Future Research .....</b>	<b>55</b>
<b>Conclusion.....</b>	<b>57</b>
<b>References .....</b>	<b>60</b>
<b>Appendices .....</b>	<b>65</b>
Appendix A: Ethical approval from AUTECH.....	65
Appendix B: Ethical approval from HDEC.....	66

## Chapter One. Introduction

A stroke is an acute neurological deficit, which lasts more than 24 hours. This occurs when the blood supply to the brain is interrupted, which is usually caused by a blood clot blocking a vessel or a blood vessel bursting (World Health Organization, n.d.). A stroke can be either ischemic or haemorrhagic, but most commonly they are ischemic with 85% of the population suffering from this type of stroke. Globally, stroke is one of the most preventable diseases and there are many factors that can be decreased in order to decrease an individual's chance of suffering from a stroke. Although it is a highly preventable disease, it is the second largest cause of death in New Zealand (NZ). Around 85% of strokes each year could be prevented through interventions and changing lifestyle factors (Feigin et al., 2016). The impact of stroke is widely felt, and annually, around six million people die from strokes (World Health Organization, 2014), with one third of these deaths occurring in individuals who have previously suffered from a stroke (Feigin, Norrving, & Mensah, 2017).

The impacts of stroke affect around 57,000 people per year in NZ alone, making it the leading cause of disability. Symptoms are often sudden and they tend to include abnormal or lost sensation on one side of the body, speaking difficulty, confusion, change in vision, paralysis, muscle weakness, balance and coordination problems and sometimes a severe headache (World Health Organization, n.d.). The first 24 to 48 hours post stroke are generally the most important in regards to rehabilitation as the earlier treatment begins, the less likely any complications and significant long-term effects, such as aphasia, will occur (World Health Organization, n.d.). The most common risk factors are high blood pressure, smoking, diabetes, high cholesterol, obesity, excessive alcohol intake or drug use (Ministry of Health, 2016). Other risk factors are age; those aged 65+ are more likely to be affected by a stroke than anyone else in New Zealand (Ministry of Health, 2016), and gender; with males at a higher risk of stroke burden than females (Barker-Collo et al., 2015).

Community integration can be described as: an individual's social, physical and psychological presence within their communities (Stumbo et al., 2015). It is a multi-dimensional concept and includes constructs such as orientation, physical independence, mobility, occupation, social integration and economic self-sufficiency (Willer, Ottenbacher, and Coad (1994). Community integration is arguably one of the most

important areas of rehabilitation to ensure someone who has suffered from stroke has the best chance of recovery when they are discharged (Mayo Clinic, 2017). Integrating back into the community is important after a major life change, as boredom or difficulty completing day to day tasks can lead to depression, emotional disturbances and social isolation (Mayo, Wood-Dauphinee, Côté, Durcan, & Carlton, 2002).

Rehabilitation post stroke is extremely important, particularly in the acute phase, which is within the first 24 to 48 hours as this can ensure the individual has the best chance of a full recovery (Mayo Clinic, 2017). It is also important following discharge from hospital when they begin to reintegrate back into the community. Early studies on community integration following stroke has shown that it can improve the burden that often occurs for stroke survivors, however there is a lack of long-term data examining community integration post stroke. In order to inform health care practice and outcomes for stroke survivors, a greater understanding is necessary on the impact that stroke has on community integration. By beginning rehabilitation as soon as possible, an individual's chance of returning to normal functioning increases significantly. Around 40 percent of individuals experience some form of disability that affects daily function after a stroke (Delgado, 2018). Understanding the factors that can influence community integration post stroke could help to ensure all stroke survivors can participate in their lives to the best of their ability.

High levels of community integration can also decrease the effects of illness, resulting in an improved quality of life for those who have suffered (Mayo et al., 2002). Not only does community integration improve individual's psychological wellbeing, it can also help a person return to normal functioning such as employment and education (Townley, Miller, & Kloos, 2013). Overall, community integration is important after a life changing event such as a stroke. It can improve life satisfaction (Mayo et al., 2002), decrease psychological issues (Townley et al., 2013) and help with integration back into their lives, particularly if they are navigating through disabilities (Stumbo et al., 2015).

The purpose of this thesis was to identify which baseline factors predict a low level of community integration for long-term stroke survivors. It used results from the community integration questionnaire at four years post stroke, and compared it to baseline factors such as sociodemographic, stroke-related characteristics, and psychological factors to identify correlations that could help identify individuals who

are at risk of having low levels of community integration long term and helping to decrease the chance of this happening.

The specific objectives of this thesis were to:

- Describe the impact of stroke and how community integration was relevant within stroke research
- Examine baseline factors which may influence the level of community integration for individuals post stroke
- Identify the predictors that can hinder or help individuals integrate back into the community post stroke

The first step of this thesis was to review the existing literature that is available on the burden of stroke as well as the impact of community integration on stroke and how it affects rehabilitation. Next, for objective two, the best way to answer the research question was using quantitative research methods on the data which had been previously collected. The data used was previously collected from a four-year follow-up of the fourth Auckland Stroke Regional Community Outcomes Study (ARCOS-IV). This data had assessed individuals at baseline as well as four years post stroke so it was possible to answer the research question looking at both the factors at baseline and at four years. An analysis of the data will provide an understanding of what the results show in regards to community integration levels and the factors that affect this. Finally, for objective three, the results of this thesis and what baseline factors predict a low level of community integration will be discussed in relation to the current literature. It will then be assessed in regard to what that means for stroke research in the future and where the research should continue from this point. By identifying individuals at risk for low levels of community integration, interventions like more rehabilitation around certain risk factors, could be put into place early on in recovery in an attempt to decrease these risks.

The thesis has been structured into five chapters:

- Chapter One will provide a brief introduction into the topic of stroke and how community integration is important within this. It will explain what the objectives of this study and what steps will be taken within this thesis.

- Chapter Two explores the literature on the burden of stroke and community integration, as well as the impact that community integration has on stroke survivors.
- Chapter Three discusses the methodology within this thesis. It will explore the design of the study, the participants, how the analysis was done and predictor variables. The outcome variables used, and the procedure will also be discussed.
- Chapter Four will discuss the results from the quantitative analysis. It will state the significant findings.
- Chapter Five will further explore what the quantitative analysis found, and discuss the results found in relation to other relevant literature. It will discuss if this is consistent with other current literature, and what makes this research different. The strengths and limitations will also be assessed. Finally, implications of the findings for further research and how they inform clinical practice is discussed.

## **Chapter Two. Literature review of stroke and community integration**

This chapter will provide a general overview of stroke, including prevalence, risk factors and ethnic disparities. It will review the current literature on the burden of stroke and how this burden relates to the outcomes that are generally felt post stroke. Next, the importance of community integration will be discussed and what the relationship between community integration and stroke means for rehabilitation. Finally, the gaps in the literature will be addressed and will provide an understanding as to why this research is important.

### **Overview of stroke / defining stroke**

A stroke is a cerebrovascular accident which occurs when the blood supply to the brain is interrupted. It can also be defined as an acute neurologic deficit which lasts more than 24 hours (World Health Organization, n.d.). This is usually due to a blood clot blocking a vessel, or the blood vessel bursting. It damages the brain tissue by cutting off the supply of oxygen and nutrients for an extended amount of time (Aye, 2016). Ischemic strokes are the most common type, accounting for 85% of strokes globally, which is when a clot is blocking an artery. The two most common types of ischemic stroke are: thrombotic stroke and embolic stroke (World Health Organization, n.d.). Haemorrhagic strokes, which is a burst brain aneurysm or a leak in a weakened blood vessel resulting in a bleed in the brain, account for the other 15% and include intracerebral (Kase, Shoamanesh, Greenburg, & Caplan, 2016) and subarachnoid (Suarez & Bershad, 2016). A possible warning sign of stroke, a transient ischemic attack resembles an ischaemic stroke, but symptoms tend to improve within an hour, and there is no permanent brain damage (Mayo Clinic, 2018). They can last as little as five minutes and should be taken as a warning sign with the aim of improving factors that can cause a stroke.

Symptoms are often sudden and long lasting and tend to include abnormal or lost sensation on one side of the body, speaking difficulty, confusion, change in vision, paralysis, muscle weakness, balance and coordination problems and sometimes a severe headache. The most common way to recognise a stroke is to use the acronym FAST. It stands for facial drooping, arm weakness, speech difficulties and then time to call emergency services (Mayo Clinic, 2018). This acronym was developed in the late 1990s to help emergency personnel and individuals who are at home recognise when someone is having a stroke, increasing their chance of early intervention and ultimately increasing their chance of survival and decreasing their chance of disability. To diagnose a stroke, doctors mainly rely on symptoms, imaging, such as a magnetic resonance imaging (MRI), and blood tests (Mayo Clinic, 2018). Recovery post stroke can vary between individuals and it depends on factors such as the location, age, amount of damage, and how quickly they were able to get treatment (World Health Organization, n.d.). The earlier treatment begins, the less likely any complications will occur and will decrease the risk of significant long-term effects, such as aphasia, occurring (World Health Organization, n.d.). Stroke rehabilitation differs between person to person because it is dependent on how much an individual is affected by the stroke and what disability they are suffering from. This can be determined by the location and size of the stroke lesion (Langhorne, Bernhardt, & Kwakkel, 2011). A general process of rehabilitation includes an initial assessment, goal setting, intervention and reassessment post intervention. Overall, survival rate of acute stroke has increased across all ethnic groups in New Zealand showing that individuals are getting help faster when they have suffered from a stroke (Feigin et al., 2015).

Although primary prevention strategies are important to reduce stroke burden before a stroke occurs, therapies that are effective in the acute phase, along with rehabilitation and long term therapies to prevent stroke recurrence and decrease the risk of long term disability also play an important role in reducing the burden of stroke within survivors (Feigin et al., 2017). Stroke care varies widely around the world, with most services available in high socioeconomic countries and less available in low socioeconomic countries (Mukherjee & Patil, 2011). It is estimated that a high proportion of stroke survivors only have access to minimal services post stroke with a lack of help in community integration or access to help for day to day activities, which does not provide enough essential support (Feigin et al., 2017).

## Prevalence

Statistics have estimated that there are around six million people die from a stroke annually (Mukherjee & Patil, 2011; World Health Organization, 2014) and around 44 million life years are lost when adjusted for disability showing the major toll it can take on an individual's life and the burden it has on health services (Mukherjee & Patil, 2011). One third of all strokes that occur globally happen in individuals who have previously suffered from a stroke often due to factors such as non-compliance of medication or failure to decrease factors that can increase stroke risk, using the following example of not decreasing high blood pressure or obesity post stroke (Feigin et al., 2017). Globally, the number of stroke survivors and individuals with incident stroke have increased by 50% to 100% in the last three decades, showing there could be a lack of effective preventative strategies (Feigin et al., 2017). Ideally, more awareness would be made for the risk factors that increase the likelihood of suffering from a stroke. This in turn would be likely to decrease stroke incidence worldwide. Portugal and Russia have the highest incidence of stroke, whilst India has the highest 28-day case fatalities at approximately 37–42%, showing a lack of immediate medical help when suffering from a stroke or a lack of individuals seeking help after a stroke (Thrift et al., 2017). Between 1990 and 2013, the number of deaths from haemorrhagic stroke was significantly higher than the number of deaths from an ischemic stroke (one million and 0.4 million respectively) (Feigin et al., 2017).

In New Zealand, there are over 57,000 people living with the effects that a stroke can cause, with these figures projected to increase with the ageing population as well as better management of inpatient stroke care, meaning less deaths caused by stroke (Feigin et al., 2015). It is currently the leading cause of adult disability and second leading cause of death in New Zealand (NZ) (Ministry of Health, 2016) showing the importance of researching stroke and finding ways to deal with the impacts of it. However, stroke is also a highly preventable non communicable disease which means that if individuals reduced the factors that put them at risk, for example high blood pressure, stroke rates could start to reduce (Ministry of Health, 2016). NZ has a higher stroke prevalence rate than any other high-income country in the world, with around 10% of individuals 75 years or older suffering from a stroke. However, although NZ has the highest stroke prevalence rates, stroke incidence rates have decreased by 23 percent over the past 30 years, between 1981 and 2012 for individuals aged 65 years or older (Feigin et al., 2015). Statistics show that NZ now has better survival rates for acute

stroke patients. This reduction in stroke incidence is mostly due to NZ European and Asian stroke rates decreasing. Unfortunately, the rate of decline for stroke incidence is faster than the decline in stroke mortality rates, suggesting an increase in stroke related disability over the coming years (Feigin et al., 2015), showing the need for good rehabilitation services throughout the country.

Stroke incidence rates have been shown to correlate highly with national per capita income (Mukherjee & Patil, 2011) meaning that higher income countries have a higher stroke incidence rates. This is likely due to the fact that many factors are related to higher income countries such as obesity or alcohol use. Over the past three decades stroke death has declined in both high and low socioeconomic countries. However, the low socioeconomic countries are where most of the burden from stroke is felt as there is limited medical facilities and a lack of medical advances. There are also very little capabilities for setting up rehabilitation services. Those who are in low socioeconomic countries may also be less likely to go and get medical help if they feel they cannot afford it. The number of younger adults dying from a stroke has increased by 36.7% in both high and low income countries (Feigin et al., 2017).

Ethnically, there are many differences in stroke worldwide, with these differences particularly seen in NZ. The ethnic differences in stroke can mostly be attributed to the differences in socioeconomic status (SES) and vascular risk factors such as an epidemic of obesity and Type 2 diabetes, particularly for Māori and Pacific groups (Feigin et al., 2015). Often these epidemics lead to other risk factors that can cause a stroke such as high cholesterol, high blood pressure and lack of physical activity (Feigin et al., 2015). In contrast, another study that was completed in the United Kingdom, they found no relationship between SES, age or sex and the increased incidence within black individuals compared to Caucasians (Stewart, Dundas, Howard, Rudd, & Wolfe, 1999). This shows that in some higher income countries, socioeconomic status does not make a difference. A 2014 report by the World Health Organisation (WHO) found that low income countries have a higher incidence and mortality rate from cerebrovascular deaths, such as stroke, compared to higher income countries. Lower SES groups within high income countries have a greater exposure to risk factors, such as poor diet, smoking, lack of physical activity and alcohol use, and vascular risk factors such as, diabetes mellitus and hypertension (World Health Organization 2014). This is shown in the NZ community where Māori and Pacific groups have higher rates of the risk factors that tend to cause stroke such as obesity or diabetes mellitus (Feigin et al., 2015).

Alongside these risk factors, there are some environmental factors that some studies have found to increase the burden of stroke. In the Feigin et al. (2016) study, the results found that air pollution and environment factors were associated with increased stroke burden in low and middle income countries. These countries also had higher rates of smoking, poor diet and high blood pressure, compared to high income countries (Feigin et al., 2016). Reducing rates of stroke is paramount to ensure the possibility of reducing stroke burden globally. As previously stated, the mortality of stroke worldwide is around six million annually, and the majority of these deaths are preventable (World Health Organization, 2014). These statistics show how education around stroke and what can increase the risk of stroke should be able to help to reduce the rate of stroke incidence as well as ensure individuals seek help as soon as they know a stroke has occurred, whether in themselves or someone around them.

### **Risk factors**

As shown through previous research, although stroke is the leading cause of disability, it is a relatively preventable disease if some major risk factors are controlled. About 85 percent of all strokes could be prevented through different interventions such as changing a variety of lifestyle factors or education around health (Feigin et al., 2016). The most important risk factor for stroke and the risk factor that is most likely to increase an individual's risk of stroke is high blood pressure. High blood pressure is commonly associated with greater alcohol consumption, lack of physical activity, obesity and high levels of salt (Ministry of Health, 2016). NZ has one of the highest rates of obesity globally which is related to all these risk factors and unsurprisingly, increases and individuals' chance of stroke.

There are two different types of risk factors in relation to stroke, they are modifiable and non-modifiable. Modifiable risk factors are factors that can be changed or treated through education and a change in lifestyle. These risk factors related to stroke include high blood pressure, smoking, diabetes, high cholesterol, obesity, lack of physical activity, excessive alcohol intake or drug use. Secondly, there are non-modifiable risk factors which are factors that cannot be changed or treated. These risk factors are increasing age, gender, genetic factors, ethnicity and suffering from a previous stroke (Deoke, Deoke, Saoji, & Hajare, 2012).

### *Modifiable risk factors*

Risk factor prevalence has increased substantially over 30 years (Feigin et al., 2015), particularly in high income countries. The proportion of stroke patients with a history of high blood pressure, myocardial infarction and diabetes mellitus has also increased drastically. Other risk factors, such as smoking rates have decreased over 30 years in NZ in most ethnic groups except for Pacific (Feigin et al., 2015). Within the Pacific ethnicity group, the current smokers' rate has doubled. An epidemic of obesity and type 2 diabetes mellitus in children and young adults within New Zealand is of particular concern as these are major risk factors for stroke (Feigin et al., 2015).

The Auckland Stroke Regional Outcomes studies (ARCOS) have identified higher rates of high blood pressure, myocardial infarction and diabetes mellitus in NZ, which may explain the disparity in stroke prevalence compared to other countries (Feigin et al., 2016). It may also explain where NZ need to focus efforts in order to decrease prevalence rates nationwide. Internationally, modifiable risk factors are attributed to 90% of stroke burden. Of the 90%, there are 74.2% of these modifiable risk factors that are behavioural factors such as smoking, poor diet and low physical activity (Feigin et al., 2016). Poor dietary habits have increased risk over the past few decades, particularly within the younger population. This reduction in good dietary habits, as well as the other behavioural risk factors that make up 74.2% of stroke burden, could possibly be improved with early education. Factors related to diet make up five of the ten most important risk factors globally, with a slight variation depending on the socioeconomic group (Feigin et al., 2016) showing how important education would be for improving stroke prevalence rates.

Another large epidemiological study that has shown major results in understanding stroke was the INTERSTROKE study. This study was a case control study across 22 countries worldwide between 2007 and 2010. The results that the study found was that five modifiable risk factors accounted for 80% of global risk for strokes which included hypertension, current smoking, abdominal obesity, diet and physical activity (O'Donnell et al., 2010). The authors of this study have suggested that interventions which target reducing high blood pressure and reducing smoking rates, as well as more education around promoting physical activity and a healthy diet could dramatically reduce the burden of stroke globally.

Additionally, another modifiable risk factor which is slightly less common but that has been found to increase stroke incidence, particularly in older individuals, is social isolation. Social isolation is defined as knowing fewer than three people well enough to visit them in their home. The study showed that individuals who indicated that they had good social support also had a decreased risk of stroke, regardless of socioeconomic status (Boden-Albala, Litwak, Elkind, Rundek, & Sacco, 2005). The same study found that social isolation can also be related to post stroke mortality due to the factor being related to studies that have shown poorer regulation of risk factors and more likely to suffer from depression and decreased medication compliance (Boden-Albala et al., 2005).

#### *Non-modifiable risk factors*

In NZ, the older population, generally considered to be 65 years of age and above, is affected by stroke more than any other age group (Feigin et al., 2016). Around ten percent of individuals 75 years and above suffer from a stroke along with four percent of individuals aged 65–74 and seven percent of individuals aged 75+ suffered from health loss due to a stroke (Ministry of Health, 2016). Across the majority of ethnic groups within NZ, the mean age of individuals with stroke increased by around three years showing an increasing population within NZ. For the NZ European ethnicity this has meant the mean age changed from 72.2 to 75.3, Māori from 56.7 to 59.6 and Pacific 55.8 to 61.6. For Asian and other ethnic groups, the mean age decreased by 4.6 years from 72.1 to 67.5. The Māori and Pacific age group has the youngest mean age for stroke onset (60 and 62 respectively) regardless of their increasing mean age, with a 15-year age gap in comparison to the NZ European mean age. This is likely due to the increase of other risk factors, such as obesity and type 2 diabetes mellitus as well as the smoking rate for the Pacific ethnicity (Feigin et al., 2015). It is clear that these two ethnic groups have additional concerning statistics in these risk factors, particularly compared to other ethnic groups in NZ. Globally, the age group at most risk was 50–69-years, for high, middle and low socioeconomic groups (Feigin et al., 2016).

As a whole, most studies have shown that males tend to be at a higher risk of stroke burden than females are, across all age groups (Barker-Collo et al., 2015). This can be partly explained by women having better health seeking behaviours, meaning they are more likely to go to the doctor if something minor is concerning them. It can also be

explained by women having better access to primary prevention and are possibly more sensitive to health information compared to men (Barker-Collo et al., 2015).

Alongside some of the health seeking behaviours more common in women, there are some risk factors are also commonly more severe in males than females, such as smoking (Barker-Collo et al., 2015). Males tend to be more likely to smoke than females and are also more likely to be heavier smokers (Barker-Collo et al., 2015). A different study that looked at gender differences in risk factors that are related to stroke incidence found that most gender differences were insignificant for the proportion of stroke burden in high income countries. These insignificant differences were due to behavioural, environmental or metabolic risks (Feigin et al., 2016). However, in low income and middle-income countries, behavioural risk was greater in males compared to females. What this means for preventative measures, is that interventions to reduce behavioural risks may be more successful in males than females in certain countries. However, as studies have shown it may not be as useful to use preventative measures in high income countries in which the focus is more on male behaviours.

Genetic factors are also considered to be a non-modifiable risk factor. Very limited research has focused on the effect that genetic factors have on the likelihood of an individual suffering from a stroke. Whilst some studies have found that stroke is likely to be both genetic and environmental, through twin, sibling and family studies (Humphries & Morgan, 2004) it is not clear exactly what these genetic factors are and how greater of a role they play in increasing the likelihood of a stroke (Humphries & Morgan, 2004; Traylor et al., 2012). Whilst genetic factors may be somewhat related, it is unlikely that these play a major role in the likelihood of an individual suffering from a stroke (Humphries & Morgan, 2004). Given the role of these factors is likely to be minor, the role that genetic risk factors play in the likelihood of suffering from a stroke could be that an individual is more likely to suffer from other modifiable risk factors that increase the risk of stroke.

### **Ethnic disparities**

Multiple studies have shown that there are significant ethnic disparities in stroke mortality rates, as well as an increased burden of stroke of certain ethnicities (Bay et al., 2015; Feigin et al., 2016; Kleindorfer et al., 2010; Stansbury, Jia, Williams, Vogel, &

Duncan, 2005). Overall in NZ, ethnic disparities are still just as prevalent as they were 30 years ago, particularly within the Māori and Pacific communities. The most obvious area of difference in ethnicities is that the Māori and Pacific age group has the youngest mean age for stroke onset (60 and 62 respectively) which has meant there is a 15-year age gap between the Māori and Pacific mean age and the NZ European mean age. Globally, minority ethnic groups are generally still experiencing poorer outcomes in terms of recovery in stroke compared to Europeans. A study conducted in the United States (US) reported ethnic disparities in stroke incidence, with black individuals more likely to have a higher stroke incidence than Caucasian individuals (Kleindorfer et al., 2010). Over time, this study found that there was a decrease in Caucasian stroke rates, but no reduction within black individuals in the community. Another US study reported that people who experienced stroke in the black population had nearly double the rates of stroke compared to Caucasian individuals (Kissela et al., 2004). This is possibly because the black population in the US are more likely to have reduced access to medical care and could also have a higher prevalence of risk factors such as high blood pressure, diabetes, smoking and excess alcohol consumption (Kissela et al., 2004). One study has shown that the ethnic disparity in the US between Caucasians and the black population has been shown to be more significant for those between the ages of 35–54 years old compared to any other age group (Kissela et al., 2004) which is significantly lower than the mean age of stroke onset worldwide. In the United Kingdom (UK), black individuals were also found to be 2.2 times more likely to suffer a stroke compared to Caucasian individuals (Stewart et al., 1999). This same study also found that the ethnic differences were likely due to a difference in SES, but they were unable to state this with certainty as there was a reduced sample to test this on. The study found that there was an overall increase in incidence for stroke for all ethnic groups of lower SES (Stewart et al., 1999). Most of these studies that have examined ethnic disparities between Caucasians and black people, (Bay et al., 2015; Kissela et al., 2004; Kleindorfer et al., 2010) did so with limited data comparing disparities between other ethnic minorities so it is hard to state whether these differences are correct for all ethnic groups globally (Stansbury et al., 2005). Unfortunately, ethnic disparities in stroke burden look to be increasing over time, due to the increasing frequency of risk factors in certain ethnic groups (Feigin et al., 2015).

A NZ study (Feigin et al., 2015) has reported that minority groups are more likely to be suffering from diabetes mellitus and hypertension and are more likely to smoke

compared to NZ Europeans. In NZ, European and Asian stroke rates have been steadily declining over the past three decades but stroke rates for Pacific people have doubled, and stroke rates have also increased for Māori, although not to the same extent as the Pacific ethnic group (Feigin et al., 2016). These decreasing and increasing rates mirror what the studies in the US have found, for the black population versus Caucasian individuals (Kleindorfer et al., 2010) and the UK for black Caribbean people versus British people (Stewart et al., 1999).

Some risk factors, that are more commonly found in minority ethnic groups, have seen a decline in recent years, such as the decline in smoking rates. However, there has been an increase in the risk factors of obesity and diabetes mellitus throughout all four of the main ethnic populations in NZ (Carter et al., 2006). Māori and Pacific suffer from stroke burden earlier (60 and 62) compared to NZ Europeans (75) as well (Feigin et al., 2015). However, whilst this is a large difference between ethnic groups, this difference also reflects the lower life expectancy that Māori groups have at birth, around eight years less than other ethnic groups in NZ (Feigin et al., 2015).

The ethnic disparity in NZ may also be attributed to the differences in SES between the ethnic groups which can often lead to higher exposure of the risk factors involved in stroke burden. For example; lower socioeconomic groups are at greater risk for exposure to certain risk factors such as hypertension, smoking, poor diet, lack of physical activity, diabetes mellitus and increased alcohol use (Feigin et al., 2015). However, there is limited data which supports this, therefore the reasons for ethnic disparities in stroke incidence still remain unclear. An increase in studies around this area within stroke research would be useful. However, it is also assume that a lack of stroke knowledge and awareness of symptoms in an urban NZ population is thought to contribute to these ethnic differences in stroke burden (Bay et al., 2015).

### **Burden in terms of outcomes in stroke**

Currently, research shows that around 75% of individuals who have suffered from a stroke will survive. There will be about 25% of the 75% of individuals who will be left with a minor disability and around 40% will experience a moderate to severe disability (Go et al., 2014). The impact of stroke tends to vary depending on how severe the stroke is, and where the lesion is located within the brain (World Health Organization, 2014).

The impact will also vary depending on how soon after a stroke occurs an individual will receive help for their stroke, as many studies have shown that the sooner an individual gets help, both medical help and rehabilitation services such as physical or speech therapy, the more likely they are to make a full recovery. The most commonly reported symptoms that individuals who have a disability post stroke tend to suffer from include physical, functional, psychological, and cognitive deficits which in turn will impact on an individual's ability to function in everyday activities (World Health Organization, 2014).

An individual's limitations in the performance of day to day activities has been found to have an impact on stroke specific health related quality of life (Chou, 2015). However, to counteract this statistic, participation in rehabilitation, after the onset of stroke, has a positive impact on improving stroke specific health related quality of life (Chou, 2015). This study found that community integration levels and reintegrating back into their own community after a stroke also had a positive impact on stroke specific health related quality of life (Chou, 2015). Rehabilitation is not only completed in a hospital setting, but often for months or years post stroke in an outpatient setting. The types of rehabilitation can range from physical therapy which is often completed both in the hospital and in an outpatient setting, as well as other rehabilitation like helping individuals make changes to their previous day to day schedule in order to accommodate issues post stroke that may arise. Support throughout all of the rehabilitation period, even after they stop accessing formal services, is important for an individual to continue recovery (Langhorne et al., 2011). Positive outcomes within rehabilitation is strongly associated with high motivation and engagement, meaning the individual and family need to actively want to focus on rehabilitation and really get involved with the services they are provided to ensure they get the best results possible (Langhorne et al., 2011). Just as rehabilitation can take varying amounts of time, often depending on a number of different factors, so too can the symptoms that have occurred as a results of the stroke (Mayo Clinic, 2017). These symptoms can be psychological, such as depression, or a change in differing cognitive, motor, speech or sensory skills (Delgado, 2018). These symptoms can even continue to show up months or years after the stroke and can take equally as long to minimise the impact of them on an individual's life.

The major and most common factors that can affect an individual post stroke can be split into four general categories: physical, cognitive, psychological and psychosocial.

### *Physical*

Physical factors are a common occurrence in individuals post stroke, as they find themselves less mobile compared to how they were. Physical factors that can become an issue post stroke have been found to influence stroke specific health related quality of life (HR-QoL) (Chou, 2015). In one study of 893 ischemic stroke sufferers, 45% of individuals had some form of disability even continuing as long as five years post stroke (Yang et al., 2016). This same study found that older age, lower education level, a previous stroke, stroke severity, depression and cognitive impairment at three months post stroke were associated with continued post stroke disability at five years post stroke.

Pain, considered a physical factor, can also be a debilitating symptom for individuals post stroke. Both pain and fatigue can occur in some stroke survivors, which is often quite a frustrating and enduring effect on individuals, commonly leading to other psychological and emotional outcomes (Lincoln, Kneebone, Macniven, & Morris, 2012). The most common physical impairment individuals suffer from post stroke is some form of motor impairment. This is described as restricting function in muscle movement and mobility therefore decreasing an individual's ability to complete day to day activities with ease (Langhorne et al., 2011). The most common type of mobility issues an individual may suffer from is spasticity. Around 20–40% of stroke survivors develop this condition, which is a muscle condition that can interfere with normal movement and speech. A study looking at the effect that spasticity has on individuals post stroke has shown that the impact this issue can have on quality of life was significant and can cause a lower quality of life due to the reliance on others, as well as the socioeconomic burden it can have (Zorowitz, Gillard, & Brainin, 2013).

Overall, stroke specific HR-QoL is generally affected due to the possibility of an individual who has had a stroke suffering from a major disability. The ability to perform daily activities can be disrupted, causing a negative effect on the emotional lives of both the sufferers and the caregivers. Unfortunately, this can last long term post stroke as well, depending on how severe the disability is. It can often take an individual a while to come to terms with their new life, and also to figure out how they need to adjust so they can be as comfortable as possible and live their best life with the continuous changes of suffering from a stroke.

### *Cognitive*

A decrease in cognitive function is a widely reported factor post stroke, with around 60 to 70% of stroke survivors (Nys et al., 2007) with a disorder in memory, executive function, attention, language or visuo-spatial ability (Lincoln et al., 2012). One study found that impairment in executive functioning affects 50% of first stroke survivors, with visual perception and construction the most common type of disability in executive functioning within these first stroke survivors (Nys et al., 2007). Most commonly, dysfunction is likely to be seen in the acute phase post stroke and can improve on its own as individuals move out of this phase (Nys et al., 2007). This study found that strokes in both the left and/ or right hemispheres have been implicated in impaired functioning. However, this study showed that a left hemisphere stroke is more likely to cause an executive dysfunction compared to a right hemisphere stroke (Nys et al., 2007). Neglect is also a common symptom in both left and right hemisphere strokes in the acute phase, which is where an individual has a deficit or cannot use the recovering side post stroke (Stone et al., 1991), but a left hemisphere stroke patient is less likely to continue to suffer from neglect three months later (33%) compared to right hemisphere stroke patients (75%) (Stone, Patel, Greenwood, & Halligan, 1992).

Executive function and perceptual disorders are the most frequently seen cognitive dysfunctions (Nys et al., 2007). Aphasia is an impairment of language that often affects a person's ability to communicate. Language disorders such as this can affect the ability to either comprehend and/ or formulate language. It often persists in 10% to 38% of long-term survivors of stroke (Lee, Lee, Choi, & Pyun, 2015). These kinds of language disorders can have an impact on quality of life, emotional distress and participation in everyday activities, highlighting the impact it has on social participation (Dalemans, Witte, Beurskens, Heuvel, & Wade, 2010). It also can decrease quality of life which can have a flow on effect, causing other day to day issues and decreasing quality of life.

### *Psychological*

Another major factor that stroke survivors can often have issues in, are psychological and emotional problems. Many individuals suffer from psychological problems such as depression, anxiety or emotional problems such as a lack of self-esteem after a stroke, given there are many life changes that may occur due to this (Lincoln et al., 2012). One

study found that prevalence rates for mild to severe depression or anxiety at 3 months post stroke sits at around 45.6% and 38.6% respectively (Barker-Collo, 2007). These prevalence rates show the large issue that psychological problems can have on an individual, given how common they are, and how this may affect rehabilitation efforts at this point in recovery. Another study has estimated that around 33% of all stroke survivors are likely to have some form of depressive symptoms (Hackett, Yapa, Parag, & Anderson, 2005), with the greatest risk of depression likely to present months to years after the stroke has originally happened (Hackett et al., 2005). Another study has found that depression has been shown to persist in 34% of elderly patients, even 20 months post stroke (Loubinoux et al., 2012) and one study that looked at depression rates for first stroke survivors found that 27.4% of these individuals are likely to suffer from some form of depression (Paolucci et al., 1999). Left hemisphere lesions have been found to be more likely to be linked to higher depression and anxiety scores compared to other lesions. These types of lesions are also linked to having higher scores when tested in processing speed and verbal memory (Barker-Collo, 2007).

One possible explanation of a high proportion of individuals suffering from these psychological factors is an increased need to rely on a caregiver's help and support post stroke, which can have detrimental effect on the psychological and emotional wellbeing of a stroke survivor. This effect is particularly felt in individuals who were independent before the stroke. One study showed that those who are unable to return to work after a stroke or they do not successfully reintegrate into social or occupational settings can suffer from a decline in their psychological health (Mayo et al., 2002). Most commonly this declined is shown in depressive symptoms or a decline in their overall functioning which in turn can lead to a decline in quality of life (Mayo et al., 2002). Depression can also cause a decrease in productive activity and social isolation which is a common issue for stroke survivors who suffer from aphasia (Lee et al., 2015). This can lead to other issues with recovery.

Factors that are commonly associated with increased rates of post stroke depression are living alone, older age, lower SES, smoking, being a female, and stroke severity (Dennis, O'Rourke, Lewis, Sharpe, & Warlow, 2000). Stroke severity and physical and social restriction post stroke also have a significant relationship with depression, showing the more severe the stroke is, or the more restricted an individual is either physically or socially, the more likely an individual will be depressed six months post stroke (Dennis et al., 2000).

### *Psychosocial*

Psychosocial factors post stroke often require a large change to what an individual is used to in their day to day life. As an individual's needs change when they are completing their rehabilitation programmes after a stroke there is a requirement for a big adjustment in their lifestyle, both short term and long term, and it can affect both the stroke survivors as well as their families and caregivers. Mayo et al. (2002) studied the quality of life for individuals six months post stroke and reported that 70% of individuals suffered from major limitations in their day to day lives. Another study has shown that there is a significant relationship between psychosocial factors, such as social participation and stroke specific HR-QoL (Chou, 2015). For example, stroke survivors with good social support networks are reintegrated back into the community more commonly and a lot easier than those with no social support (Boden-Albala et al., 2005). Stroke severity has also been found to impact level of social participation post stroke (Dalemans et al., 2010). Social support and social participation have also been shown to have a large impact on stroke specific HR-QoL (Chou, 2015) which is why it is important to understand these factors and help an individual through these life changes.

Stroke impact can continue long term as well, depending on the severity of the stroke and the disability an individual has suffered from. The impact is particularly felt on their own stroke specific HR-QoL. Whilst there can be a large variability between quality of life levels post stroke, stroke survivors five years post stroke tended to score at least half a standard deviation below the population norm for quality of life (De Wit et al., 2017). Another study, found that six months after a stroke, survivors were more disabled and suffered from limitations in performing household tasks such as housework, preparing meals or shopping, lacked meaningful activity to fill the day and were more restricted in traveling than those who had not suffered a stroke (Mayo et al., 2002). Whilst this alone is not unexpected, what is a concerning factor is that some of these tasks imply that most stroke survivors who have been integrated back into the community will either need a full time caregiver at home, or significant home help to sustain independent living (Mayo et al., 2002) which they are not guaranteed to be receiving. This can impact the overall psychological health of an individual if they feel they are not confidently able to look after themselves.

## **Community Integration**

Community integration can be described as an individual's social, physical and psychological presence within their communities (Stumbo et al., 2015). It is a multi-dimensional concept and includes constructs such as orientation, physical independence, mobility, occupation, social integration and economic self-sufficiency (Willer et al., 1994). Community integration is arguably one of the most important areas of rehabilitation to ensure that someone who has suffered from stroke can have the best chance of recovery when they are discharged from inpatient care (Mayo Clinic, 2017). Integrating back into the community is important after a major life change, as boredom or difficulty completing day to day tasks can lead to depression, emotional disturbances and social isolation (Mayo et al., 2002). High levels of community integration can also decrease the effects of illness, resulting in an improved quality of life for those who have suffered from a stroke (Mayo et al., 2002). Not only does community integration improve an individual's psychological wellbeing, it can also help a person return to normal functioning, such as returning to previous employment and/ or education (Townley et al., 2013).

To ensure that an individual who has suffered from a stroke has the best chance of recovery post stroke rehabilitation should happen as soon as possible, ideally when they are still in the acute phase which is within the first 24 to 48 hours post stroke (Mayo Clinic, 2017). Generally, the largest part of the recovery is within the first few weeks to months after a stroke has happened but major recovery can continue even 12 to 18 months post stroke depending on the level of rehabilitation (Mayo Clinic, 2017). Community integration is one area of rehabilitation that often happens later on in the recovery process, when an individual is beginning to move from a hospital or inpatient treatment into an outpatient rehabilitation centre. It is an important area to ensure a good level of long-term recovery. There are only around 10 percent of individuals who suffer from a stroke recover completely, and 25 percent with minor impairments (Delgado, 2018). The largest group of individuals that experience some form of disability has found that it affects their day to day function, with 40 percent of individuals who have suffered from a stroke having to deal with this level of disability. The final ten percent of individuals generally require some form of long-term care, often living in an

inpatient facility and can never reintegrate back into their lives outside of an inpatient facility (Delgado, 2018).

As community integration can be described as an individual's social, physical and psychological presence within their communities (Stumbo et al., 2015), it is arguably one of the most important goals within stroke rehabilitation services and can improve an individual's ability to return to normal functioning after many different life changing events, such as a stroke. Given it is a multi-dimensional concept (Willer et al., 1994) it is able to help an individual's ability to integrate back into the community, which is important for overall levels of quality of life. For example, Townley et al. (2013) found that a better level of community integration within individuals with psychiatric disabilities can increase life satisfaction and mental health, as well as the possibility of reducing loneliness.

Whilst a full recovery can be made after a stroke, some individuals still find there are issues that interfere with living a normal life, such as integrating back into their usual family roles or attempting to get back into work (Willer et al., 1994). There can often be a struggle with the feeling of loss of control over their own life after a serious injury and having to change how they are used to living (Sveen, Thommessen, Bautz-Holter, Wyller, & Laake, 2004; Willer et al., 1994). There has also been evidence that suggests there is a strong relationship between social support and health, with high levels of social support associated with healthier aging, improved functional status, lower stroke incidence and decreased mortality rates (Boden-Albala et al., 2005). Social support and community integration often come hand in hand when relating to rehabilitation post stroke.

Generally, females and individuals who are more highly educated tend to experience higher levels of community integration compared to males and those who are less educated (Dijkers, 1997). One explanation for this could be because females and those who are highly educated are more sensitive to health information and have better health seeking behaviour (Barker-Collo et al., 2015) meaning they will seek help earlier than their counterparts. Those who are highly educated also tend to have better access to primary prevention so may suffer from less disability post stroke (Barker-Collo et al., 2015). Males also tend to be declining slower than women in some neurovascular risk factors such as smoking, which can increase the risk of stroke (Barker-Collo et al.,

2015). Unsurprisingly, these are very similar to the explanations for why different socioeconomic groups have better levels of recovery from stroke.

Age can also influence community integration, with younger individuals tending to score higher in community integration compared to those who are older (Dijkers, 1997). This study shows that community integration is particularly important for the aging population. Another study showed that a large proportion of individuals who are older in age who have suffered from a stroke, are living longer with chronic conditions compared to 30 years ago (Stumbo et al., 2015). Mobility has been found to be a major factor in integrating back into the community, which can decrease with age (Stumbo et al., 2015). Rehabilitation as an outpatient has been proven to help improve an individual's leisure, kitchen and mobility activities which overall had a positive impact on satisfaction levels and was found to significantly relate to improved levels of well-being.

A study of 11000 individuals in a healthy population aged 60 and above reported that over 40% of the aging population had either no contact at all or contact with only one individual within a week, making it difficult to reintegrate back into the community (The Tompkins County Office for the Aging, 1999). This is worrying, as these statistics are from a healthy population which could suggest that a stroke population would be expected to have lower levels of contact within the community. Another study found that higher levels of community integration in older adults helped to improve their mental health and also helped them to improve their perceptions on their independence, stress management and self-worth (Hebblethwaite & Pedlar, 2005)

Some studies have shown that a high level of community integration can decrease the effects of illness which can result in an improved quality of life (Mayo et al., 2002). For example, Townley et al. (2013) found that a better level of community integration for individuals with psychiatric disabilities can increase life satisfaction and mental health, as well as reduce loneliness. This shows that not only does community integration improve individual's psychological wellbeing, it can also help with a person returning to normal functioning such as employment and education (Townley et al., 2013).

Overall, because community integration can improve life satisfaction (Mayo et al., 2002), decrease psychological issues (Townley et al., 2013) and help individuals who have suffered from a stroke reintegrate back into their lives with as much ease as

possible, particularly as they may be navigating through disabilities due to the stroke which can cause significant changes in their life (Stumbo et al., 2015).

### **Community Integration and Stroke**

There are many factors that influence community integration post stroke. These factors can vary from social support (Boden-Albala et al., 2005) to the level of disability an individual who has had a stroke has suffered from (Liu, Ng, Kwong, & Ng, 2015). It is important that those working in stroke rehabilitation gain an understanding of these factors so that they can ideally be worked on before individuals are out in the community. Importantly, extra help can be given to those that are more at risk of low levels of community integration if it is known what factors may influence low levels of community integration (Stumbo et al., 2015).

Social support following a stroke has been shown to provide a means for faster reintroduction into the community (Boden-Albala et al., 2005). This Boden-Albala et al. (2005) study showed that those who have more people they are able to rely on and ask for help, the more likely they will be able to ease back into living at home and reintegration in the community. Another study showed that social isolation, which is defined by knowing fewer than three people well enough to visit the home, was related to higher rates of stroke mortality, stress, depression and poorer regulation of other risk factors such as lowering high blood pressure or reducing smoking (Boden-Albala et al., 2005). Comparatively, a 2002 study, found that having adequate social support and appropriate access to resources such as physiotherapy increased overall quality of life, and reduced the impact of stroke on the family (Mayo et al., 2002). Distal support, another form of social support which tends to be more tangible support such as individuals offering to carry groceries to the car or provide free food, has also shown a significant positive effect on community integration, alongside emotional support (Townley et al., 2013). This type of support tends to help individuals engage more in the community and feel more satisfied and productive with their lives post stroke (Townley et al., 2013).

A systematic review of community integration after stroke reported that there is a lack of quantitative research that studied the factors that can affect community integration levels post stroke (Jellema et al., 2016). This review found that there was only a small

amount of studies that were researching what the effects of community integration were and what factors can affect how well someone can integrate back into the community. However, the studies that have looked at this area have found that consistent social support is one of the most important factors in regard to levels of community integration post stroke (Dalemans et al., 2010; Jellema et al., 2016). There are many different reasons as to why social support can be a huge strength when helping someone integrate back into the community. One important reason is that given the exploration of new activities can often be anxiety provoking for individuals post stroke, having a support system in place for when the individual is struggling can be vital. Furthermore, without having any social support individuals that have survived a stroke tended to restrict their involvement when it came to challenging situations and in turn, isolated themselves from the community (Jellema et al., 2016).

Another study found that individuals who have positive perceptions on how well they are able to participate in activities that they previously enjoyed before their stroke were found to have higher levels of life satisfaction (Eriksson, Carolyn Baum, Wolf, & Connor, 2013). Alongside their perceptions on participation, if their perception of recovery six months post stroke was positive, they were more likely to have higher levels of life satisfaction compared to someone who had a negative perception. This study also found that it did not matter what level of recovery an individual was at post stroke, those who had positive perceptions around their own levels of community integration post stroke had a higher life satisfaction (Eriksson et al., 2013).

The research from one study found that predictors for good levels of community integration were whether an individual has reduced mobility, whether they have depressive symptoms, how much they use fear avoidance behaviours and what their confidence is with balance (Liu et al., 2015). A different study showed that 82% of stroke survivors reported mobility problems and 77% reported emotional problems (Walsh, Galvin, Loughnane & Horgan, 2015). Even six months post stroke, over 50% of survivors still needed help with household tasks and over 20% of survivors needed help with mobility (Mayo et al., 2002). These statistics show how important it is to help individuals who are suffering from reduced mobility and possibly put more measures in place to ensure they are able to get out into the community and integrate back in.

Another factor that has been found to effect levels of community integration post stroke is whether an individual who has had a history of falls. The study showed that stroke

survivors who have a history of falls, tend to have lower levels of community integration. A 2015 study of 57 stroke survivors reported that individuals who experienced frequent falls had higher levels of fear-avoidance behaviours, which resulted in the individual generally preferring to stay at home (Liu et al., 2015). Another study found similar results, where motor function is positively associated with community integration and that the improvement of motor function could enhance community integration levels post stroke (Obembe, Mapayi, Johnson, Agunbiade, & Emechete, 2013).

Depression has also been found to be associated with community integration levels, with one study showing that as depression levels increase, community integration and satisfaction levels post stroke decreased (Obembe et al., 2013). Relative to this study, a systematic review of stroke survivors found that their level of anxiety and their attitude towards both rehabilitation and how they viewed their life post stroke correlated with levels of community integration (Jellema et al., 2016). The Jellema et al. (2016) study found that anxiety and depression are quite common in individuals two to five years post stroke, at 36% and 28% respectively and another study found that between one third to half of those who suffered from one of these disorders also suffered from the other (Bergersen, Frosli, Stibrant Sunnerhagen, & Schanke, 2010). However, unlike the other studies, this study showed no significance between psychiatric disorders and lower quality of life, showing that there could be other factors that account for low quality of life (Bergersen et al., 2010).

Jellema et al. (2016) also found that most factors related to community integration levels were associated with living environment. Individuals who were attempting to live their normal lives with no changes to account for their change in lifestyle, had lower levels of community integration. A different systematic review, completed by Stumbo et al. (2015) found that a lack of companionship, how an individual was able to get around and socioeconomic status can be barriers to community integration. The inability to drive has shown to cause lower levels of community integration due to a reduction in mobility within the community and those who could drive were more productive with their time than those who do not (Griffen, Rapport, Coleman Bryer, & Scott, 2015). However, another study found that socioeconomic status had no impact on community integration levels and found the only factor that did have a relationship on community integration was how well they were able to reintegrate to normal living after their stroke (Olaoye, Adejumbi, Olasusi, Aladesuyi, & Emechete, 2017).

The current research on community integration shows how important it is for rehabilitation programmes to understand what factors may affect an individual's ability to fully reintegrate back into the community and ultimately live a fulfilling life post stroke. Given the current research available has shown that there is a variety of factors that could affect community integration and the different stages of recovery make a difference as to what factors can affect levels of community integration.

To date, the research on community integration within stroke is limited, particularly looking at longer term community integration. Very little research has explored the potential psychological factors that could influence long-term outcomes especially when it comes to the factors that are relevant at baseline. Whilst there is a lack of studies that have looked at the long-term effects of stroke on community integration within the stroke population, there are multiple studies examining the effect of traumatic brain injury (TBI) and long-term community integration. Burleigh, Farber, and Gillard (1998) found a significant relationship between community integration and life satisfaction, with individuals who were eight to 23 years post injury. This study showed how individuals who are involved in programmes to help them reintegrate back into the community early on in their recovery can improve their level of satisfaction, with the results continuing years after the initial injury. Further research on community integration at different stages post stroke would be useful in providing a better understanding of the effect that community has on stroke recovery. It would also be useful to explore what areas of rehabilitation would be most useful for individuals who are struggling to integrate themselves back into daily life (Jellema et al., 2016). What is clear from the literature review, is that there is a real lack of studies that have looked at how baseline factors can predict rehabilitation levels in the long-term recovery of an individual who has suffered from a stroke.

The overall aim of this study is to examine the level of community integration in a cohort of long-term four-year stroke survivors. The objective is to understand which baseline factors can affect low levels of community integration four years post stroke. The current study will use data collected from the Auckland Regional Community Stroke Study (ARCOS-IV) follow-up study.

By determining what factors may influence levels of community integration, rehabilitation programmes could tailor the work that individuals need to complete in order to get them functioning in the community to the best of their abilities. The aim of

this is to ultimately improve life satisfaction regardless of disability levels post stroke (Burleigh et al., 1998; Eriksson et al., 2013). This literature review has shown the lack of research around the factors that influence community integration levels post stroke and how that understanding can affect other factors of rehabilitation over the years. It is expected that this study will find similar results to studies that have looked at community integration levels. For example, those who have suffered from anxiety and depression at baseline would be more likely to have low levels of community integration (Liu et al., 2015).

Understanding what factors may influence community integration at four years post stroke, would help to improve the recovery of stroke survivors. A better understanding could also help to decrease the statistics of the 40 percent of individuals who need daily help post stroke (Delgado, 2018). Furthermore, individuals recovering from a stroke may struggle to fully function in their day to day lives, regardless of the amount of time from when the stroke occurred and increasing community integration could help. Given the impact that stroke has on many individuals in New Zealand, the research would be useful to inform stroke management strategies that may help to decrease that impact and improve stroke outcomes for many individuals. This information has the potential to increase knowledge around the factors which may impede or assist recovery following a stroke, in terms of community integration. By studying this and gaining a greater understanding on what factors can predict community integration, the hope is that it can help rehabilitation programmes become more tailored to individuals when helping them get back to functioning as best they can within the community.

After reviewing the current literature on community integration and stroke, it is hypothesised that the results will show there are a number of different factors that can affect low levels of community integration. In particular, it is expected that the factors that will show significance are suffering from a previous stroke, being of older age, gender, and suffering from either anxiety and /or depression.

### **Chapter Three. Methodology**

This methodology chapter will provide an understanding of the design of the study, what the research aim is, who the participants of this study are and procedure of this study. It will also discuss what ethical considerations need to be understood before the

study begins, as is important in every study. Finally, data collection and statistical analysis will be discussed to make clear the reasoning behind the study.

## **Design**

The current study is a quantitative design and uses previously collected data from a follow-up study of the fourth Auckland Regional Stroke Community Outcomes (ARCOS-IV), population-based study (Krishnamurthi et al., 2014).

## **Research Aim**

The overall aim of this study is to examine the level of community integration in a cohort of long-term four-year stroke survivors. The objective is to understand which baseline factors can affect low levels of community integration four years post stroke.

## **Participants**

The sample used for this analysis comprised of 255 participants. All participants within this study had suffered a stroke, been interviewed with the first two weeks after they suffered a stroke and had been interviewed again at four years post stroke. The original inclusion criteria for the ARCOS IV study were that individuals must have had a stroke between March 1, 2011 and February 29, 2012; and resident of the Auckland, NZ region and they were older than 16 years old (Krishnamurthi et al., 2014). The participants had all completed the community integration questionnaire at four years post stroke, and baseline data was collected at baseline and again four years post stroke.

## **Procedure**

The data for this study was obtained from a follow up study of the ARCOS-IV study at four years. The ARCOS-IV study was a HRC funded programme (2010-2015) consisting of five inter-linked, cohesive components utilizing three distinct study designs to provide a multi-perspective evidence-base for measuring and reducing stroke (Krishnamurthi et al., 2014). Methods for the ARCOS-IV have been described previously (Krishnamurthi et al., 2014). In brief, participants were approached four years after their stroke if they had indicated interest in being contacted for future research. Participants had previously completed assessments at baseline which is within two weeks of stroke, and/or 1, 6 and 12 months post stroke. All participants of this study had completed two assessments, one between two weeks to 12 months post

stroke, and the other four years post stroke. Participants who had consented to the study completed face-to-face assessments, which measured health-related outcomes, psychological, psychosocial and cognitive outcomes. The data was entered into a password protected database (Microsoft Access 2010) to be stored for analysis.

### **Predictor Variables (baseline factors)**

Demographic variables collected at baseline included age, gender, ethnicity, marital status, education level, employment, recurrent stroke, stroke type (haemorrhage, ischemic), hemisphere of lesion (left, right, cerebellar, both), stroke subtype according to the Oxfordshire Community Stroke Project (OCSP) (Partial Anterior Circulation Infarct (PACI), Lacunar Infarct (LACI), Total Anterior Circulation Infarct (TACI), Posterior Circulation Infarct (POCI)), location of lesion (subcortical, cortical). Other health conditions such as a previous heart attack, and vascular risk factors including, cholesterol levels, hypertension, diabetes, coronary artery disease, and arrhythmia were also measured. Outcome measures administered at baseline included the Hospital Anxiety and Depression Scale (HADS) (Snaith, 2003) which measures level of mood, the Modified Rankin Scale (mRS) (Rankin, 1957) measuring stroke severity, Barthel Index (BI) (Mahoney & Barthel, 1965) which measures functional independence, the Montreal Cognitive Assessment (MoCA) (Nasreddine et al., 2005) to measure cognition, and the Fatigue Visual Analogue Scale (Shahid, Wilkinson, Marcu, & Shapiro, 2012) which assesses for fatigue.

### **Outcome Variables**

#### *Community Integration Questionnaire (CIQ)*

The CIQ is a psychometric tool used to measure community integration (Willer et al., 1994). The questionnaire comprises of 15 items which aims to measure the level of community integration in a range of populations (Willer et al., 1994). It was originally produced for TBI but more recently the CIQ has been used within stroke populations to assess their level of integration post stroke (Griffen et al., 2015; Lee et al., 2015; Walsh et al., 2015).

The community integration questionnaire evaluates three of the main aspects of community integration: home integration, social integration and productive activities (Willer et al., 1994). Home integration is defined as active participation within a home-like setting, however an individual chooses to live. It assesses how

much an individual participates in the operation of the home rather than placing judgement on how they are living. Social integration is related to the participation in activities outside of the home, such as shopping, leisure activities and social events. This is assessed by the time that individuals spend outside of the home and does not include entertaining friends inside the home. Finally, performance in productive activities is the third area that is assessed in the community integration questionnaire and looks at how regularly they are performing these productive activities. It is described as how much an individual gets out of the house each day and includes areas like employment, education or volunteering in the community (Willer et al., 1994). It is a flexible measure which means that it can be administered in person or over the phone and takes around 15 minutes to complete. The scores range from zero to 29 and the higher the score, the better the community integration is considered to be.

When the CIQ was first assessed as an appropriate measure, Willer et al. (1994) used a healthy control sample to compare the mean CIQ scores. The mean scores for healthy controls were 19.79 in males and 20.98 for females. Lee et al. (2015) also used a healthy population control group of both males and females who scored 18.30. The control group in the Lee et al. (2015) study has shown similarities to the ARCOS-IV study. As there is no sample scores to compare and use their scores from this study will use the score of 18.3 to guide our knowledge on what a healthy CIQ score should be. The study by Lee et al. (2015) found the mean scores for stroke patients to be 8.3, however all participants suffered from severe aphasia. The cut off score for poor community integration within this study will be <14 versus good >14. This score has been based on the CIQ study, where they used a healthy control with mean scores for males and females of 19.79 and 20.98 respectively (Willer et al., 1994) as well as the study by Lee et al. (2015). Limited research has been done on what a cut off score would be within a control group for stroke, so this study has had to use research from other studies to determine what would be the cut off score.

### **Ethical Considerations**

Ethical approval was granted by the Auckland University of Technology Ethics Committee (AUTEC; 11/297) (see Appendix A) and additional approval was also given by the Health and Disability Ethics Committee (HDEC; NTX/10/09/090/AM07) (see Appendix B). All participants data was de-identified to protect the participants anonymity,

and the data was coded so there were no identifying features. This ensures that the necessary ethical considerations were met, and there was no risk of the participants being identified when the studies were published.

### **Data Collection**

The data from the ARCOS study was collected using individuals who suffered from a stroke and were found as they had previously agreed to be contacted for a further follow up after their last interview. This last interview was at 12 months post stroke. The three modes of data collection were telephone, self-completion and/ or face to face with a researcher. As previously stated, to ensure privacy, particularly because this study has been published, each individual participating was given a unique registration number as a way of identifying the participant without any identifying features being used.

### **Statistical Analysis**

A quantitative approach will be used to analyse the data in this study. In particular, a descriptive analysis and a multiple logistic regression will be used to ensure it is possible to answer the research objective. As the sample of this study is large (255) and the analysis will be conducted by looking at binary variables, such as good CIQ levels (14 and above) versus low CIQ levels (<14). This is done as it suits a quantitative approach compared to any other analytical approach. After assessing for all variables that were significant ( $p < 0.05$ ) another multiple logistic regression of significance will be conducted and all significant variables will be assessed against the other variables. Statistical Package for Social Sciences (SPSS) (IBM Corporation, 2017) was used for all statistical analysis.

## **Chapter Four. Results section**

This chapter will present the results from the data analysis. This analysis has been conducted to assess what baseline factors predict good levels of community integration. It will ensure there is an understanding of what the data has found. There will be a number of tables showing the different results, with the final table showing which baseline factors are significant for predicting low community integration levels post stroke.

### **Demographic Characteristics**

The sample was comprised of 136 (52.9%) males and 119 (46.3%) females. The ages of the participants ranged from 28 to 95, with a the mean age of  $71.2 \pm 13.52$ . The ethnicity within this sample comprised of NZ European (n = 205, 79.8%), Māori (n = 12, 4.7%), Pacific (n = 7, 2.7%) and Asian (n = 31, 12.1%). The majority of participants were married or were in a civil union or de facto relationship (n = 155, 61.5%) this is compared to n = 100 who were either not married, separated, divorced or widowed. 171 (66.5%) participants were retired and 49 (19.1%) were in current employment. Education levels varied, with all the participants relatively evenly split throughout all the levels.

Most participants suffered from an ischaemic stroke (n = 222), compared to those who sustained a subarachnoid haemorrhage (n = 18) or an intracerebral haemorrhage (n = 15). In terms of location of stroke in regards to hemisphere, n = 119 participants had a right hemisphere stroke, compared to n = 113 who had a stroke in the left hemisphere, n = 14 people had strokes in both hemispheres, and n=8 in the brainstem. The location of the stroke varied from frontal (n = 38), internal (n = 36), cerebellum (n = 35), basal ganglia (n = 29), thalamus (n = 17), brainstem (n = 15), parietal (n = 15), occipital (n = 12), temporal (n = 4) and unknown (n = 54).

**Table 1.** Demographic and Clinical Features of Participants

	ARCOS Sample <i>n</i> =255	%
Age		
<50	33	12.9%
51–64	57	22.4%
65–74	79	31.0%
75+	86	33.7%
Gender		
Female	119	46.7%
Male	136	53.3%
Ethnicity		
European	205	80.4%
Māori	12	4.7%
Pacific	7	2.7%
Asian/Other	31	12.2%
Marital status		
Married, civil union or de facto	158	62.0%
Never married	2	0.8%
Separated, divorced or widowed	95	37.2%
Education		
Did not complete school	68	26.7%
Completed school	51	19.8%
Degree	50	20.0%
Diploma/Certificate	48	18.8%
Trade/Technical	27	10.6%
Other post-school education	7	2.6%
Missing data	4	1.5%
Employment status		
Retired	171	67.1%
Unemployed	22	8.6%
Not specified	13	5.1%
Employed	49	19.2%
Stroke Type		
Ischaemic	222 (86.4)	87.0%
Subarachnoid Haemorrhage	18 (0.7)	7.1%
Intracerebral Haemorrhage	15 (0.6)	5.9%
Hemisphere		
Left	113	44.3%
Right	119	46.7%
Brainstem	8	3.1%

Both	14	5.6%
Uncertain	1	0.3%
Location		
Basal ganglia	29	11.4%
Frontal	38	14.9%
Thalamus	17	6.7%
Internal	36	14.1%
Cerebellum	35	13.7%
Brain stem	15	5.9%
Occipital	12	4.7%
Parietal	15	5.9%
Temporal	4	1.6%
Unknown	54	21.1%
Vascular Territory		
MCA	137	53.7%
PCA	50	19.6%
PICA	36	14.1%
ACA	9	3.5%
SCA	2	0.8%
Unknown	21	8.3%
	Mean	SD
Age (Mean, SD)	71.18	13.52

Table 2 shows a multiple regression analysis, reported as adjusted odds ratios (AOR) and significance ( $p = <0.05$ ) for low community integration levels (scoring  $<14$  in the CIQ). This was conducted to determine the relationship between baseline predictors and low community integration four years post stroke and was reported as AOR and confidence levels. Anything below  $p = <0.05$  was considered significant. Those who had had either a previous stroke (AOR= 2.04, 95% CI: 1.04-3.99,  $P<0.05$ ), coronary artery disease (AOR= 1.901, 95% CI: 1.029 – 3.511,  $P<0.05$ ), hypertension (AOR= 2.288, 95% CI: 1.315 – 3.981,  $P<0.05$ ) and /or epilepsy (AOR= 1.015, 95% CI: 1.020 – 24.661,  $P<0.05$ ) had lower levels of community integration.

Individuals who were 75 years or older were more likely to have lower levels of community integration (AOR= 4.029, 95% CI: 1.570 – 10.340,  $P<0.05$ ). Individuals who were employed (AOR= 0.157, 95% CI: 0.067 – 0.370,  $P<0.0001$ ) were less likely to have lower levels of community. Those who completed school (AOR= 0.409, 95% CI: 0.192 – 0.871,  $P<0.05$ ), had a trade/technical education (AOR= 0.444, 95% CI: 0.209 – 0.943,  $P<0.05$ ), had a degree (AOR= 0.444, 95% CI: 0.209 – 0.943,  $P<0.05$ ) or had a diploma/certificate (AOR= 0.323, 95% CI: 0.146 – 0.712,  $P<0.05$ ) had a lower likelihood

than any other education level of suffering from low levels of community integration post stroke.

**Table 2.** Multiple Logistic Regression of all Baseline Factors

	CIQ (%)	AOR	95% CI	<i>p</i> -value
Age				
<50	21.2%	1		
51–64	31.6%	1.737	0.633 – 4.769	0.284
65–74	45.6%	3.136	1.213 – 8.110	0.018
75+	51.2%	4.029	1.570 – 10.340	0.004
Gender				
Female	37.0%	1		
Male	44.9%	1.426	0.858 – 2.371	0.171
Ethnicity				
European	42.9%	1		
Māori	50.0%	1.273	0.397 – 4.082	0.685
Pacific	28.6%	0.636	0.114 – 3.554	0.607
Asian/Other	29.0%	0.573	0.249 – 1.320	0.191
Education				
Did not complete school	57.4%	1		
Completed school	37.3%	0.409	0.192 – 0.871	0.02
Degree	40.0%	0.444	0.209 – 0.943	0.035
Diploma/Certificate	31.3%	0.323	0.146 – 0.712	0.005
Trade/Technical	22.2%	0.211	0.074 – 0.598	0.003
Other post-school education	57.1%	0.889	0.184 – 4.303	0.884
Employment Status				
Retired	50.3%	1		
Unemployed	36.4%	0.525	0.209 – 1.318	0.17
Unspecified	30.8%	0.459	0.133 – 1.585	0.218
Employed	14.3%	0.157	0.067 – 0.370	<0.001
Marital Status				
Married, civil union or de facto	44.3%	1		
Never married	0%	<0.001	0.000 – ∞	0.982
Separated, divorced or widowed	36.8%	0.75	0.442 – 1.272	0.286
Stroke Type				

Ischaemic	41.4%	1		
Subarachnoid Haemorrhage	33.3%	0.663	0.240 – 1.833	0.428
Intracerebral Haemorrhage	46.7%	1.16	0.406 – 3.315	0.781
OCSF				
PACI	37.2%	1		
TACI	50.0%	1.862	0.646 – 5.364	0.249
LACI	43.8%	1.432	0.739 – 2.771	0.287
POCI	42.7%	1.297	0.664 – 2.535	0.446
N/A	33.3%	0.828	0.280 – 2.444	0.732
Hemisphere				
Left	43.4%	1		
Right	42.0%	0.989	0.584 – 1.674	0.966
Brainstem	12.5%	0.211	0.025 – 1.810	0.156
Both	35.7%	0.703	0.221 – 2.233	0.55
Uncertain	0%	<0.001	0.000 – $\infty$	0.987
Stroke Location				
Basal ganglia	44.8%	1		
Frontal	29.0%	0.439	0.157 – 1.229	0.117
Thalamus	47.1%	0.957	0.284 – 3.227	0.944
Internal	50.0%	1.212	0.441 – 3.332	0.71
Cerebellum	40.0%	0.794	0.285 – 2.207	0.658
Brainstem	33.3%	0.598	0.158 – 2.259	0.449
Occipital	33.3%	0.538	0.130 – 2.223	0.392
Parietal	53.3%	1.231	0.348 – 4.358	0.748
Unknown	42.6%	0.826	0.326 – 2.093	0.686
Temporal	25.0%	0.359	0.033 – 3.901	0.4
Vascular Territory				
MCA	44.8%	1		
PCA	34.0%	0.687	0.347 – 1.363	0.283
Unknown	42.9%	0.993	0.386 – 2.551	0.988
PICA	44.4%	1.078	0.507 – 2.292	0.845
ACA	22.2%	0.347	0.069 – 1.730	0.196
SCA	0%	<0.001	0.000 – $\infty$	0.982
Stroke Region				
Subcortical	40.7%	1		
Cortical	40.0%	1	0.557 – 1.798	0.999
Unknown	45.7%	1.239	0.585 – 2.621	0.576
Previous Stroke				
No	38.2%	1		
Yes	55.8%	2.041	1.042 – 3.998	0.037
Heart Attack				
No	40.9%	1		
Yes	100.0%	<0.001	0.000 – $\infty$	0.987
Cholesterol				
No	35.7%	1		

Yes	45.3%	1.491	0.891 – 2.494	0.128
Hypertension				
No	29.2%	1		
Yes	47.6%	2.288	1.315 – 3.981	0.003
Diabetes				
No	39.3%	1		
Yes	49.0%	1.387	0.740 – 2.598	0.307
Coronary Artery Disease				
No	37.5%	1		
Yes	53.7%	1.901	1.029 – 3.511	0.04
Arrhythmia				
No	36.9%	1		
Yes	52.3%	1.903	1.066 – 3.396	0.029
Heart Failure				
No	40.6%	1		
Yes	45.8%	1.165	0.500 – 2.714	0.724
Epilepsy				
No	39.8%	1		
Yes	77.8%	5.015	1.020 – 24.661	0.047
HADS Anxiety				
Abnormal	36.4%	1		
Borderline	23.1%	0.525	0.088 – 3.118	0.478
Normal	48.4%	1.791	0.489 – 6.560	0.379
HADS Depression				
Abnormal	60.0%	1		
Borderline	45.5%	0.556	0.065 – 4.755	0.592
Normal	42.1%	0.523	0.083 – 3.280	0.489

Multiple logistic regression analysis revealed that sociodemographic factors including, age (AOR= 1.020, 95% CI: 0.993 – 1.047,  $p<0.05$ ) employment status (AOR= 0.641, 95% CI: 0.467 – 0.880,  $p<0.05$ ) and education level (AOR= 0.796, 95% CI: 0.668 – 0.949,  $p<0.05$ ) were significantly associated with lower levels of community integration. The predictors that were found to be significant were retained in the regression model and after the analysis continued to add in employment status it was revealed that only education level and employment status were significant predictors, as age became non-significant after adding in employment status and education it became insignificant (0.143). Regardless of significance, gender and age were kept in the multiple logistic regression as they are general predictors of community integration.

**Table 3.** Multiple logistic regression of significance for variables affecting community integration within the ARCOS-IV samples

	AOR	95% CI	<i>p</i> -value
Gender	1.613	0.940 – 2.768	0.082
Age	1.020	0.993 – 1.047	0.143
Employment Status	0.641	0.467 – 0.880	0.006
Education	0.796	0.668 – 0.949	0.011

## **Chapter Five. Discussion of results**

The final chapter will discuss a brief summary of the results in this study, then it will discuss the results from the current study and how it relates to the current research on community integration post stroke. It will discuss whether the results agree or disagree with the literature that is available presently. Finally, implications of the study, strengths and weaknesses and what future research should focus on will be stated and a conclusion will be made.

### **Brief summary of results**

This study found that there were some factors at baseline that could predict levels of community integration four years post stroke. The first multiple logistic regression found age, education, employment status, previous stroke, hypertension, coronary artery disease, arrhythmia and epilepsy to be significant in predicting levels of community integration. After testing these factors against each other, three came out significant for predicting community integration levels four years post stroke. These factors were age, employment status and education levels at the time of stroke.

### **The results and other studies**

This study has used multiple analysis techniques, a descriptive analysis in the beginning and then a multiple regression analysis, to understand what factors were significant in predicting low community integration levels four years post stroke. Understanding the factors that can influence community integration post stroke could help to ensure all stroke survivors can participate in their lives to the best of their ability. The research currently shows that rehabilitation post stroke should begin in the acute phase, within the first 24 to 48 hours to ensure the individual has the best chance of a full recovery (Mayo Clinic, 2017). By beginning rehabilitation as soon as possible, an individual's chance of returning to normal functioning increases significantly. One study has shown that the earlier treatment begins, the less likely any complications and significant long-term effects, such as aphasia, will occur (World Health Organization, n.d.). Around 40 percent of individuals experience some form of disability that affects daily function after a stroke (Delgado, 2018). This requires individuals to rely on a caregiver or home

help to complete some of the necessary day to day responsibilities that they are not able to do themselves. Some of the following results from this study were in agreement with current literature but there have also been a number of findings did not agree with any of the current literature, which is likely as there is a lack of research in this area. Particularly studies that attempt to look at baseline factors and how they affect community integration levels. Analyses were done on all of the factors to test what ones significantly predict community integration levels post stroke.

In this study, when all of the factors were tested for significance in relation to low community integration levels there were a number that showed up as significant. The factors that were found to be significant were age, education levels, employment status, as well as individuals who had suffered previous stroke, coronary artery disease, hypertension, arrhythmia and epilepsy had lower levels of community integration. Many of these factors were found to agree with the current research available. However, there were some factors such as depression and anxiety levels or gender that interestingly were not found to be significant which was originally expected.

Current studies have shown that the most common risk factors are high blood pressure, smoking, diabetes, high cholesterol, obesity, excessive alcohol intake or drug use (Ministry of Health, 2016). Some other risk factors that are related to increased chance of suffering from a stroke are age; those aged 65+ are more likely to be affected by a stroke than anyone else in New Zealand (Ministry of Health, 2016), and gender; with males at a higher risk of stroke burden than females (Barker-Collo et al., 2015). The current study found that many of these common risk factors were found to be significant in predicting low levels of community integration. Two particular factors found to be significant, that has other research to back these results up were coronary artery disease and hypertension. One study found that health status before a stroke was related to the level of disability an individual would likely suffer from, particularly coronary artery disease and hypertension (Kelly-Hayes et al., 2003) which are known to be two of the most common risk factors for those who suffer from a stroke. This is similar to what the current study found.

One third of all strokes occur in individuals who have already had a previous stroke (Feigin et al., 2017) which could explain the significant low community integration results that the results found from this study. Given that the individual has already had a stroke, they may already suffer from low levels of community integration or they might

still be in the recovery phase and have not attempted to reintegrate themselves back into the community. Another possibility is that it has something to do with how recurrent strokes can lead into a progression to dementia, and cognitive impairments or restrictions could harm the integration into the community. Another study found similar results as the one above, showing that those who had a previous stroke were more likely to suffer from post stroke disability five years post stroke compared to those who have only suffered from one stroke (Yang et al., 2016). This disability, depending on how severe would have an impact on how well they are able to get back into their lives.

Other factors within this study that were shown to be significant for lower levels of community integration were those who completed school, had a trade/technical education, had a degree or had a diploma/certificate and finally, individuals who were employed. These results were not surprising as research has shown that education and employment can make a difference with rehabilitation efforts post stroke. Although there has been some research into how some factors can influence community integration post stroke, with studies showing how individuals who are able to improve these factors post stroke often have higher levels of community integration there is a lack of research for how factors at baseline affected community integration levels long term. The Townley et al. (2013) study has explored the effect that community integration can have on the rest of an individual's life and has shown that higher community integration levels can help individuals return to normal functioning in their lives. For example, this study has shown that higher community integration levels can help improve an individual's ability to get back into employment and education (Townley et al., 2013). This is interesting given that this study found higher levels of education and employment pre stroke relates to higher levels of community integration four years post stroke. This shows that there may be other benefits of community integration and that it can work both ways in helping individuals recover from a stroke, given that this study showed that individuals who were employed, or had completed school, had a trade/technical education, had a degree or a diploma or certificate had higher levels of community integration. Another study has shown that other benefits of community integration is that higher levels of community integration could also help individuals return to a level of functioning that was expected before stroke rather than only the other way around (Townley et al., 2013).

Integrating back into the community is important after a major life change, as boredom or difficulty completing day to day tasks can lead to depression, emotional disturbances and social isolation (Mayo et al., 2002). This could explain why people who were

working at the time of a stroke or who had higher levels of education tended to have higher levels of community integration compared to individuals who were unemployed as they may find that reintegrating back into their lives, given they will be different at the beginning of an individual's rehabilitation journey could cause boredom. This would be exacerbated given they may be unable to work as they are used to, and it could possibly be because the stroke may have caused a larger life change compared to someone who was already unemployed before a stroke.

Other predictors of good community integration are mobility levels, depressive symptoms, fear avoidance behaviour and confidence with balance (Liu et al., 2015). Interestingly, this study disagreed with the previous findings and did not find depression or anxiety levels to have any significance in relating to community integration levels. This was unexpected as there have been many studies that have found mood to be a good predictor of levels of community integration. It would be interesting to look at this in more depth considering depression and anxiety are extremely common in post stroke patients at 45.6% and 38.6% respectively (Barker-Collo, 2007), therefore they were found to relate to low levels of community integration it could explain why there are many individuals who suffer from low levels of community integration.

This study also found that age was significant in predicting community integration levels post stroke, showing that particularly those who are 65 years and above were more likely to have lower levels of community integration four years post stroke than any other age group. Other studies have also shown that age is another influencer of community integration. This is particularly relevant with the aging population, who has been found to generally have more problems reintegrating back into the community after something life changing, such as a stroke (Stumbo et al., 2015).

The first analysis within this study found there were many factors that were significant in predicting low levels of community integration. It was important to determine whether these factors were still significant when they were tested against each other. The results found that many factors must have had some overlap in significance as many of them became insignificant when analysed again. After the next analysis there were only three factors that were still significant after being tested against each other. The three factors that were found to be significant for determining lower levels of community integration four years post stroke were age, employment status and education. These factors will be discussed in detail in relation to other studies.

## Age

The results from the current study showed that age was the most significant factor for predicting low levels of community integration. As stated previously, the results found that the older someone is when they suffer from a stroke, the more likely their levels of community integration will be low compared to someone who is younger. This is particularly for individuals who are 65 years or older. In general, studies have shown that when a stroke occurs in older adults, rehabilitation tends to be more likely associated with lower outcomes in health compared to those who have suffered from a stroke at a younger age (Kelly-Hayes et al., 2003). The Dijkers (1997) study also found similar results to the current study's findings, with their study showing that younger individuals tended to score higher on the community integration questionnaire post stroke compared to those who are older.

Whilst not primarily related to community integration, another study found that older age was a significant predictor of disability at five years post stroke (Yang et al., 2016). This is relevant to the current study's results as disability post stroke generally tends to have a flow on effect for causing other issues within rehabilitation, such as lower levels of community integration (Barker-Collo et al., 2015, Stumbo et al., 2015, Townley et al., 2013). Also relevant, is that one of the domains for assessing disability is social assessment which is very commonly assessed by checking community integration levels (Kelly-Hayes et al., 2003), therefore a diagnosis of disability may be related to the level of community integration that one has. In an epidemiological study, age was a large contributor to disability two years post stroke, particularly for those who were 65 years or older at the time of the stroke (Kelly-Hayes et al., 2003).

A study that has looked at the overall impact of age and community integration within a healthy population found that 40% of those aged 60 and above had very little contact with other people each week, with some only seeing one or two people within their week (The Tompkins County Office for the Aging, 1999). This study showed that in general, older people tended to have very low levels of community integration, regardless of whether they were in a healthy population or had some form of disability. This study shows that even in individuals with no disability or health concerns, age is a factor in low levels of community integration. It increases the importance of rehabilitation programmes considering age when helping individuals get back into their

lives as the study showed the importance of ensuring individuals post stroke have help with reintegration.

Another indirect factor that may be affected as an individual gets older is mobility levels. A study found that mobility was a major factor in determining levels of community integration, with lower mobility levels showing lower levels of community integration (Stumbo et al., 2015). This study relates to age predicting low levels of community integration as mobility often decreases with age. This could show a relationship between why there have been studies that have shown age as a significant factor in determining low levels of community integration (Dijkers, 1997, Kelly-Hayes et al., 2003). Another study also found that mobility was a factor in low levels of community integration. This study found that if an individual is unable to drive or get around as they normally would, they are more likely to have lower levels of community integration (Griffen et al., 2015). Driving status commonly deteriorates with age which is why this is another factor that may make age more significant when discussing lower levels of community integration.

The results that the current study found in relation to age and low levels of community integration show that age is significant in determining whether an individual will have low levels of community integration at four years post stroke. This result is in line with what many other studies that are currently available have found, with these studies looking at differing stages of recovery after a stroke. Individuals who have suffered from a stroke at a later age are a lot more likely to have long term disabilities and less likely to fully integrate back into the community compared to those who are younger and have suffered from a stroke. All of the current studies that have been discussed have been found to back up the results from this study. Most of the studies show that age is an important predictor in determining both long term levels of community integration post-stroke as well as short term levels.

Whilst there has been some research into the relationship between age and community integration, there is a real lack of research that assesses how the age of an individual at baseline can affect community integration. Some more future research would be useful to understand the relationship that age has with community integration as well as studies going more in depth within this area would be useful to determine how important the relationship is, and whether these results can be replicated.

## **Employment status**

Employment status was the second most significant factor in determining low levels of community integration post stroke in this study. This study found that individuals who were employed before their stroke were more likely to have good levels of community integration compared to those who were retired or unemployed. Interestingly, these findings may relate to the study's other findings on the relationship between age and community integration, given that the age plays a role on employment status as well.

There has been very little research on the relationship between employment status when a stroke occurs and level of community integration four years post stroke. Whilst there are a few studies on the relationship between getting back into employment post stroke and how that affects community integration, any studies that has assessed the relationship of employment status and community integration before a stroke is limited. One study that assessed the relationship between community integration and employment status as a whole, found that community integration can help individuals return to their normal employment after a stroke (Townley et al., 2013). Another study focusing on employment levels four years after a subarachnoid haemorrhage found that a large proportion of individuals had unmet needs and in turn, were unemployed four years after their accident (Boerboom, Heijenbrok-Kal, van Kooten, Khajeh, & Ribbers, 2016). It showed that when an individual has unmet needs within their rehabilitation efforts, they are not able to continue progressing back into normal life. This study also found that there was a significant relationship between unmet needs and low community integration levels. Again, this is one of the few studies that has looked at employment status and community integration, however they have looked at the impact community integration has on employment status after the injury.

Not only can community integration improve an individual's psychological wellbeing, it can also help a person return to normal functioning. By improving community integration, individuals are more likely to get back into areas of their life they were successful in before such as employment and education (Townley et al., 2013). The lack of research in the area of employment status in relation to community integration shows how important future research looking at baseline factors pre-stroke and how they relate to community integration in long term stroke recovery and how this knowledge can help to ensure individuals have their needs met after an injury of this scale.

## **Education level**

The final factor that was found to be significant in determining levels of community integration at four years post stroke is the level of education an individual has at the time of stroke. An individual with higher education levels before a stroke is more likely to have good levels of community integration compared to those who are less educated. More specifically, in this study the results found that those who completed school, had a trade or technical education, had a degree or had a diploma or certificate had better levels of community integration compared to those who did not complete school or had other post school education.

There has been limited research done at this point on education levels prior to a stroke and the impact this has on rehabilitation and more specifically, community integration levels. Some studies have shown the impact that community integration can have on normal functioning post stroke, such as maintaining education levels or how getting back into education can help improve other areas (Townley et al., 2013) but this study has not looked at the impact education levels can have on community integration levels.

Of the studies that have looked at the relationship between pre stroke education levels and community integration post stroke, there have been a couple that have found that education levels before a stroke can impact community integration levels post stroke (Barker-Collo et al., 2015; Dijkers, 1997) which is similar to the results found by the current study. The results from this study showed that those who had a lower level of education, for example not completing school, were more likely to have lower levels of community integration four years post stroke compared to those who were more highly educated. The Dijkers (1997) study also found that highly educated individuals experience higher levels of community integration compared to those who are less educated. Barker-Collo et al. (2015) has explained why these results are likely to have happened. This study's reasoning is that stroke survivors who are highly educated tend to be more sensitive to health information therefore more likely to take on board rehabilitation programmes or areas they need to change in order to improve their chances of recovery. They are also more likely to have better health seeking behaviour, so getting in touch with professionals when they first feel that something is not right therefore more likely to have better improvements in rehabilitation. They are also more likely to have better access to primary intervention which may help with the severity of symptoms in the acute phase (Barker-Collo et al., 2015). Another study found that

higher education levels were positively associated with lower levels of disability at five years post stroke (Yang et al., 2016), which generally has a flow on effect similar to older age as discussed earlier. Therefore, the likelihood of having higher levels of community integration if there are lower levels of disability is increased.

Whilst there has been some previous research completed on education levels before stroke and how that impacts on community integration long term post stroke, very little research has gone into detail on the impacts on rehabilitation and community integration and how it affects an individual's recovery long term. Although this study did find that education levels were important for predicting community integration as the results showed low levels of education at baseline were a predictor for low levels of community integration, it has not explained how it is important and how it is possible to counteract these issues when looking at rehabilitation programmes and integration individuals back into the community. This would be an important next step for future research so that there can be more of an understanding into how it relates to rehabilitation.

Interestingly, within the current study gender was not found to be significant in determining whether an individual will be likely to have either high or low levels of community integration after stroke. This was unexpected given that many studies have found that gender has a significant role in regards to whether and individual is likely to have high or low levels of disability and /or community integration. Generally, studies have found that females tend to experience higher levels of community integration compared to males. The Dijkers (1997) study was one study that agreed with this statement and found that females were more likely to have higher levels of community integration post stroke compared to males. Another study found that females are less likely to be functionally disabled than their male counterparts, regardless of how similar the severity of neurological deficits were (Kelly-Hayes et al., 2003). The differences could be explained due to females being more sensitive to health information and they also tend to have better health seeking behaviour (Barker-Collo et al., 2015) meaning they will seek help earlier than their counterparts. This is very similar to the reasons why individuals who are more highly educated could have improved levels of community integration compared to those who are less educated. Research has shown that males are also slower to decline in some neurovascular risk factors that can increase the risk of stroke, such as smoking, drinking, drug abuse or other factors such as obesity (Barker-Collo et al., 2015). This would therefore mean they have a higher risk of stroke

overall, regardless of severity or disability levels post stroke. It could also affect whether an individual would have a higher chance of suffering from a secondary stroke, which could be more severe if they have not decreased their risk factors.

Another surprising result from this study was that an individual who has diabetes mellitus at the time of stroke were not more likely to have low levels of community integration compared to those who did not have either of these baseline factors. The study by Kelly-Hayes et al. (2003) found that diabetes mellitus affected disability post stroke which would be expected to impact community integration levels long term post stroke (Kelly-Hayes et al., 2003). As stated earlier, it was surprising to find that depression and anxiety levels at baseline were not found to be significant for predicting community integration levels in this study. Many studies have found that depression and anxiety are very common in individuals who have suffered from a stroke and that they are likely to have an impact on levels of disability or community integration when completing rehabilitation programmes. One study to disagree with the findings of this current study was the Liu et al. (2015) study, which found that depression and anxiety levels in post stroke individuals were an important factor in predicting community integration levels.

Finally, another unexpected result from this study was that whether individuals had suffered from a previous stroke was found to be a significant factor in predicting community integration levels post stroke initially but was not a significant factor for predicting community integration levels after it was analysed against other significant factors. This means that whilst it may be a significant factor on its own, when other factors are taken into account, such as age, having suffered a previous stroke becomes insignificant. Some studies have found that previous stroke is related to increased levels of disability and decreased levels of community integration. One study disagreed with the current study's findings and stated that those who have had a previous stroke will likely suffer from lower levels of community integration (Yang et al., 2016).

Overall, community integration is important after a life changing event such as a stroke. It can improve life satisfaction (Mayo et al., 2002), decrease psychological issues (Townley et al., 2013) and help with integration back into their lives, particularly if they are navigating through disabilities (Stumbo et al., 2015). Community integration is arguably one of the most important areas of rehabilitation to ensure someone who has suffered from stroke has the best chance of recovery when they are discharged (Mayo Clinic, 2017). High levels of community integration can also decrease the effects of

illness, resulting in an improved quality of life for those who have suffered (Mayo et al., 2002). By understanding the factors that influence community integration levels post stroke, better rehabilitation programmes can be utilized in order to ensure individuals are able to function in the community to the best of their abilities. By doing this, the aim would be to ultimately improve life satisfaction regardless of disability levels post stroke (Burleigh et al., 1998; Eriksson et al., 2013).

The literature review earlier in this thesis, alongside the discussion of results alongside other research has shown that there is a real lack of research around the factors that influence community integration levels post stroke and how that understanding can affect other factors of rehabilitation over the years. The hypothesis of this study was that the results will show there are a number of different factors that can affect low levels of community integration. In particular, it was expected that the factors that will show significance are suffering from a previous stroke, being of older age, gender, and suffering from either anxiety and /or depression. Whilst this study did find some similar results as other studies that have looked at community integration levels, as hypothesised, there were some significant results, or lack of significance, that was surprising, such as gender, previous stroke and depression and anxiety levels at baseline having no impact on the levels of community integration post stroke.

Ideally, this study will help to produce a small understanding of what factors may influence community integration at four years post stroke, and what areas would be useful to focus on in order to help improve the recovery of stroke survivors. In doing this, the aim would be to decrease current percentage of individuals who need daily help post stroke and aim to help individuals live a fulfilling life after suffering from a stroke. Although individuals recovering or have recovered from a stroke may struggle to fully function in their day to day lives, regardless of the amount of time from when the stroke occurred and increasing community integration could help providing more research into what could cause a lack of community integration may help to improve individuals lives.

## **Implications**

It is important to remember that whilst this study has shown that there is the possibility for some baseline factors to determine the levels of community integration an individual

may have four years post stroke, these results may vary between people and they should be used as more of a guide than a rule. The aim of this study was to examine the level of community integration in a cohort of long-term four-year stroke survivors with the objective of understanding what factors at baseline can affect low levels of community integration which it has done, however it was only examining one cohort of long term stroke survivors so it will not necessarily be able to be representative of the population as a whole. Regardless of this, the results from this study should be able to help future research to create rehabilitation programmes, which will in turn ideally lessen the impact that stroke has on an individual's life in the long term.

Furthermore, the aim of this study was to identify factors which may influence low levels of community integration, in order to develop interventions when may improve overall integration back into the community following a stroke. This will ideally help to decrease the 40 percent of individuals who suffer from disability following a stroke (Delgado, 2018) and also help to improve quality of life overall (Mayo et al., 2002). Outside of the discussed studies, there are a limited number of studies that are currently available which look at the long term impact of community integration on stroke. This makes it difficult to assess what the effects are outside of the acute phase. It is also difficult to compare research given the lack of studies that have looked at baseline predictors and how they relate to community integration levels. Ideally, this study has added to the current research that is available on this topic.

### **Strengths and Limitations**

One strength of this study is the size of the study and how many participants were involved. There were 255 individuals who participated in this study, with both their baseline and four year post stroke results being analysed. This large sample ensures that the results can generally be analysed more reliably and could be generalized to the general population of New Zealand relatively easily. Generalising the population should still be done with some caution as should always be the case with studies. Another strength is that this study has data which spans across four years, which gives a good understanding of how individuals have recovered and their level of rehabilitation. The baseline data from this study was also relatively early on post stroke which means that it can be a reliable source for what an individual was like at the time, and just before the stroke. The average age for the stroke population was 71.18 which sits in between the average ages for both Māori and Pacific (60 and 62 respectively) and New Zealand

Europeans (75) at which these ethnicities suffer from a stroke (Feigin et al., 2015). This is a strength within the study as it shows that the results will be relevant to the population.

One main limitation in this study is the proportion of ethnic groups within the study. In some ethnic groups, there was a relatively low number which does not necessarily provide a representative sample of New Zealand society. Another limitation is that with quantitative research, whilst the results were able to answer the aim of this study, they are not able to describe why the baseline factors can predict community integration levels four years post stroke. This would be a useful next step for future research.

### **Future Research**

Although stroke is the leading cause of disability and second leading cause of death in New Zealand (Ministry of Health, 2016), there is still a lack of research on factors that can influence recovery and rehabilitation. Future research on the factors that can influence community integration would be useful as it would hopefully give a better understanding on how to help individuals integrate themselves back into their daily lives, especially if they are struggling to adjust to a change in lifestyle or a change in their abilities (Jellema et al., 2016). Additionally, it would be useful to do more research on the three factors that this study found could predict low levels of community integration: age, employment status and education levels before the stroke. Given that stroke survivors tend to score at least half a standard deviation below a normal population for quality of life five years post stroke (De Wit et al., 2017), research into what rehabilitation would be most useful could be beneficial.

In this study, there was around 41% of individuals who reported having low community integration levels, which is a very high percentage of individuals. This results shows that this is an area which would be important to do more research on in order to get a better understanding of how to help individuals reintegrate into the community. Helping individuals to return to normal functioning is one of the most important goals within stroke rehabilitation services, (Stumbo et al., 2015). Research on understanding why these low community integration levels four years after a stroke are common and what can help to decrease these statistics would ensure that those who have suffered a stroke have a better quality of life (Townley et al., 2013).

Whilst this study did not look at social support levels, this is another area that has been

shown to help community integration levels. If an individual has adequate social support after a stroke, multiple studies have shown that this is one of the most important factors for a faster reintroduction into the community (Boden-Albala et al., 2005; Dalemans et al., 2010; Jellema et al., 2016). Evidence also suggests that there is a strong relationship between social support and health, with high levels of social support associated with healthier aging, improved functional status, lower stroke incidence and decreased mortality rates (Boden-Albala et al., 2005). The current study did not assess what levels of social support an individual had at baseline, however it did not find any significant difference within marital status in relation to predicting community integration levels, possibly suggesting the need for other types of social support. This would be a useful area to continue research on, given the emerging research showing that good social support levels can affect levels of community integration post stroke.

Another area that may provide some insight on community integration levels post stroke, particularly on those who are older, would be dementia levels at the time of a stroke. Studying the impact that dementia could have on community integration levels in long term stroke survivors would be useful as it is a very common disability, particularly in those who are older, therefore meaning there is likely to be a large overlap of individuals who have suffered from a stroke and individuals who have dementia.

Given the impact that stroke has on many individuals in New Zealand, more research in this area would be useful to inform stroke management strategies, particularly provided to individuals who are outpatients, may help to decrease that impact and improve stroke outcomes for many individuals. The research completed around this subject has the potential to increase the current knowledge around which factors at baseline which may impede or assist recovery following a stroke, particularly in regard to community integration. By studying this and gaining a greater understanding on what factors can predict community integration, the hope is that it can help rehabilitation programmes become more tailored to individuals when helping them get back to functioning as best they can within the community.

Overall, any research looking at community integration for long term stroke survivors would be beneficial in helping New Zealand decrease the disability levels caused by stroke, given it is the current leading cause of disability (Ministry of Health, 2016) and help to improve many areas of an individual's life when they are returning to their old life. It is also important for New Zealand to focus on decreasing their stroke prevalence

rates given that NZ has a higher stroke prevalence than any other high-income country in the world, with around 10% of individuals 75 years or older suffering from a stroke.

## **Conclusion**

It is estimated that around six million people die from a stroke and one third of all strokes that occur globally happen in individuals who have previously suffered from a stroke. Globally, the number of stroke survivors and individuals with incident stroke have increased by 50% to 100% in the last three decades. In New Zealand, there are over 57,000 people living with the effects of stroke in, with these figures projected to increase with the ageing population and better management of inpatient stroke care. However, it is also a highly preventable non-communicable disease which means that if risk factors are reduced, stroke rates could be reduced. NZ has a higher stroke prevalence than any other high-income country in the world, with around 10% of individuals 75 years or older suffering from a stroke. Although incidence rates in NZ has decreased over the last 30 years, the rate of decline for stroke incidence is faster than the decline in stroke mortality rates which suggests that there has been an increase in stroke related disability over the coming years. Over the past three decades stroke death has declined in both high and low socioeconomic countries. Although stroke incidence rates have decreased by 23 percent over the last 30 years and there has been an improvement in mortality rates for acute strokes it is still the leading cause of adult disability and second leading cause of death in New Zealand. New Zealand also has the highest stroke prevalence rate compared to any other high-income country in the world. These statistics alone show the importance of education around rehabilitation post stroke. Ideally, more awareness would be made for the risk factors that increase the likelihood of suffering from a stroke. This, in turn would decrease stroke incidence worldwide.

The overall aim of this study is to examine the level of community integration in a cohort of long-term four-year stroke survivors. The objective is to understand which baseline factors can affect low levels of community integration four years post stroke, using an existing cohort of long-term stroke survivors in New Zealand. By studying this and gaining a greater understanding on what factors may be able to predict community integration levels in long term stroke rehabilitation, the hope is that it can help rehabilitation programmes become more tailored to individuals when helping them get

back into their own community as an outpatient and to functioning as best they can within the community.

The results from this study found that age, employment status and education levels at the time of a stroke have an impact on community integration levels four years post stroke. Unlike other studies, gender, suffering from a previous stroke and suffering from depression and /or anxiety were not found to be statistically significant for predicting low levels of community integration. The results showed that age at time of stroke had an effect on levels of community integration four years post stroke which was unsurprising, and other research agreed that the older an individual is the more likely they were to have low levels of community integration. However, in regard to the other findings from this study, there was a lack of literature to back up the findings of employment status and education levels having a significant relationship with community integration levels. Most studies that have looked at these predictors have studied the impact that getting back into employment or education post stroke can have on community integration levels.

To further understand the results from this study, future research should focus on the predictors that were found to be significant: age, employment status and education levels, and how these predictors at the time of a stroke can affect community integration levels and what long-term impact they have overall. Future research focusing more generally on community integration would also be useful. It is clear from what current research is available that it would be beneficial to look at stroke and community integration in more detail as there is still a lack of understanding of how community integration can be helpful and how it is impacted through rehabilitation.

This unique study has investigated which factors can predict low levels of community integration in long term stroke survivors and has provided an understanding of what factors can influence community integration levels. It was a population-based study which means it should be possible for the results to be generalized to the New Zealand population, however more research into whether these results are generalizable would be useful. The results from this study were both surprising and unsurprising in regards to what was found to be significant and what was not significant. For example, age was expected to affect community integration levels, however depression and anxiety had no significance in affecting these levels which did not agree with many of the other current studies. The results from this study highlights that there are factors pre-stroke that can

influence how well rehabilitation work for an individual and whether they are likely to have high levels of community integration post-stroke. The study also highlights the importance of rehabilitation post stroke as well as the importance of further research in this area.

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## Appendix A: Ethical approval from Auckland University of Technology Ethics Committee



A U T E C  
S E C R E T A R I A T

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 (AUTC):

- 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 AUTC is notified of any adverse events or if the research does not commence. AUTC 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.

AUTC 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](mailto: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](mailto:ethics@aut.ac.nz)

## Appendix B: Ethical approval from the Health and Disability Ethics Committees



### Health and Disability Ethics Committees

Ministry of Health  
C/- MEDSAFE, Level 6, Deloitte House  
10 Brandon Street  
PO Box 5013  
Wellington  
6011

0800 4 ETHICS  
hdec@moh.govt.nz

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:	<b>Ethics ref:</b>	<b>NTX/10/09/090/AM07</b>
	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

(Chiu, Wu, Hung, & Tseng, 2017)