

Equipment use and equipment provision  
services for people after stroke:

A mixed methods study

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## **Abstract**

**Background:** As people live longer with more complex disability in their own homes, adaptive equipment is one way to enable their safety and participation. However, it is not well understood how people with stroke use adaptive equipment and how they interact with the services which provide equipment. The reasoning used by therapists who issue equipment, the outcomes achieved by equipment provision and the cost of equipment remain ambiguous. A theoretical framework which explains how services for equipment provision currently operate, with specific attention to the relationships between health policy, health provider behaviour, and equipment user experiences and outcomes was required.

**Aim and objectives:** The aim of this study was to explore whether the policies and procedures for provision of adaptive equipment to people with stroke are fit for purpose in terms of maximising safety, independence and choice. The objectives for this research were to: 1) describe who is more likely to receive publicly-funded equipment after stroke and what outcomes are achieved by them using equipment, 2) estimate the annual cost of adaptive equipment prescription for people with stroke, 3) explore the experiences of people with stroke about equipment provision services and, 4) explore the perspectives of therapists who prescribe equipment.

**Methods:** A sequential explanatory mixed methods approach was used to gather data over three phases, initially from people with stroke who use equipment (n = 258 surveyed using a postal survey, with n = 15 interviewed using a semi-structured schedule) and then therapists via six focus groups (n = 30).

**Results:** Findings indicated that no one demographic characteristic significantly increased the likelihood of equipment receipt. The most valued equipment after stroke was mobility related which made people feel safer, more confident and in control. The cost of new equipment for people who had a stroke in 2012 was estimated to be NZD \$1.2 million. Overall satisfaction with equipment provision services was high. People with stroke initially relied on their therapist to guide equipment choice as they transitioned out of hospital; thereafter they assumed greater control for decision making regarding equipment. As time passed, equipment became more meaningful in the context of their lives, often happening when equipment enabled community participation. A theoretical framework was developed

which illustrated seven inter-related influences on the reasoning of therapists during equipment provision: ‘client engagement (willingness and capacity)’, ‘others (family members and healthcare staff)’, ‘risks vs benefits’, ‘environment (physical and cultural)’, ‘professional philosophy’, ‘equipment provision system’ and the ‘wider health system’.

Discussion: Adaptive equipment and equipment services were found to provide a low cost, useful and valued service. Some challenges existed for equipment provision services, however, including a tension between policy objectives to limit costs associated with provision of equipment for use outside of the home and clinical, person-centred objectives to encourage community participation. Challenges like this resulted in moral distress for therapists and raised questions about the degree to which the health system may be increasing disease burden, and potentially long-term health costs, by failing to fully address equipment-related barriers to outdoor mobility and participation.

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Coslorga/ Footprints

Tá daoine a shiúlann inár saolta agus shiúlann amach astu go luath.

Tá daoine a fhanann ar feadh tamaill.

Agus fágann siad rianta a gcos ar ár gcroíthe.

Agus casann ár n-anamacha port nua go deo deo

Some people come into our lives and quickly go

Some people stay awhile

And leave footprints on our hearts

And we are never, ever the same

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**List of abbreviations**

ACC	Accident Compensation Corporation
ADL	Activities of daily living
AT	Assistive Technology
ARATA	Australian Rehabilitation and Assistive Technology Association
ARCOS	Auckland Regional Community Stroke
CI	Confidence interval
CRPD	Convention on the Rights of Persons with Disabilities
CVA	Cerebral vascular accident
DHB	District health board
GP	General practitioner
HAAT	Human Activity Assistive Technology
HRQoL	Health-related Quality of Life
ICF	International Classification of Functioning, Disability and Health
ICD-10	International Classification of Disease (Version 10)
MOH	Ministry of Health
MPT	Matching Person and Technology
NZD	New Zealand dollar
OT	Occupational therapist
PT	Physiotherapist
RCT	Randomised Controlled Trial

SD	Standard Deviation
SPSS	Statistical Package for the Social Sciences
UN	United Nations
WHO	World Health Organisation





## Chapter 1. Introduction

Over 6,000 people have a stroke in New Zealand each year (Brown, 2009) and up to 70% of those people have some ongoing impairment as a result (Bonita, Solomon, & Broad, 1997). The average age of stroke onset for New Zealand Europeans is 76, while it is 61 years for Māori and 65 years for Pacific people (K. Carter et al., 2006). The number of people living with stroke in New Zealand was estimated to reach 50,000 by 2015, with predicted annual costs of more than NZD \$700 million (Stroke Foundation of New Zealand, 2010). Improving the quality of life for this group is therefore an increasingly urgent issue (National Health Committee, 2013), alongside reducing the burden of stroke on the health care system (K. Carter, Anderson, Hackett, Barber, & Bonita, 2007; Feigin & Howard, 2008). Providing adaptive equipment for people after stroke can be a cost-effective means of reducing healthcare burden (Agree, Freedman, Cornman, Wolf, & Marcotte, 2005; Gramstad, Storli, & Hamran, 2014) and prescribing equipment is routine practice for many therapists (Duncan et al., 2005; Mann, Ottenbacher, Fraas, Tomita, & Granger, 1999; Somerville, Wilson, Shanfield, & Mack, 1990).

Equipment provision is woven into the role of rehabilitation therapists and the requirement to be formally accredited to prescribe equipment is often an explicit part of their job description. Prescribing equipment is usually embedded as part of functional or occupation based goals, such as being able to have a shower or move around one's house. The administration associated with equipment provision can be time consuming, requiring the completion of extensive paperwork and potentially lead to challenging interactions with clients, their family, other health professionals or health service funders. Therefore, the clinical reasoning therapists use when assessing and prescribing adaptive equipment needs to be well described and understood (Angelo, Buning, Schmeler, & Doster, 1997; A. Rose & Mackenzie, 2010). Additionally, the outcomes realised by people who use equipment after stroke requires clarification (Anttila, Samuelsson, Salminen, & Brandt, 2012), particularly in the face of increasing demand for justifying the use of healthcare resources (Canning, 2005; Hoenig, Giacobbi, & Levy, 2007).

Prior to this thesis, I had spent 12 years working as an occupational therapist and I have

been involved in issuing equipment for most of that time. The idea for this thesis originated from observing many diverse interactions with different stakeholders involved in equipment prescription. I observed that the ways in which equipment was issued by therapists, and used by people with stroke, varied widely. Furthermore, I witnessed how these equipment items could be imbued with meaning, from either the therapist or the person using them.

Adaptive equipment doubtlessly holds the potential to enable activity and to support meaningful participation for people who have disabilities (Scherer & Craddock, 2002; Scherer & Glueckauf, 2005; Verbrugge & Sevak, 2002). Nevertheless, equipment is also associated with a number of problems. Adaptive equipment can become a symbol of difference, leading to people who use equipment being stigmatised (Krantz, 2009). Non-use of publicly funded equipment is a resource concern for health services (Kraskowsky & Finlayson, 2001; Wessels, Dijcks, Soede, Gelderblom, & De Witte, 2003). Despite how frequently common items of equipment are prescribed, there is a lack of high quality research testing the benefits of this equipment (Hoenig et al., 2007; Lovarini, McCluskey, & Curtin, 2006; Rust & Smith, 2005). Unsafe use of equipment is a risk for those living with disability (Mortensen, 2005), as well as for the health service, where resultant falls and other accidents can lead to hospitalisation for clients and increased care costs (Stevens, Thomas, Teh, & Greenspan, 2009).

As a result of these issues, there has been a call for ‘an ethical discussion of subtle factors that might influence use and experience of assistive devices’ (Haggblom-Kronlof & Sonn, 2007, p. 335). This thesis examines the processes around equipment provision for people after stroke. It also explores the clinical reasoning process used by therapists when prescribing equipment for people with stroke, including the influence of systemic factors. The practical and ethical challenges associated with equipment prescription are explored from both the user and prescriber perspective and the implications of the current policy and structure for funding equipment are critically examined.

## **1.1 A call for evidence-based equipment prescription**

There has been a shift in perspective in the last 20 years from a position of acceptance of equipment as a pragmatic solution to obvious difficulties, to one where ambiguous variables inherent in the equipment provision process have been questioned (Gelderblom & de Witte, 2002). Edyburn and Smith (2004) stated:

Prior to 1996, we never asked ourselves for evidence concerning the impact of assistive technology ... We observed a problem, provided appropriate assistive technology devices and services, and then watched the transformation that occurred when an individual completed a task that was formerly difficult or impossible to do. To the extent that we sought to collect data, we simply asked the individual if they liked the new device and whether they found it helpful. In hindsight, we appear so naïve. (p. 8)

Despite the expense of equipment, information on the use of equipment for people after stroke has not been comprehensively reported (Garber, Bunzel, & Monga, 2002). There is increasing demand within the healthcare sector for clearly articulated outcomes for equipment provision, yet there remains a significant lack of high quality evidence in this field (Anttila et al., 2012; Lovarini et al., 2006). Equipment provision meets many of the criteria from the Medical Research Council for being a complex intervention including: the degree of flexibility required in clinical decisions around equipment provision, the influence of behavioural components on equipment prescription and its use, and the wide variation possible in outcomes (Craig et al., 2008).

The Australian Rehabilitation and Assistive Technology Association (ARATA) have called for therapists to take a greater political interest in the funding and dissemination of information about equipment (Friesen et al., 2014). This association is primarily comprised of therapists but also includes equipment manufacturers, service delivery administrators and healthcare consumers. With New Zealand's much smaller population, no comparable research or lobby group exists. A report from the United Nations' Secretary-General entitled 'The way forward: a disability-inclusive development agenda towards 2015 and beyond' noted that the 'scarcity of disability data and statistics inhibits building an evidence-based case on ways in which eliminating barriers and promoting accessibility would be conducive to social progress' (United Nations, 2013, p. 3). Along with four similar international groups with an interest in the access to and development of equipment services, ARATA endorsed a United Nation's recommendation in 2013, advocating for an increase in understanding about 'political [and] socio-economic factors that affect the diffusion and acceptance of assistive technology' (Association for the Advancement of Assistive Technology in Europe (AAATE), Rehabilitation Engineering and Assistive Technology Society of North America (RESNA), Asociacion Iberoamericana de Tecnologías de Apoyo a la Discapacidad (AITADIS),

Australian Rehabilitation & Assistive Technology Association (ARATA), & Rehabilitation Engineering Society of Japan (RESJA), 2013, p. 1). The aims of this thesis are aligned with these internationally acknowledged imperatives.

## **1.2 Overview of working definitions**

### **Adaptive equipment**

There are multiple terms that refer to the equipment that people with disabilities use to help them perform everyday activities. These include: adaptive equipment, assistive technology, assistive devices and other combinations or variations on these words. Indeed, researchers have reported that there is a lack of clarity around terminology relating to such products or technology (Bernd, Van Der Pijl, & De Witte, 2009). For the purpose of this thesis, the term ‘adaptive equipment’ has been used because, over the course of this study, adaptive equipment was the term that appeared to be most easily understood by study participants. Where the term ‘equipment’ is used in this thesis, it can be presumed that this equipment fits the definition of ‘adaptive equipment’ unless otherwise specified.

‘Adaptive equipment’ is considered to be, ‘equipment that enables an individual, who requires assistance, to perform the daily activities essential to maintain health and autonomy and to live as full a life as possible’ (WHO, 2004, p. 10). This definition, however, can include an almost limitless list of equipment types. The equipment that was central to my research area were items that are typically used during recovery from stroke, those which were familiar to people with stroke, and, importantly, those which were funded by the public health system in New Zealand. Therefore, for the purpose of this research, I focussed on adaptive equipment that included any device which enables a person to move around their home or community, make a meal, use the toilet or enable self-care such as bathing. Furthermore, I specifically excluded from the scope of this thesis the following: robotics, housing modifications, communication devices (such as iPad and speech enhancing devices), virtual reality technology, functional electrical stimulation, orthotics and prostheses, hearing aids, personal electronic devices, personal alarms, and computers.

Another term used at times in this thesis is ‘assistive technology’, often abbreviated to AT in literature on this topic. Assistive technology is a broader term than adaptive equipment, including a wider range of products and technologies. This is the most common generic term

used in published literature in this area and so this was sometimes appropriate in this thesis to describe research findings from others.

There are two primary taxonomies used to describe assistive technology: the International Standards Organisation standards' assistive products for persons with disability: classification and terminology (International Standards Organisation, 2011) and the International Classification of Function, Disability, and Health (ICF) (WHO, 2001). The former describes products, but lacks wider application to personal or societal contexts (Hersh & Johnson, 2008) and the latter is an internationally accepted classification system where equipment is essentially viewed as an environmental facilitator of function (Steel, Gelderblom, & de Witte, 2010). While researchers have challenged whether the ICF is the most appropriate classification system for modelling outcomes from equipment use (Karlsson, 2010), it is increasingly linked to the development of assistive technology specific models such as the Matching Person and Technology model (Scherer & Craddock, 2002) and the Human Activity Assistive Technology model (Cook & Polgar, 2015b). The ICF is therefore a useful reference point when discussing equipment use and related outcomes throughout this thesis.

Of note, while such operational definitions and classifications of adaptive equipment are helpful for describing the scope of a research project such as this thesis, these somewhat reductionist descriptors do not encapsulate everything that equipment might mean to people. Hocking (1999) has challenged many researchers' ideas by taking a broader societal view equipment and its application, asserting that adaptive equipment are objects that people possess to 'use in day to day occupations and reflect a sense of self and social identity' (Hocking, 2000, p. 148). These ideas are further reflected in research on embodiment of disability, where people coming to terms with disability often evaluate the usefulness of adaptive equipment in tandem with the value of activities which equipment could facilitate (Krantz, 2012; Robison et al., 2009). Whether or not a piece of adaptive equipment will be used, and if used, how it will be used, appears to be an internal cognitive and emotional process that takes into account the relative effort of using the equipment and being seen by others while using the equipment (I. Pettersson, Ahlstrom, & Tornquist, 2007).

Considering wider arenas than healthcare for information on this topic, (Hendren, 2014),

a researcher, designer and engineering teacher, has argued that all technology is assistive:

Honestly - what technology are you using that's not assistive? Your smartphone? Your eyeglasses? Headphones? And those three examples alone are assisting you in multiple registers: They are enabling or augmenting a sensory experience, or providing navigational information ... All people, over the course of their lives, traffic between times of relative independence and dependence. So the questions cultures ask, the technologies they invent, and how those technologies broadcast a message about their users - weakness and strength, agency and passivity - are important ones. (para. 6)

Such ideas about assistive technology speak to the complexity of the relationship between physical objects, how and where they are used and how they influence interactions between people who use them and their physical and social world. Disability theorists such as Lupton and Seymour (2000) have extended understanding of this complexity, highlighting that people with disabilities often have conflicting feelings about even their most valued equipment, where they enjoy the control such items offer but resent that these objects can mark them as different. In fact, more radically, Hammell (2006) describes adaptive equipment, along with other disability related technologies, as dehumanising for people with disabilities and evidence of an 'ableist' agenda. These tensions and ambivalence about equipment use are discussed further in Chapter 2.

## **Stroke**

Stroke, also known as a cerebral vascular accident, is defined by the WHO (1988) as the 'rapidly developing signs of focal (or global) disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than vascular origin' (p. 108). Stroke, is the leading worldwide cause of disability in people over 60 years and risk of stroke increases exponentially with age (Rothwell et al., 2004; Strong, Mathers, & Bonita, 2007). Feigin, Lawes, Bennett, and Anderson (2003) reported that over half of all strokes occur in people over 75 years. Stroke incidence decreased in high income countries by 42% between 1970 and 2008, but increased in low to middle income countries by over 100% during this time (Feigin, Lawes, Bennett, Barker-Collo, & Parag, 2009). These demographic details are important to consider when contextualising research related to the stroke population.

Fifty percent of stroke survivors are discharged from rehabilitation with moderate to severe impairments (Anderson et al., 2000). While it has been reported that six months after

stroke, 30% of people require assistance from a person or equipment to mobilise (Pappas & Salem, 2009), there is little other literature clearly describing the nature of the equipment provided to people with stroke. In a systematic review on the impact of mobility devices on users of equipment, Auger et al. (2008) recommended that researchers need to be more explicit in the categorisation of their study groups, arguing that populations in these studies were frequently defined only as ‘older adults’, with no further information on their health conditions or demographic details. This concern was, in part, why stroke was selected as the population of interest for this thesis. The other reason was that stroke is associated with natural recovery whereby someone’s abilities often increase over time, a process which can be further enhanced by rehabilitation intervention (Legg, Drummond, & Langhorne, 2006; Pollock et al., 2014). I was particularly interested in exploring issues regarding the role that adaptive equipment plays in assisting or hindering this recovery.

### **Therapists**

Any health professional can be involved with supporting someone to use a piece of adaptive equipment after stroke. Occupational therapists and physiotherapists are the group who pre-dominantly assess, prescribe and organise the delivery and funding of adaptive equipment and the vast majority of existing literature on this topic relates to these two professional groups. For this reason, the term therapist is used throughout this thesis to describe these professional groups.

### **Equipment provision services**

The ways in which rehabilitation is provided, including consultation for equipment, training and review, can have a profound influence on how people make sense of their new life and their body after stroke (Kielhofner, 2005). Equipment provision cannot, however, be evaluated without considering the financial and political context in which services are situated (Ripat & Booth, 2005). For example, through the 1990s in America, equipment provision increased for people with self-care difficulties, while the provision of personal carers reduced (Freedman, Agree, Martin, & Cornman, 2006). As noted by Hart (2001), it is impossible to conduct research about living with stroke without also critically evaluating the experience of interacting with the healthcare service.

There is a need to increase outcomes-led research about the services which prescribe,

provide, maintain and evaluate adaptive equipment (DeRuyter, 1997; Lenker, Harris, Taugher, & Smith, 2013) as well as an increasing expectation for therapists to be financially responsible when making recommendations (Andrich & Caracciolo, 2007; Chiatti & Iwarsson, 2014). While objective measures of user satisfaction with equipment do exist, as discussed further in Chapter 2, these measures have generally been used for research purposes rather than in routine clinical practice. There is a lack of theory about what influences user satisfaction with equipment (Wessels, De Witte, & Van Den Heuvel, 2004) and equipment provision services (Ripat & Booth, 2005). The breadth and complexity of outcomes related to equipment use have made evaluation of costs and benefits challenging (Gelderblom & de Witte, 2002). Reasons for non-use or abandonment of equipment are still poorly understood and could relate to better technology becoming available, equipment no longer meeting a need, or a need no longer existing (Martin, Martin, Stumbo, & Morrill, 2011).

There is a lack of understanding about how the equipment provision system influences user experiences and clinical decisions (Chaves et al., 2004) and few studies have explored the views of both those using equipment and those who prescribe these items (Gitlin, Levine, & Geiger, 1993; Reisinger & Ripat, 2014; Ripat & Booth, 2005). Recently, Lenker et al. (2013) reported that further user-led research was required to clearly illustrate how adaptive equipment influenced social participation, what the costs of equipment issued by a service are and what the main drivers of quality in equipment provision services. This thesis addresses all three of these elements.

### **Policy on adaptive equipment and New Zealand**

Decisions about healthcare resource allocation are subject to public scrutiny, heightening the need for explicit justification (Dobrow, Goel, & Upshur, 2004) and public policy decisions on equipment provision has ethical implications (Canning, 2005; Peterson & Murray, 2006). New Zealand has a health service where there is public funding that theoretically enables equal access for all people to rehabilitation services (McNaughton et al., 2011). Despite slowing in the last six years, health expenditure in New Zealand has continued to grow as it has in other developed countries (Ministry of Health, 2013a). Priorities for accessing health services include providing value for money, being person-centred, ensuring equity, timeliness and effectiveness as well as sustainability (Ministry of Health, 2013a). This



thesis provides empirical data on whether these goals are being adequately met in the context of adaptive equipment provision for people with stroke.

The Equipment and Modification Services are funded by the Ministry of Health and are responsible for managing and prioritising the funding available for this sector. This service is guided, in terms of policy, by the New Zealand Disability Strategy (Ministry of Health, 2001) which is administered by the Office for Disability Issues, a department which is part of the Ministry of Social Development. As such, there are many policy stakeholders involved in the formulation of policy for this sector in New Zealand. Internationally, the United Nations Convention of the Rights of Persons with Disabilities (UNCRPD) is seen as the strongest international policy instrument yet to further the rights of people with disabilities (Umeasiegbu, Bishop, & Mpofu, 2013) and this convention advocates for all people with disabilities to have access to available and affordable equipment as a human right (Borg, Larsson, & Ostergren, 2011). For example, Article 26 states that ‘Parties shall promote the availability and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities, giving priority to technologies at an affordable cost’ (p. 6). The UNCRPD does not recommend that additional rights be afforded to people with disabilities, rather that they receive equal rights to their non-disabled peers (Siegert & Ward, 2010). The recommendations of the UNCRPD should have an influence on how equipment services in New Zealand are provided as the New Zealand government ratified this convention in 2008.

A New Zealand Human Rights Commission report in 2012 cited lack of data on the experience of people with disabilities as one of the key barriers to implementing the principles of the UNCRPD, with another being access to adequate support services (Disabled Persons Assembly New Zealand, 2012). The New Zealand Disability Strategy was reviewed by the UNCRPD in 2014 and while there were some commendations given for progress on disability issues, the committee expressed concern about higher rates of disability among people identifying as Māori and that there appeared to be a lack of choice and range of support to ensure people with disabilities were included in their communities (United Nations, 2014). Following up on criticisms of progress towards UNCRPD adherence, the Disability Action Plan (2014 – 2018) (Office of Disability Issues, 2014) was commissioned. One objective of this action plan was to ensure that people with disabilities were actively engaged in the

disability support system and that maximum progress towards the UNCRPD was made within available resources. Both of these areas are of interest in this thesis.

While disability in New Zealand is common - one in five New Zealanders lives with an impairment (Statistics New Zealand, 2013b) - particular challenges exist for certain ethnic groups with regards to healthcare provision and therefore possibly equipment provision. The Treaty of Waitangi/Te Tiriti o Waitangi is an important constitutional document signed between Māori, the indigenous people of New Zealand, and the British in 1840. This treaty assures that Māori have equal standards and outcomes of healthcare to non-Māori (Harwood, 2010). Of concern, Māori are 1.3 times as likely to have a stroke compared to non-Māori (Ministry of Health, 2012b), stroke affects Māori on average 14 years earlier than non-Māori (Dyall, Feigin, Brown, & Roberts, 2008), and Māori and Pacific people report being more dependent, disabled, and dissatisfied with their quality of life after stroke than New Zealand Europeans (McNaughton, Weatherall, McPherson, Taylor, & Harwood, 2002). Designing disability support services, including equipment provision, to optimise access for Māori is important so issues related to equipment provision and use specific to Māori were considered in this thesis.

### **1.3 Research aims**

The aim of this thesis was to explore whether the policies and procedures for provision of adaptive equipment to people with stroke are fit for purpose in terms of maximising safety, independence and choice. The following objectives were designed to address this aim:

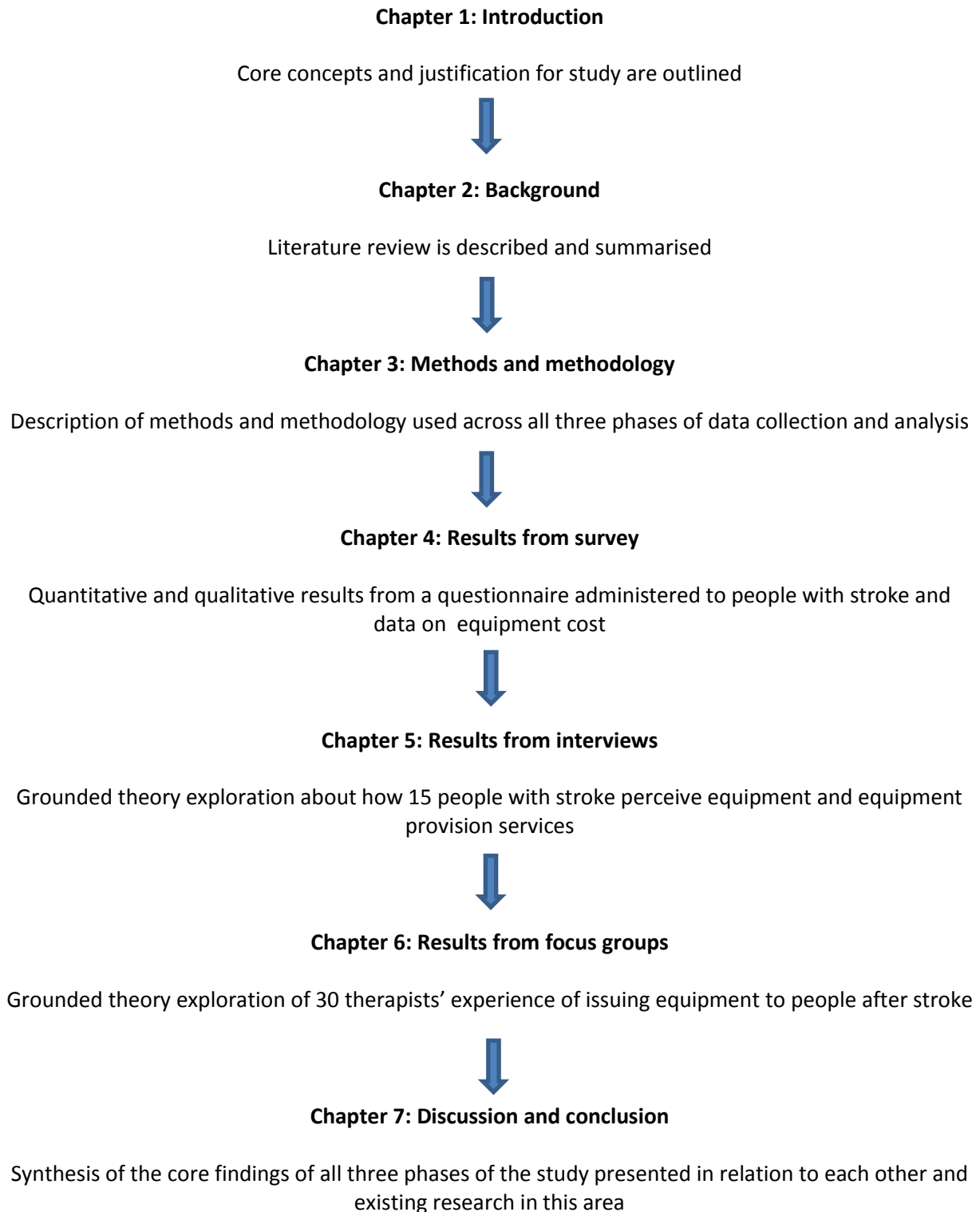
1. Describing who is more likely to receive publicly-funded equipment after stroke and what outcomes are achieved by them using equipment using a postal survey to people with stroke
2. Estimating the annual cost of adaptive equipment prescribed for people with stroke using a postal survey to people with stroke cross-referenced with Ministry of Health data.
3. Exploring the experiences of people with stroke regarding their use of equipment and provision services during interviews using a semi-structured schedule.
4. Exploring the perspectives of therapists who prescribe equipment regarding their role and the influences on their decisions regarding equipment funding via focus groups.

## **1.4 Research design**

Any robust evaluation of adaptive equipment should include the views of people with stroke as well as those of representatives of disability support services (McMillen & Soderberg, 2002; Stroke Foundation of New Zealand, 2010), as happened in this research. An explanatory sequential mixed methods model (Creswell & Plano Clark, 2011) was used. This research started with developing an understanding of the experience of people with stroke about receiving and using adaptive equipment, before moving on to examine the beliefs and experiences of the therapists who prescribe this equipment.

## **1.5 Thesis structure**

This thesis is divided into seven chapters. This chapter has set the scene for the thesis, providing information about the origin of the research topic and outlining the core concepts. Chapter 2 describes previous research conducted in the area of stroke and adaptive equipment and develops an understanding of the principles of decision making regarding prescription of equipment for people with stroke. Chapter 3 describes the methodology used to meet the research objectives of this study, including recruitment of participants, data collection and analysis. Chapter 4 reports on the findings of the first phase of this study, from a questionnaire which collected quantitative and qualitative data from users about equipment and related services. Chapter 5 illustrates themes developed from qualitative data collected from a sample of those who responded to the questionnaire. Chapter 6 reports the qualitative findings from focus groups conducted with therapists about their perception of equipment provision as part of their clinical work. Chapter 7 draws together salient findings and discusses these results in relation to the current literature and recommendations for future research before presenting a conclusion for the study. These chapters are illustrated further in Figure 1.



*Figure 1 Structure of thesis by chapter*

## **Chapter 2. Background**

### **2.1 Chapter outline**

This chapter introduces core concepts about equipment provision and the influence on these from policy, legislation, and research. It introduces key outcome measures related to equipment use and stroke rehabilitation, and discusses how these are currently used to evaluate effectiveness. Information about stroke, particularly cultural issues and costs, are introduced, and an overview of research on the perspectives of users and therapists regarding adaptive equipment is provided. This chapter also summarises the current structure of healthcare systems for provision of equipment to people with stroke in New Zealand and the challenges related to equipment provision and stroke, thereby identifying the gap in current research which this thesis addresses.

### **2.2 Policy and legislative trends in equipment provision**

In 1993, the National Advisory Committee on Core Health and Disability Services in New Zealand (now known as the National Health Committee) established prioritisation criteria to guide funding for health services such as non-urgent surgical procedures - an approach which later spread to other areas like disability services:

The primary objectives of the system are to ensure that those in greatest need are given priority, to iron out regional inequities in access, and to make clinical decisions more systematic and transparent. However, the cut-off thresholds are funding driven. (Howden-Chapman & Ashton, 2000, p. 30)

This shift of focus in health planning resulted in an emphasis on price and number of criteria met, with much less reporting on the quality of such services, particularly from the service user's perspective. Decisions about eligibility are made by people throughout the layers of the health system. There is a tension between the current model of funding prioritisation, which aims to achieve equal access for equal need versus one where a support service aims for equality of outcomes - a worthy but far more complex goal (Howden-Chapman & Ashton, 2000).

In New Zealand, increasing life and health expectancy is coupled with an acknowledgment that people will live longer with more disability - this is a serious consideration in long term healthcare expenditure (Ministry of Health, 2015b). In 2006, up to

12% of adults had medium to high disability related support needs, with medium support needs defined as requiring some sort of assistive device, aid or equipment (Ministry of Health, 2013a).

The UNCRPD is the most recent of a list of legal documents that captures a human rights approach to disability (Bickenbach, 2009). Other prominent documents including the United Nations Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (1993) and the Americans with Disabilities Act (1990). These legal frameworks enshrine equal rights to participate in society to people with disabilities and place a responsibility on a society's governing bodies to ensure that this happens. The New Zealand government's current Disability Action Plan (Office of Disability Issues, 2014) is strongly influenced by the UNCRPD, which includes advocating for better cross agency collaboration and acknowledging people with disabilities as experts in their own lives. The four areas targeted by the Disability Action Plan are:

1. Increasing employment and economic opportunities
2. Ensuring personal safety
3. Transforming the disability support system
4. Promoting access in the community.

These objectives align well with the purpose of this thesis, in particular those relating to personal safety and promoting access in the community. Other policy documents with similar recommendations include Whāia Te Ao Mārama: The Māori Disability Action Plan for Disability Support Services, 2012-2017 (Ministry of Health, 2012c) and Faiva Ora: National Pasifika Disability Plan, (Ministry of Health, 2014b). Both of these policy initiatives included a mandate to develop culturally responsive disability support services (such as equipment provision services) and reduce inequities in access for diverse groups.

A recent Australian report on two studies, combined in the Equipping Inclusion project, outlined the use of equipment and unmet need for equipment reported by people with disabilities (Layton, Wilson, Colgan, Moodie, & Carter, 2010). Respondents used over 100 different types of equipment and reported on significant failures of the equipment provision

system in meeting articles of the UNCRPD as well as other life areas. The findings indicated that there were systemic design flaws in relation to government policy governing equipment provision, which in turn reduced the ability of people with disabilities to take part in many activities (Layton & Wilson, 2011) .

The New Zealand Disability Strategy states that ‘government agencies, publicly funded services and publicly accountable bodies [need to] co-operate to ensure that the disabled person is at the centre of the service delivery’ (Ministry of Health, 2001, p. 25). While this is an aspirational commitment at a policy level, it is not immediately clear how this is operationalised in practice. A recent report from the Disabled Person’s Assembly in New Zealand emphasised that access to disability services was mired in difficulties to do with choice, funding, consistency of decision making and respect for service users (Disabled Persons Assembly New Zealand, 2012). This report also noted that there was a lack of information about people with disabilities using health services and that many disability policies are perceived as having a one size fits all approach which does not necessarily work when people present with a wide range of diagnoses and impairments.

Most policy on publicly funded equipment has two goals: 1) to improve delivery of equipment provision services and 2) to realize the full potential for equipment to enable people with disabilities (Mountain, 2004). In their narrative review of evidence for effective use of equipment, Mountain (2004) reported that evaluating evidence in this area is hindered by a lack of an agreed definition of assistive technology. A drawback for most studies evaluating effectiveness of equipment is that they measure rates of equipment use rather than the impact of the equipment on activities of daily living and quality of life. This thesis extends beyond considering rates of equipment use to address these less acknowledged impacts of equipment.

### **Relevance of the ICF to equipment prescription**

The ICF offers a comprehensive framework to view disability with the same spirit and intention as the UNCRPD (Bickenbach, 2009) and the WHO has prioritised the production, delivery and distribution of equipment in its Disability and Action Plan, 2014–2021 (WHO, 2014). The concepts and definitions within the ICF have become embedded within international disability policies and outcome measures related to equipment provision. Prior

to the development of the ICF, participation was rarely the focus of interest when it came to examining outcomes for people with disabilities, yet is a key outcome for equipment provision (Brandt et al., 2008). Equipment is categorised under the 'Products and Technology' chapter of the 'Environmental Factors' domain in the ICF (Scherer & Glueckauf, 2005; WHO, 2001). In combination with the domains for 'body structures and function' and 'activities and participation', the interrelationship of these four domains is intended to 'capture all aspects of human health' (Harris, 2007, p. 138). There has been increasing interest in how categories of the ICF relate to equipment use, provision and potential (Arthanat & Lenker, 2008; G. C. Jones & Sinclair, 2008; Karlsson, 2010), as well as how the ICF is helpful for users of equipment to articulate their needs (Schranner, De Jonge, Layton, Bringolf, & Molenda, 2008).

A common criticism of outcome measures in the field of adaptive equipment has been that they are overwhelmingly focussed at the level of impairments of body structure and body function, with only some attention to a few specific activities like wheelchair skills (Mortenson, Miller, & Miller-Pogar, 2007). Also, the participation and activity domains developed by the ICF have been criticised as not being conceptually distinct enough from each other for research purposes (Salminen, Brandt, Samuelsson, Toytari, & Malmivaara, 2009) so, though somewhat useful for furthering the field of equipment-related research, these concepts are still maturing (Gray & Hendershot, 2000; Harris, 2007; Scherer & Glueckauf, 2005; Wielandt, McKenna, Tooth, & Strong, 2006). Also, while there has long been a call for development of outcome measures specific to the field of assistive technology, and the ICF assists in describing what areas of activity and participation assistive technology might be useful for, Lenker and Jutai (2002) have argued that the ICF does not enable prediction of who would find what assistive technology most useful. That said, the ICF was designed to enhance description of client related issues across disciplines; it was not designed to be a selection tool and should therefore not be the only framework used in this process (Friederich, Bernd, & De Witte, 2010).

Scherer et al. (2005), leading researchers in the field of assistive technology, have been exploring how concepts from the ICF can be applied to assistive technology, such as personal factors (Scherer, Sax, Vanbiervliet, Cushman, & Scherer, 2005) and developing ICF core sets for people with dementia (Scherer et al., 2010). They too have concerns that the ICF does not contain reference to all the factors necessary for assistive technology selection (Scherer, Jutai,



Fuhrer, Demers, & Deruyter, 2007). As argued by Sivan et al. (2014), the ICF core sets for stroke can be useful when developing technology for people with stroke, however ‘person factors like gender, age, interest, compliance, motivation, choice, and convenience that might determine device usability are yet to be categorised within the ICF comprehensive core set’ (p. 164).

There are challenges with coding assistive technology within the ICF, with concerns that coding for assistive technology lacks precision. For instance, the ICF code ‘e1151’ encompasses all assistive products and technology for personal use in daily living (Arthanat & Lenker, 2008), which is a broad and varied group of items. Hersh and Johnson (2008) reported that while the ICF is product and application orientated, it does not enable an understanding of the societal application of assistive technology. Furthermore, while the ICF as a classification model is useful for developing taxonomies for assistive technology, it has been criticised as being closely aligned with the medical model and lacking in capacity to include users’ perspectives (Hammell, 2004; Sivan et al., 2014).

### **2.3 Stroke**

As the population of interest in this thesis was people with stroke, pertinent information about stroke and rehabilitation are introduced here, along with issues specific to stroke and Māori and the financial implications of stroke. Stroke is the third leading cause of death in New Zealand (Ministry of Health, 2013a) with similar rates of stroke between men and women, 1.9% and 1.7% respectively. Approximately 8% of people who are 75 years or older report having a stroke and the rates of stroke are higher for people who identify as Māori (2.1%) and those living in areas of deprivation (2.7%) (Ministry of Health, 2013a).

There is a growing number of people who have a stroke and survive to live with impairments (Mayo, Wood-Dauphinee, Durcan, & Carlton, 2002; Tobias, Cheung, Carter, Anderson, & Feigin, 2007) and between 50% and 70% of people with stroke have ongoing functional deficits (Bonita et al., 1997; Tobias et al., 2007; Wiles, Ashburn, Payne, & Murphy, 2004). As a result, the concept of chronic stroke has gained traction in health service planning (Stroke Foundation of New Zealand, 2010). While many people experience residual disability after stroke, most do regain their ability to walk (Jorgensen, Nakayama, Raaschou, & Olsen, 1995), however, one cohort study looking at 141 people one year after stroke reported that

mobility had declined for 40% (Paolucci et al., 2001).

New Zealand has benefitted from three comprehensive longitudinal population-based stroke incidence studies, known as the Auckland Regional Community Stroke Studies (ARCOS) which occurred in 1981-1982, 1991-1992 and 2002-2003 (Bonita et al., 1997; K. Carter et al., 2006; Feigin, McNaughton, & Dyllal, 2007). Results indicated that people identifying as Māori and as Pacific people are disproportionately affected by stroke, where the stroke incidence for Māori continued to rise in the last 20 years and the incidence has doubled for Pacific people (K. Carter et al., 2006). In comparison, stroke incidence has fallen for New Zealand Europeans during this time (K. Carter et al., 2006). In addition, Māori and Pacific peoples have strokes at a younger age than New Zealand Europeans - the mean age of stroke is 61 for Māori and 65 for Pacific peoples, but 76 for New Zealand Europeans (K. Carter et al., 2006). After adjusting for age and sex, Māori are 1.3 times more likely to have had a stroke than non-Māori (Ministry of Health, 2012b), with Māori women being 2.3 times more at risk than women in other ethnic groups. Ethnic disparity in stroke outcome has been acknowledged in other countries such as the UK (Wolfe, Rudd, & McKeivitt C, 2014) and the USA (Stansbury, Jia, Williams, Vogel, & Duncan, 2005).

In a publication using epidemiological modelling based on the ARCOS data, Tobias et al. (2007) stated that ‘Stroke mortality is falling faster than stroke incidence. This, together with population growth and ageing, will lead to a rising burden of stroke-related disability over the next decade’ (p. 520). Length of stay in hospital has decreased dramatically in the last 15 years in the UK (Wolfe et al., 2014), placing a greater emphasis on rapid assessment and discharge from hospital based rehabilitation services, which in turn increases pressure on equipment assessment and provision services in the community sector (Whitehead, Fellows, Sprigg, Walker, & Drummond, 2014).

With the shift to earlier discharge after stroke, there is more focus on training carers (Kalra et al., 2004; McNaughton, Thompson, Stinear, Harwood, & McPherson, 2014; Patel, Knapp, Evans, Perez, & Kalra, 2004), which often relates to them safely using prescribed equipment (Roelands, Van Oost, Stevens, Depoorter, & Buysse, 2004). There is also an increasing demand on therapists to reduce discharge planning home visits, which can be lengthy, and to reduce the time available for new clients by introducing strategies such as

family members taking photographs and measurements to plan for equipment needs (S. Sim, Barr, & George, 2014; Whitehead et al., 2014). Both of these trends place more expectation on family members of people with stroke to set up and use equipment and pressure on equipment provision services for rapid, yet effective, intervention.

Research about stroke rehabilitation and equipment provision share similar challenges in that ‘the greatest difficulty in rehabilitation research is to define accurately the intervention being studied’ (Wade, Collen, Robb, & Warlow, 1992, p.613). Both are contextual and embedded in actions directed towards different goals, often simultaneously, so that defining and deciding on outcomes of relevance is an enormous challenge. Loss of social interaction and participation, areas which can be enabled by equipment provision, remain substantial issues for stroke rehabilitation services (Hartman-Maeir, Soroker, Ring, Avni, & Katz, 2007; Logan et al., 2004; Lord, McPherson, McNaughton, Rochester, & Weatherall, 2004; Reed, Wood, Harrington, & Paterson, 2012; Woodman, Riazi, Pereira, & Jones, 2014).

There has been a presumption that care needs will decrease as rehabilitation and recovery after stroke progresses. However, it has been noted that dependency, particularly with personal care tasks and activities involving social and cognitive skills, can actually increase rather than decrease (Grimby, Andren, Daving, & Wright, 1998). This counter-intuitive finding was possibly due to people having less intense encouragement to extend their functional fitness after they have been discharged from rehabilitation services. As stated by Pallesen, Pedersen, and Holst (2013), ‘the body was perceived as being far more vulnerable and aged functionally [after stroke], and trust in the body’s capabilities had diminished’ (p. 238). The fear of falling and community mobility is often a lingering barrier for people surviving stroke (Robison et al., 2009), so improving confidence as well as actual safety is an important outcome in rehabilitation, with depression a statistically significant predictor of reduced mobility 12 months following stroke (van Wijk, Algra, van de Port, Bevaart, & Lindeman, 2006).

The issues of power and empowerment during the stroke rehabilitation journey have received increasing attention (Bourke, Snell, Sinnott, & Cassidy, 2012; Crawford et al., 2002; Hart, 2001; McNaughton et al., 2014; Rudman, Hebert, & Reid, 2006). Indeed, in a meta-summary of qualitative studies to develop client-centred guidelines for occupational therapy

provision for people living with stroke, power and empowerment emerged as the core themes. These two themes comprised of six sub-themes: coping with a new situation, informational needs, physical and non-physical needs, being personally valued and treated with respect, collaboration with health care professionals, and assuming responsibility and seizing control (Peoples, Satink, & Steultjens, 2011). All of these ideas are relevant when conceptualising best practice in equipment provision after stroke. In contrast to Peoples et al. (2011), researchers who conducted an earlier qualitative meta-synthesis about the experience of life after stroke extrapolated five themes from the combined findings: change, transition and transformation, loss, uncertainty, social isolation and adaptation and reconciliation (Salter, Hellings, Foley, & Teasell, 2008). While the findings of these two reviews share some similar concepts, the difference between them was a result of subtle differences in the question and intent of the researchers; Peoples et al. (2011) were interested in using qualitative evidence to better understand and develop client-centred guidelines for occupational therapy, whereas Salter et al. (2008) were more focussed on experiences of life after stroke.

In a recent qualitative study by Nanninga, Meijering, Schonherr, Postema, and Lettinga (2015) the importance of going and being at home after stroke was highlighted. Rehabilitation services were criticised for not targeting enough resource when people were discharged from hospital to home, a place which for many, felt like it had shrunk:

The participants' selves had changed, while the spatial and social contexts of their homes had remained the same. Their spatial scope became smaller in both a social and a geographical sense. It was difficult to achieve a feeling of being at home in their bodies and own living environments again. (p. 1125)

The three phases explored by Nanninga et al. (2015) included a clinical inpatient phase, post-discharge phase and reintegration phase, with the concept of 'longing' as an overarching theme across all three phases. The longing at inpatient phase related to bodily recovery and domestic places, at post-discharge it was for pre-stroke activities and roles and at three months it was about a redefined sense of belonging.

In a recent systematic review of qualitative studies examining 40 studies on adjustment and stroke, Sarre et al. (2013) concluded that 'stroke survivors' accounts suggest that relationships with health care professionals and structural factors such as access to health services, employment possibilities and welfare systems, mediate efforts to adjust after stroke'

(p. 716). Many of the studies in the review by Sarre et al. (2013) reported that engaging in meaningful activities, often in an adapted way, was important for adjustment. The researchers acknowledged that adjustment has a strong temporal component and structural issues such as relationships with health care providers and availability of information are much less understood than intra-personal issues such as coping strategies. One of the few studies to explore the impact of health system failures causing setbacks in people with stroke, Hart (2001) reported that of the 17 service failures they identified, examples included not getting timely support due to a lost referral or difficulties with re-admission. Discharge from hospital was noted as a time with particular vulnerability to health service failures. These researchers concluded that having access to someone who knows how the healthcare system works was imperative to enable people to navigate through the process (Hart, 2001).

### **Māori**

As already established, there are many health disparities between Māori and non-Māori in New Zealand and this in turn affects how Māori fare when accessing disability services (K. Carter et al., 2006; Feigin et al., 2007; McNaughton et al., 2002). The rate of stroke for Māori is rising, meaning that there will be more Māori who are younger with stroke compared to non-Māori. This is particularly relevant where funding for, and access to, rehabilitation in New Zealand is more restricted for people who are under 65, thereby increasing the challenge for people identifying as Māori or Pacific peoples (Fink, 2006). It is currently not clear how equitable current equipment provision services are for Māori. In this context, equity can be considered as a system wide intention to produce actions which reduce disparities in health between social groups with differing levels of advantage (Braveman, Starfield, & Geiger, 2001).

In addition, Māori are more likely to be ineligible for superannuation, have families who rely on them for income (Dyall et al., 2008) and are more likely be discharged back to their own home following stroke (McNaughton et al., 2002). Māori concepts of health and disability can differ to the New Zealand European perspective, for example, in te reo<sup>1</sup> Māori there is no clear definition for disability, more commonly health concepts relate to the ability of people to participate in their families and communities and contribute to their own and

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<sup>1</sup> Māori language – literal translation is ‘the language’.

others wellbeing (Ministry of Health, 2012c).

Māori and Pacific peoples report being more dependent, disabled, and dissatisfied with their quality of life after stroke than non-Māori (Curtis, Harwood, & Riddell, 2007). Losses for Māori as a result of stroke include financial, ‘mana<sup>2</sup>’ and the ability to take part in cultural activities with their whānau<sup>3</sup> and their community (Dyall et al., 2008). Māori worldviews may differ from Western ideas about independence in particular, where interdependence, with the strengthening of family, can be of greater importance (Hopkirk & Wilson, 2014; V.A. Wright-St Clair et al., 2012). For these reasons, acknowledging potential diversity of experience with equipment provision services and focusing on cultural nuances of equipment use were important in this thesis.

### **Cost**

Many stroke-related costs are difficult to quantify, such as the cost of residential care, opportunity costs borne by family members and secondary costs such as people becoming unemployed (Scott & Scott, 1994; Wolfe et al., 2014). Though international comparisons of cost of stroke are greatly complicated by differences in methodology (Luengo-Fernandez, Gray, & Rothwell, 2009) and the range of costs are considered heterogeneous (Truelsen, Ekman, & Boysen, 2005), most research findings agree that costs are greatest during the chronic phase, particularly when residential care is a factor (S. Smith et al., 2012). This endorses the need to maximise functional outcomes as early as possible. In the UK, the cost of stroke per year is estimated at over UK£7 billion (approximately NZD \$14.5 billion) (Wolfe et al., 2014) and in Ireland, a country with similar population size to New Zealand, nursing home care and indirect costs accounted for more than 70% of total cost of stroke (S. Smith et al., 2012). In New Zealand, the lifetime cost for someone having a stroke has previously been conservatively estimated at NZD \$73,600 (Brown, 2009) but given the increasing older population living longer with greater disability after stroke, annual costs due to stroke are now estimated to be NZD \$700 million (Stroke Foundation of New Zealand, 2010).

Wolfe et al. (2014) reported on six research streams which evaluated cost effective

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<sup>2</sup> Māori language word for authority, control, influence, prestige, power or honour

<sup>3</sup> Māori language word for extended family

stroke services in the UK for an inner-city population of 271,817 people with first stroke between 1995 and 2012. These researchers concluded:

Clients do not simply progress through a care pathway and that quality of care can be affected by multiple factors including complexity of needs, moral evaluations, divergent staff views and client/carer knowledge and agency. (p. 75)

This conclusion recognises the complexity of factors affecting the way cost is managed in stroke rehabilitation.

## **2.4 Use of adaptive equipment in rehabilitation**

This section summarises literature predicting who receives and uses equipment among general disability populations, the issue of equipment non-use, research on types of equipment relevant to this thesis (primarily mobility and self-care equipment), and relevant concepts in outcome measurement for equipment provision. I also discuss what is known about the interaction of culture and equipment use which is a relatively under-researched area (Ripat & Woodgate, 2011). This section addresses what outcomes are achieved by providing equipment and introduces some key tools commonly used to measure these outcomes.

Much research addressing equipment use has been combined with the effect of providing housing modifications (Sorensen, Lendal, Schultz-Larsen, & Uhrskov, 2003) or carer assistance (Verbrugge, Rennert, & Madans, 1997), which can make it difficult to analyse the independent effects of adaptive equipment on health and impairments. Therefore, where possible, I have reported on research which concentrated solely on equipment use. Where research foci were mixed, I have specified when findings related specifically to equipment use and when findings related to equipment in combination with other interventions such as taking part in exercise or cognitive re-training.

There is a lot of information about what outcomes equipment can potentially offer (Hansson, 2007). Though equipment provision is mentioned as best practice in most guidelines for stroke rehabilitation (Dawson, Knox, McClure, Foley, & Teasell, 2013; National Institute for Health and Care Excellence, 2013; Scottish Intercollegiate Guidelines Network, 2010; Stroke Foundation of New Zealand, 2010), descriptions of how the recommendations from these guidelines should be applied to practice are often broad, vague

and based on limited evidence such as observational studies or expert opinion. At a recent UK conference, Cowan and Judge (2014) reported that the key areas for research in this area currently are:

The importance of user involvement in the design and specification of assistive technology; of evidencing the impact of service provision on users; of basing this provision on sound evidence and of understanding the reasons why users may decide not to take up use of these technologies. (p. 31)

Most of the literature available about equipment use has been published after 1990, with only two earlier studies identified (Haworth, 1983; Keating, McLean, & Quinsey, 1989) and the majority have been published since 2000. While this is encouraging for knowledge development, repeated reviews of research in this area have concluded that many of the studies are difficult to compare, poorly designed or are not generalisable (Anttila et al., 2012) and that there is a lack of information about methods and data from assessments prior to trial of equipment (Mountain, 2004).

Until the introduction of the ICF, many reviews of equipment use focussed on occupational therapy's practice and philosophy (Salminen et al., 2009), most typically reviewing literature with reference to the Person-Environment-Occupation model (Fearing, Law, & Clark, 1997; Law et al., 1996; Murphy, Gretebeck, & Alexander, 2007). As a consequence, Ivanoff, Iwarsson, and Sonn (2006) concluded following one such review that occupational therapists were targeting research efforts primarily at the interaction between individual therapists and their clients and they advocated for greater emphasis on systemic and population based research. Recent theoretical models conceptualising equipment prescription and use have been more interdisciplinary in their focus (Friederich et al., 2010; Lenker & Paquet, 2003). Key examples from these will be discussed in more detail later in this chapter.

### **Demographics of equipment users**

While there are variations on how equipment use is defined and measured, there are some consistent findings from a range of cross sectional surveys. Between 14% and 18% of people aged 65 and older, and 39% and 44% of people aged 85 and older use one or more assistive technology devices (Cornman, Freedman, & Agree, 2005). Unsurprisingly, severity of disability has been identified as one of the strongest predictors of equipment use (Agree &



Freedman, 2000), with poorer overall health and obesity identified as weak but correlated factors (Mann, 2005; Pressler & Ferraro, 2010). People ageing with a disability lose independence faster than other groups but equipment allocation can reduce the rate of this functional decline (Gitlin et al., 2006; Mann et al., 1999; Wilson, Mitchell, Kemp, Adkins, & Mann, 2009).

It remains challenging, however, to accurately predict who will receive and use equipment in general (Copolillo & Prohaska, 2001), with conflicting reports on this topic. Some research based on cohorts of people with mixed disabilities and health conditions, reports that females, older people and those with higher education are more likely to continue to use adaptive equipment (LaPlante, 1992), while others have found no such relationships (Verbrugge & Sevak, 2002). Dudgeon et al. (2008) conducted a cross sectional survey of 14,500 Medicare beneficiary recipients and concluded that while use of personal care and equipment were common, the type of equipment used, the activity equipment was used for and the age of respondents varied. In terms of emotional state affecting equipment use, the research is even less coherent. For example, Wielandt et al. (2006) found that people who were less anxious were more likely to use their issued equipment following hospital discharge, whereas others have reported that people who use adaptive equipment are three times more likely to have depression than matched control clients (Okoro, Strine, Balluz, Crews, & Mokdad, 2010). One consideration here is that Okoro et al. (2010) could not provide data on the severity of disability of their participants, which may have been a confounding factor in their findings. Therefore, depression may be related to problems with the health of people with stroke impeding their functional ability and quality of life, rather than the use of adaptive equipment being a causative factor.

It has been identified that communication difficulties may be associated with equipment use. In one study, 17% of people with communication difficulties were reported to have unmet need for home aids compared to 11% of people without communication difficulties, indicating that there may be particular issues for this group accessing equipment appropriate to their needs (Wolfe et al., 2014).

There are also challenges with equipment use specific to life in residential care. While the environment tends to be more accessible than private homes, people in institutions are

often more physically or cognitively impaired. There can also be work cultures present which create tensions between individual and group safety and, relatedly, tensions with residents' right to mobility (Bland, 1999). Mortenson et al. (2005) conducted interviews with care residents to explore how they learnt about powered mobility equipment. They reported that rules for powered mobility equipment were negotiated with staff and that organisational processes focussed on keeping all residents and staff safe could take priority over the risk required to support residents' building competency and confidence with powered mobility equipment.

### **Outcome from equipment use**

Discussion of how to evaluate the consequences of providing adaptive equipment to people with disability requires consideration of which outcomes are most likely to reflect changes in health status and how to measure these changes. An important risk relevant to outcome measurement and assistive technology has been outlined by Gramstad et al. (2014):

Outcome studies that aim to verify whether an ATD [Assistive Technology Device] is causally responsible for observed changes seem to imply two underlying assumptions. First, the ATD is assumed to be the main factor in instituting a change. Second, the users' task is to apply the ATD in certain defined situations for it to be effective. Both these assumptions signal a view of the user as a passive recipient and of the ATD as having intrinsic power to produce a change. (p. 494)

Equipment provision can result in a wide array of potential outcomes, including improved functional ability, participation and engagement in social roles (Gelderblom & de Witte, 2002). Equipment is most commonly prescribed for self-care and mobility after stroke (Hass et al., 1995; Sainty, Lambkin, & Maile, 2009). Mobilisation is considered a vital prerequisite for independence (Guralnik, Ferrucci, Balfour, Volpato, & Di Iorio, 2001) and occupational performance (C. Pettersson, Iwarsson, Brandt, Norin, & Mansson Lexell, 2014) and it is the only area, according to the UNCRPD, where governments are obligated to provide affordable equipment (United Nations, 2007).

Mobility equipment is issued to people after stroke to enable them to move as safely and independently as possible (Samuelsson & Wressle, 2014) and to reduce fear of falling (Gitlin et al., 2006; McMillen & Soderberg, 2002). This is important as people with stroke are twice

as likely to fall as control groups (Auger et al., 2008) and fear of falling can be a barrier for people up to 8 years after their initial stroke (Da Silva, Carlegis, Suchma, & Ostwald, 2014). Schmid et al. (2013) reported, from a cohort in the USA recruited as part of a longitudinal study of sleep apnoea in veterans with stroke that of their 160 participants, 33% had a fall over a 12 month period, 70% of these falls happened in their own home and were associated with inattention during an activity of daily living such as tying shoelaces (40%). Most people who fell were injured (70%) and 55% of those who were injured sought medical care, with 32% of people going to an emergency department. In New Zealand, falls account for half of all costs for people aged over 65 and result in 75% of injury-related hospital admissions (Accident Compensation Corporation, 2014), so reducing falls by issuing equipment could, hypothetically at least, reduce healthcare costs. Though likely to improve confidence and a sense of safety (Tyson & Rogerson, 2009), the extent to which mobility equipment is issued to, and used by, people with disabilities is poorly understood, particularly in relation to activity and participation (Kunkel, Fitton, Burnett, & Ashburn, 2015; Salminen et al., 2009).

Introducing equipment can potentially have the reverse effect of increasing risk of falls and physiological demands (Bateni & Maki, 2005). While analysing data from a national injury register for 66 emergency departments from 2001 to 2006, Stevens et al. (2009) estimated that 47,312 older adult fall injuries were associated with use of walking aids, with over a third of these resulting in hospital admission. Walking frames were much more strongly associated with falls (87.3%) than walking canes (12.3%), though the research design in this case could not account for probable poorer health and mobility that one would expect from someone using a frame as opposed to a walking stick. Nevertheless, it seems feasible that equipment which increases people's activity levels could also expose them to greater risk of falls.

Wheelchair use is a common topic in research on disability and equipment use and the prevalence of wheelchair use is growing rapidly, having doubled in the last decade (Harris, 2007). Wheelchair users engage in fewer activities than people who do not need mobility devices (Harris, 2007) and some have reported that their equipment is more limiting to their participation than their physical injury (Chaves et al., 2004). Wheelchair users have been observed to undergo an embodiment process in relation to their equipment, where wheelchairs are viewed as an extension of their physical selves (Gibson, Carnevale, & King, 2012;

Papadimitriou, 2008). It appears that users of mobility equipment, such as wheelchairs, go through an emotional and cognitive process where their equipment becomes meaningful as they adjust to life after stroke (Gramstad et al., 2014; Nihei, Inoue, & Fujie, 2008).

Understanding the impact of equipment on people other than the user is poorly understood (Roelands, Van Oost, Depoorter, Buysse, & Stevens, 2006), but the complexity of the equipment as well as the time and training required can be a source of stress for family members (Demers et al., 2009). Understandably, use of mobility equipment is associated with use of paid care services as both increase with higher levels of disability (Agree & Freedman, 2000) and the involvement of paid carers in particular is increasingly recognised as relevant to successful uptake of equipment by people with disabilities (Roelands et al., 2006). While it can be tempting to view equipment as a one-off cost compared to ongoing carer costs (Agree et al., 2005), reductions in formal carer costs as a result of equipment provision usually only occur where people have mild impairments, good social support and higher cognitive abilities (Agree & Freedman, 2000; Agree et al., 2005; Allen, Foster, & Berg, 2001; Freedman et al., 2006; Hoenig, Taylor Jr, & Sloan, 2003; Wilson et al., 2009).

There is also an assumption that provision of adaptive equipment results in savings of healthcare costs (Harris & Sprigle, 2003; Samuelsson & Wressle, 2014), which is increasingly being tested to ascertain exactly where savings occur. As a secondary aim to a study evaluating the effect of electric powered wheelchairs on a group of 24 people in Sweden, Samuelsson and Wressle (2014) collected costs of therapist contact time related to equipment provision, hire and storage of equipment and in-home formal and informal carer time reported by users. Their results concluded that while provision of equipment made no significant impact on health status (as measured by the EQ-5D<sup>4</sup> Visual Analogue Scale), equipment provision resulted in a mean decrease of four hours per week for publicly-funded homecare assistance, translating into an average societal cost saving of €6,227 per year per wheelchair user. The societal costs of equipment provision appear to be important but also the most difficult to ascertain which makes policy decisions difficult to formulate (Andrich, Ferrario, & Moi, 1998). Though the sample in the Samuelsson and Wressle (2014) study was small and their pre and post design was vulnerable to bias influencing the results, the researchers

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<sup>4</sup> EuroQol 5D - standardised instrument for use as a measure of health outcome

estimated that an average saving of even one hour per week of personal care would offset the cost of equipment.

### **Outcome measures and equipment provision**

Researchers have developed and used different types of outcome measures to evaluate the effects of providing equipment to people with disabilities. However, in a systematic review conducted by S. Kenny and Gowran (2014), of the thirteen outcome measures reviewed which were developed in the last 15 years, two focussed on comfort only, five did not address equipment provision services, and six lacked information on psychometric properties or were not available in English. There are a number of domains often associated with evaluation of equipment provision and use including cost effectiveness, utility, impact on functional abilities, increased participation and improved quality of life (Gelderblom & de Witte, 2002). Few outcome measures of impairment, activity or health status specifically mention equipment and these often do not distinguish between completing an activity with physical assistance or with equipment (Rust & Smith, 2005; Verbrugge & Sevak, 2002). Where equipment is mentioned in outcome measures, using equipment is usually considered indicative of lower functional ability (Hammel, 2003) or of lower levels of participation (Harris, 2007).

There is a role for outcome measures that focus on goal achievement, such as Goal Attainment Scaling and the Canadian Occupational Performance Measure (R. O. Smith, 1996; Wessels et al., 2004) as well as outcome measures designed specifically for equipment use. Increasingly, in equipment-related research, outcome measures based on ICF categories have been used. For example, the WHO Disability Assessment Schedule (WHO-DAS II) has been used to detect change after provision of adaptive equipment (Raggi, Albanesi, Gatti, Andrich, & Leonardi, 2010) and outcome measure development in the field of adaptive equipment has increasingly incorporated the ICF as a tool for item selection or categorisation (Scherer, Craddock, & Mackeogh, 2011; Scherer & Glueckauf, 2005; Scherer et al., 2007).

In a review of the psychometric properties of outcomes measures typically used in assistive technology research, Lenker, Scherer, Fuhrer, Jutai, and DeRuyter (2005) reported that more standardisation was required to improve rigour and comparability across studies. Of the 82 studies reviewed between 1990 and 2001, almost 80% of studies used tools designed

exclusively for that particular study. Outcome measures were most likely to address the extent of equipment use, followed by the role of the equipment in participation and quality of life, with cost being the least measured outcome. Researchers recommended that equipment prescribers need to consider outcome measures other than just those for impairment (for example, balance and muscle strength). These researchers reported a need to incorporate how the user perceives the activity and participation outcomes achieved through equipment use and the impact of the equipment on the person's ability to engage in meaningful activities or social roles (Chaves et al., 2004; Lenker & Jutai, 2002; Lenker et al., 2012).

The most commonly used outcome measures, in the literature reviewed for this thesis, specific to the wider field of assistive technology, were the the Quebec User Evaluation of Satisfaction with Assistive Technology and the Psychosocial Impact of Assistive Devices Scale. The Assistive Technology Device Pre-disposition Assessment is not an outcome measure, however as an assessment predicting the likely use of equipment, it has received some attention from theorists in this area. The format of these three tools influenced the development of a questionnaire reported on later in this thesis. However, as it was not the intent of this thesis to use these outcome measures, this section provides simply a brief overview of each one rather than a comprehensive review of their psychometric properties.

Wessels et al. (2004) noted a lack of theoretical models informing measure development related to user satisfaction with equipment and they reported that the most cited assistive technology specific outcome measure for this domain was the Quebec User Evaluation of Satisfaction with Assistive Technology (Demers, Weiss-Lambrou, & Ska, 2002). It was also one of the first outcome measures developed for equipment and equipment provision (DeRuyter, 1997; R. O. Smith, 1996). It includes items that examine a range of variables which influence satisfaction with equipment and asks users to rank these variables according to importance. This outcome measure crucially included an explicit acknowledgement of the need to prioritise user satisfaction with equipment when measuring the impact of equipment provision as opposed to simply prioritising use or non-use (Wessels et al., 2004).

The Psychosocial Impact of Assistive Devices Scale (Jutai & Day, 2002) is focussed on the psychosocial impact of equipment and this outcome measure has been commended as one of the most rigorous psychometric scales in this field (Fuhrer, 2001). It has been used, for

example, to evaluate the psychosocial impact of standing aids given to 284 people with a variety of neurological conditions in Sweden, demonstrating that most aids had a positive impact for users across all condition groups (Nordstrom, Nyberg, Ekenberg, & Naslund, 2014).

The Matching Person and Technology model has led to the development of a suite of assistive technology specific assessments (Scherer & Craddock, 2002), with the Assistive Technology Device Pre-disposition Assessment being one of the core tools recommended to ensure the best match possible between a user and a piece of equipment. The Assistive Technology Device Pre-disposition Assessment is an assessment tool rather than an outcome measure and it is based on the assumption that people will be more likely to use equipment if they are explicitly and systematically involved in its selection (R. O. Smith, 1996). The Matching Person and Technology model requires prospective research in order to establish if and how it supports decision making for therapists and what impact this has on outcomes for users (Lenker & Paquet, 2003).

The Consortium for Assistive Technology Outcomes Research (2007) reported that the field of outcome measurement continues to be problematic for equipment provision. Though traditional outcome measures in rehabilitation are seen as too narrow in scope, the relative explosion in alternative, equipment-specific outcome measures is leading to a lack of comparability across studies. Regardless of the number of outcome measures developed, many therapists rely on clinical expertise when making assessments and recommendations, and use outcome measurement data to support rather than dictate their clinical actions (Greenhalgh, Flynn, Long, & Tyson, 2008).

### **Abandonment and non-use of equipment**

There has been long standing consideration from researchers and those designing equipment provision services on what factors maximise people using adaptive equipment. Abandonment of equipment rates vary between populations and equipment type but a recent study in Italy estimated that close to one fifth of publicly funded adaptive equipment is abandoned after being purchased and issued (Federici & Borsci, 2016).

The impact of personal factors and stigma on equipment non-use (Myers et al., 1996; Parette & Scherer, 2004; Pippin & Fernie, 1997; Scherer & Glueckauf, 2005) have been

researched, and to a lesser extent, the influence of family members and health care professionals (I. Pettersson & Fahlstrom, 2010; Roelands, Van Oost, Depoorter, & Buysse, 2002; Roelands et al., 2006; Verza, Carvalho, Battaglia, & Uccelli, 2006). There are also procedural factors affecting people's decision to use equipment such as assessment, fitting, follow up and their relationship with therapists (Hagglom-Kronlof & Sonn, 2007). This interest in equipment use is fuelled by two drivers: to ensure people with disabilities have access to equipment that actually improves their quality of life and that money spent on equipment is allocated as effectively as possible.

A number of studies have explored the processes that people apply when incorporating equipment into their daily life. Typically this involves weighing up the benefits of the equipment for pursuing activities important to them against the effort or negative consequences arising from use of the equipment. For instance, being viewed differently by others when using equipment can alter a person's sense of identity, which can be a negative consequence of using equipment (Hagglom-Kronlof & Sonn, 2007; McCreadie & Tinker, 2005; McMillen & Soderberg, 2002). The reverse can also be true. For example, Samuelsson and Wressle (2014) reported that while motorised wheelchairs did not impact greatly on activity limitations, using these devices had a positive effect on self-esteem and sense of safety. The internal process users of equipment go through helps them to establish the relative advantage of equipment, including the impact using equipment has on their sense of self (Riemer-Reiss, 1999; Riemer-Reiss & Wacker, 2000). As another example, in research on the optimal timing to trial powered forms of mobility aids, Mortenson, Hammell, Luts, Soles, and Miller (2015) recently described three distinct stages: reluctant use, strategic use and essential use. These findings are echoed in other research such as by Lund and Nygard (2003) who outlined that people who used equipment could be grouped as pragmatic users, ambivalent users or reluctant users. Riemer-Reiss and Wacker (2000) argued that discontinuance of equipment could result from two processes: replacement, where a person or other equipment item can help a person achieve their goals, or disenchantment, where the relative advantage of the equipment is outweighed by its disadvantages. From these examples, it appears that how someone with a disability views themselves, their abilities and their equipment is inter-related.

Decisions to keep or discard objects can be heavily dependent on a person's self-image (Csikszentmihalyi & Halton, 1981; Kleine, Kleine, & Allen, 1995). Consequently if the



message projected by using equipment is perceived to be negative, that one is old or disabled, then it makes sense that people would decline to use such objects. There is a tendency for researchers and service providers to consider abandonment or non-use as a negative outcome, due to potential waste of healthcare resources, though from a users' perspective this is not necessarily true (Hocking, 1999). For example, a longitudinal study with a stroke population by Sorensen et al. (2003) found that the most common reasons for abandonment of equipment were that they no longer required the equipment, the function of the equipment were provided by a support person or the person with stroke had chosen to change how (or even whether) they completed their usual activities. Hocking advocates focusing on reasoning employed by therapists when prescribing equipment, encouraging a shift from functional assessment to narrative reasoning to understanding the client's personal perspective: 'Therapists need to be sensitive to who might find assistive devices too complicated, intimidating or unsafe' (Hocking, 1999, p.7).

So, deciding who has 'failed' when equipment goes unused is an interesting dilemma. Verza et al. (2006) argued that the responsibility for non-use should lie with a provision system which did not tailor an assessment and equipment item adequately enough. As stated by Scherer (2014):

For 30 years we have used a 30% ATD [assistive technology device] non-use or abandonment rate. It is unlikely that the stability of this figure is due to the lack of product options. It is likely that it is a result of the means by which products are obtained, that is the assistive technology service delivery system. (p. 1)

Other researchers contend that incorporating equipment into one's sense of identity needs to be seen more broadly than a pass or fail with equipment use (Gibson et al., 2012; Hocking, 1999; Lund & Nygard, 2003; Papadimitriou, 2008). Research suggests that people with stroke undertake a process of weighing up the pros and cons of using a piece of equipment, with varying levels of influence on this decision making from the services which provide the equipment.

### **Culture, ethnicity and equipment use**

Many of the influences on equipment use discussed so far relate to interpersonal factors and environmental considerations. However, the impact of cultural and ethnic factors on

equipment prescription and use also needs to be taken into account, as these can influence how and if equipment is accessed and how meaning is attributed to equipment (Ger & Belk, 1996; Gitlin et al., 1993). For example, in America, people of Hispanic origin are over represented when it comes to severe disability, yet they are the least likely group to access support services (Cristancho, Garces, Peters, & Mueller, 2008). In one of the first research projects to look at disparity of equipment provision related to ethnicity, Guzman (2008) reported that people identifying as Hispanic had increased odds of learning about equipment options from family, friends and neighbours, when compared to those who identified as white ( $p = .001$ ). In different study involving the Navajo Nation in America, Reisinger and Ripat (2014) reported from focus groups with users and providers of equipment that users prioritised feeling understood by providers, whereas providers were more focussed on their roles and following due process. This speaks further to people of different cultural and ethnic backgrounds having different experiences of learning about equipment. The equipment providers expressed frustration at being the point of contact for relaying situations about funding and waiting lists which they could not control but were expected to explain to their clients.

It can be a substantial challenge for therapists to appreciate perspectives outside of their own cultural experience (Whiteford & Wilcock, 2000). As outlined in a review about the intersection of culture and equipment use by Ripat and Woodgate (2011), people who have a similar disability can identify with a culture related to that disability. These researchers also claimed that as many disability researchers come from a Western philosophy which favours independence and self-determination, the research in this area is therefore flavoured by these cultures. Social relationships and interdependence preferences, like expecting family to automatically provide care, vary across cultures which may in turn determine reactions to equipment provision services which prioritise independence (R. Smith, 1995). Culturally considerate policies and economic realities can come into conflict where services aim to be culturally sensitive, however, should someone decline a refurbished item in preference to a new one based on cultural preference, the processes to manage such a situation are often ambiguous (L. Walker & Friesen, 2015). An equipment user's attitude to their illness and the ageing process affects whether they use equipment (McMillen & Soderberg, 2002). This point is important when considering how self-identity, disability and ageing are viewed

differently across cultures (Resnik, Allen, Isenstadt, Wasserman, & Iezzoni, 2009). In other words: ‘racial and ethnic identity shapes and conditions individuals’ choices, which influences need-related and enabling factors that in turn may affect mobility device use’ (Cornman & Freedman, 2008, p. S35).

The role of equipment in rehabilitation and life after stroke for Māori is poorly understood. According to a 2006 report, 1,600 of Māori with disability aged 65 and over (16%) reported an unmet need for special equipment, compared to 11 percent of disabled non-Māori (Office for Disability Issues and Statistics New Zealand, 2010). In response to recent health care frameworks (Ministry of Health, 2012c) and disability specific strategy statements (Ratima & Ratima, 2007), there has been a growth in Māori led health service initiatives, however this trend has been much less prevalent in rehabilitation services (Harwood, 2010), which typically are responsible for initiating equipment provision.

The other large ethnic group in New Zealand are Pacific people, who comprise 7.4% of the population (Ministry of Health, 2014b). Traditionally, this group have had low uptake of disability support services, though this is changing with recent efforts to increase awareness and access of such services (Ministry of Health, 2013b). While there is little data about equipment uptake and satisfaction with disability services for this group, there appears to be a trend for adults who identify as Pacific people to be less likely to use equipment than other ethnic groups (Ministry of Health, 2008). The reasons for this may be due to systemic failures about access, information and delays for funding or that disability can have negative implications within this culture, making people less likely to draw attention to a disability by using equipment (Pacific Information Advocacy and Support Services Trust, 2005).

## **2.5 Equipment use and stroke**

In order to establish what is currently known about equipment prescription and stroke, a scoping review of the literature was conducted with a focus on the concepts and challenges this specific subset (equipment use and stroke) of literature would contribute to what has already been presented thus far in the thesis. A scoping review is an approach to literature review and synthesis which aims to map key concepts which underpin an area of research, determine where gaps exist and summarise findings (Arksey & O'Malley, 2005). In contrast to a systematic review, scoping reviews are best suited to address broad research questions

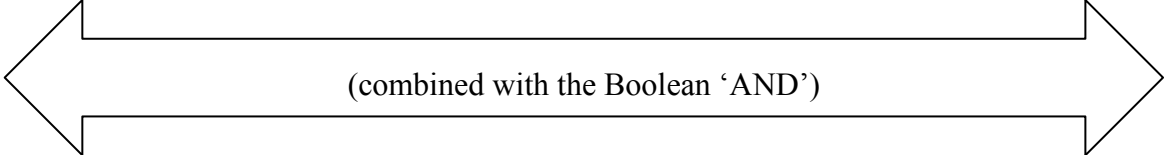
where differing types of research design need to be synthesised (Mays, Roberts, & Popay, 2001). Therefore, the aim of this scoping review was to examine available literature to date on equipment provision specifically for people who have had a stroke.

There are challenges with synthesising findings from research in this area. Multiple systematic reviews in equipment use have concluded that the diversity of quality and breadth of methodology in this area means that studies are not easily comparable (Anttila et al., 2012; Salminen et al., 2009). Most of the research is non-experimental, in part due to the complexity of the intervention, making comparative assessments of study quality difficult (Arksey & O'Malley, 2005). However, synthesising different types of research can still maximise what results do exist and use those findings to inform policy and practice (Joanna Briggs Institute, 2014).

To be included in this review, articles needed to describe the findings from a study on equipment use involving a population of people 16 years or older who had experienced a stroke, be published in English and in a peer-reviewed journal. Studies on people with traumatic ischaemic attack were excluded. Research which centred on equipment other than that which was the focus of this thesis (See Chapter 1, Section 1.2) was also excluded from this review. Year of publication, study methodology, and study quality were not used to exclude papers.

In order to identify papers a search electronic database was conducted and included: Medline, CINAHL, OTseeker, PEDro, VISTA-Rehab (an archive dedicated to stroke specific rehabilitation trials) (Ali et al., 2010), the Cochrane Database of Systematic Reviews, and TRIP database. To guide the identification of relevant papers, a list of key search terms was drawn up (Table 2.1). Boolean terms were used to combine terms associated with the population, topic and outcomes of interest for databases where this was appropriate. These terms were added to after consultation with a medical librarian, and in an iterative fashion as new terminology was identified. The database searches were first conducted in 2012; with electronic alerts used to continue to identify potentially relevant papers in key journals (for example, Disability and Rehabilitation: Assistive Technology; Occupational Therapy International). The search strategy was repeated in July 2015.

**Table 2-1 Overview of search terms**

<b>Terms related to population of interest</b> (combined with the Boolean 'OR')	<b>Terms related to equipment</b> (combined with the Boolean 'OR')	<b>Terms related to outcomes of interest</b> (combined with the Boolean 'OR')
 (combined with the Boolean 'AND')		
Stroke	Assistive technology	Independent/ence
CVA	Adaptive equipment	Use/utility
Cerebral vascular disease	Assistive equipment	Safety
Cerebral infarct	Self-help devices	Mobility
Cerebral haemorrhage	Disability aids	Quality of life
	Assistive technology devices	Cost
	Special equipment	Satisfaction
	Community equipment	
	Quality of life technology	
	Home aids	
	Durable medical equipment	

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CVA = cerebral vascular accident

Overall, 29 articles were identified for inclusion in this review (see Appendix A for a table with details on each article and search history). However, when different publications on the same study participants were combined, there were 19 different research projects represented by these 29 articles. Of these 19 research studies, seven were conducted in the USA (Cushman & Scherer, 1996; Garber et al., 2002; Gitlin, 1998; Gitlin, Schemm, Landsberg, & Burgh, 1996; Mann, Hurren, Tomita, & Charvat, 1995; Skolarus, Burke, & Freedman, 2014; Winkler et al., 2010), four in Sweden (Gosman-Hedstrom, Claesson, & Blomstrand, 2002; Hass, Freden-Karlsson, & Persson, 1996; Lampinen & Tham, 2003; I. Pettersson, Appelrosi, & Ahlstrom, 2007), three in Canada (Barker, Reid, & Cott, 2006; Jutai et al., 2007; Reid, Hebert, & Rudman, 2001) and one each in Hong Kong (Chiu & Man, 2004), the United Kingdom (Tyson & Rogerson, 2009), Switzerland (Allet et al., 2009), Germany (Hesse, Gahein-Sama, & Mauritz, 1996) and Denmark (Sorensen et al., 2003). Two studies were randomised control trials (RCTs) (Chiu & Man, 2004; Tyson & Rogerson, 2009) while the others used either descriptive designs such as cross sectional or cohort studies, at times in combination with economic evaluations, or qualitative research. No systematic reviews specific to equipment use for people after stroke were found.

Overall, findings from this scoping review demonstrated that research to date largely has focussed on frequency of equipment use and on estimating non-use, with some more recent studies exploring experiences of equipment use and equipment provision after stroke. The methods used to address research questions in this field have become increasingly sophisticated and there has been a growing acknowledgement of the need to understand the users' perspective on equipment, in order to maximise the utility of equipment. There has also been a growth in research addressing the cost of equipment after stroke. As a side note, this review also illustrated the development of academic journals solely dedicated to the design and implementation of assistive technology over the last 15 years, further indicating the rise in interest in this as a research topic.

Findings arising from these studies specific to equipment use after stroke were synthesised and are presented in the next four sections of this chapter, with reference to related other research to enhance clarity. These findings have been organised into four key areas: 1) equipment and stroke-specific impairments, 2) conflicts between equipment provision and models of stroke rehabilitation practice, 3) cost of equipment after stroke, and

4) acceptance and meaning of equipment for people with stroke.

### **Stroke specific impairments and consequences for equipment use and training**

Perceptual impairments which result in visual-spatial neglect commonly occur when people have a stroke and introduce a significant and often poorly understood challenge (Beis et al., 2004; Prangrat, Mann, & Tomita, 2000). For example, in research by Cushman and Scherer (1996), pre-disposition towards equipment use for 47 people with stroke, using the Assistive Technology Device Pre-disposition Assessment was assessed while they were inpatients and again 3 months later, along with their functional outcome. These researchers concluded that people with left hemisphere stroke ended up not using their equipment which was speculated to be related to higher rates of perceptual neglect in this population.

Using phenomenological methods, Lampinen and Tham (2003) described three themes regarding how people with visual-perceptual difficulties related to physical objects. This study illustrated how people with perceptual deficits struggle for control of their physical world, where participants described difficulties interacting with everyday objects, in addition to new items like adaptive equipment. For example, wheelchairs were perceived as unruly and disobedient, therefore their equipment could become a source of stress and mistrust. Lampinen and Tham (2003) recommended that therapists take time to support clients to know their adaptive equipment and to slowly build up familiarity with it, until it becomes a habitual part of a person's life:

Well known objects like a butter knife or a cheese slice, were experienced as unfamiliar objects and could not, therefore be incorporated into the participants' new habits after stroke (Lampinen & Tham, 2003, p. 151)

One of the first studies to assess the rate of equipment issued to people with stroke was by Schemm and Gitlin (1998) where they observed that people with stroke received more devices (mean number of devices = 10.8, SD +/- 3.8) than clients with orthopaedic diagnoses (mean number of devices = 8.9, SD +/- 2.7). Schemm and Gitlin (1998) also reported that occupational therapists gave verbal instructions that they usually included some demonstration, with few examples of written instructions being used. They noted that few people received information on maintenance services for equipment and that family members were rarely included in education and recommended that that better scheduling would be

required to achieve this. In a modest RCT in Hong Kong, Chiu and Man (2004) trialled additional home based training for equipment users with stroke compared to usual care, with 30 people in the intervention group and 27 in the control group. The authors reported a significant difference for both the users' functional abilities and their satisfaction with the equipment in the intervention group. This result confirmed earlier researchers' findings (Hesse et al., 1996; Sorensen et al., 2003), that more in-home training, in the form of pre-discharge visits, increased the uptake of equipment in people with stroke.

In one of the few longitudinal studies of equipment use by people after stroke, Sorensen et al. (2003) established that 75% of 155 consecutive clients discharged from hospital with stroke had received equipment. The researchers reviewed consenting survivors at 6 months and between three and five years later to find almost all were using their equipment. The mean number of items of equipment provided was 4.4 (SD +/- 2.39). Eighty three percent (96/116) were prescribed mobility aids and 63% (73/116) rated bathing and mobility as their most valued items, though many (44/116) had equipment prior to stroke. They found a statistically significant difference in the number of equipment items issued when people had a home visit before leaving hospital, compared to those without a home visit ( $p = .003$ ) which endorsed recommendations from other researchers about the value of home visits and equipment use (Clarke & Gladman, 1995; Schulz et al., 2012; Whitehead et al., 2014).

Finally, people with stroke are likely to have cognitive problems and Jutai et al. (2007) and Mann, Hurren, and Tomita (1993) both noted that older people with cognitive problems were less likely to have or use equipment than people without cognitive problems. Overall, from this review, it appears that the wide range of impairments which can be associated with having a stroke increase the complexity of how people interact with equipment.

### **Conflicts between equipment provision and models of stroke rehabilitation**

Compared to more progressively disabling conditions, stroke is characterised by a sudden onset of disability, which challenges people to adjust quickly to a great many new difficulties and presents an unknown trajectory of recovery (Ferrucci et al., 1996). These factors can all have an impact on a person's acceptance and use of equipment after stroke. The decision about whether, and when, after stroke to focus on body structure impairments like muscle weakness or on compensatory techniques such as equipment provision can be



challenging for people with stroke and their therapists (Ferrarello et al., 2011; Lennon & Ashburn, 2000). To complicate matters further, though equipment is often provided to prevent falls, the evidence for many non-pharmacological falls prevention strategies, such as equipment provision, remains unclear (Verheyden et al., 2013).

Balance support provided by equipment can result in a significant reduction in the energy required for walking after stroke, the magnitude of which depends on a person's mobility and the nature of the walking task (IJmker et al., 2013). Allet et al. (2009) reported in an observational study that simple cane use by people mobilising after stroke resulted in greater walking distance and velocity, compared to Nordic<sup>5</sup> walking poles and 4-point canes. These authors acknowledged that in some neurological approaches to stroke rehabilitation which focus on normal movements:

The use of any type of walking aid is considered detrimental. The use of 4-point canes is consistently discouraged, while elongated canes, which are said not to enable compensatory weight shifting, are suggested only if absolutely necessary. However, this approach is not supported by current scientific work and furthermore, modern health care policies stress the need for functional improvement and early independence rather than movement quality. (Allet et al., 2009, p. 1408)

This perspective is supported by a review on five international guidelines for stroke management (Zorowitz, 2011) and a Cochrane review comparing physiotherapy approaches for recovery of participation and mobility after stroke (Pollock et al., 2014). Tyson and Rogerson (2009) conducted a crossover RCT with 20 non-ambulant clients with stroke undergoing mobility retraining in the rehabilitation units of three UK hospitals. Each intervention group trialled five pieces of compensatory equipment, including a walking cane, slider shoe and orthosis. They reported a statistically significant improvement in mobility with all assistive devices ( $p > .0001$ – $.005$ ; effect sizes as  $1.68$ – $0.52$ ; number needed to treat 2–5) and that participants reported they would prefer to walk as soon as possible rather than work on what might be considered 'normal' gait patterns.

Based on the few studies which have empirically evaluated the efficacy versus the risks of using equipment in (often early) stroke rehabilitation, it appears that on the whole,

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<sup>5</sup> Poles, often with hand straps, originally designed to increase stability when trekking and skiing by engaging upper body muscles when striking the ground with poles.

equipment provision is preferred by people with stroke if it enables their independence more quickly and that equipment provision does not disadvantage people with stroke in terms of functional mobility.

### **Cost of equipment after stroke**

Similar to research on other populations who use equipment, there is little published information on the cost of equipment used by people after stroke. Please note that all figures reported here and in Appendix A have been adjusted for inflation, where possible, where they were greater than 5 years old<sup>6</sup> (NZ Foreign Exchange Services, 2016; Reserve Bank of New Zealand, 2016). One Swedish study published in 1995 indicated that equipment contributed approximately 1% of total healthcare cost following stroke, with an average of 2,307 Swedish krona (approximately NZD \$493 in 1995 or NZD \$740 in 2016, when adjusted for inflation) being spent per person on adaptive equipment in the first year of post-stroke recovery (Hass et al., 1995). Higher costs of equipment were, unsurprisingly, associated with greater disability. In a retrospective study of people discharged from a stroke unit with equipment in Germany, also in 1995, Hesse et al. (1996) reported that 690 ECU<sup>7</sup> (approximately NZD \$320, taking Euro at 1999 rates, rather than now defunct ECU, as unit of currency, or NZD \$464 in 2016) was spent per person receiving equipment after stroke. In another Swedish study of equipment costs after stroke, no difference was found between the cost of equipment issued on a specialist stroke ward compared to a general medical ward, and the overall cost of equipment was low compared to other stroke related costs (Gosman-Hedstrom, Claesson, & Blomstrand, 2002; Gosman-Hedstrom, Claesson, Blomstrand, Fagerberg, & Lundgren-Lindquist, 2002). These authors also concluded that health related quality of life was lower for people who used equipment, however this was attributed to this group also having increased dependency on others as a confounding variable, rather than being caused by the equipment directly (Gosman-Hedstrom & Blomstrand, 2003).

Further, three publications resulted from a study on the cost and funding policies regarding assistive devices for people entitled to support from Veteran's Affairs or Medicare in the USA (Hubbard Winkler et al., 2010; Hubbard Winkler, Wu, Cowper Ripley, Groer, &

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<sup>6</sup> Using free online historical exchange rate calculator and then online calculator for inflation adjustment

<sup>7</sup> Used as the unit of account of the European Community before being replaced by the euro on 1 January 1999

Hoening, 2011; Winkler et al., 2010). It was noted that equipment provision varied significantly by administrative region and by disability severity (Winkler et al., 2010) and that funding for in-home equipment only does not necessarily lead to decreased costs (Hubbard Winkler et al., 2010). The finding about regional variation points to the power of administration services in directing and ensuring adequate provision of equipment.

As with other areas of stroke rehabilitation and cost, the lack of good quality evidence about cost of equipment after stroke makes policy decisions in this area challenging and unmet need remains difficult to quantify (Skolarus et al., 2014; Wolfe et al., 2014).

### **Acceptance and meaning of equipment for people with stroke**

One of the first studies to address meaning making for people with stroke who were issued with equipment was conducted by Gitlin (1998). Six dimensions of client concerns were identified using a qualitative approach, which included the operation and utility of devices, social contexts and consequences, and attributions of cultural meanings of use. The large sample size in this study (n = 103) provided a wide range of experiences for the researchers to explore. This researcher contributed to the literature the idea that equipment could have cultural meaning attributed to it, the first time this had been overtly considered.

Understanding about the relationship between social context and consequences of equipment use have since been expanded upon, particularly in the area of wheelchair use after stroke (Barker, Reid, & Cott, 2004; Garber et al., 2002; I. Pettersson, Ahlstrom, et al., 2007; Rudman et al., 2006). Concurrently, there has been development of outcome measures for evaluating the psychosocial impacts of equipment use (Jutai et al., 2007). Earlier studies had started to focus on the experience of the equipment user more generally (Hass et al., 1996; Mann et al., 1995), often as an adjunct to other more primary study objectives such as exploring perceptions of life after stroke. Where equipment was linked explicitly to a social interaction or occupational performance goal, participants' ranked the value and use of the piece of equipment more highly (Barker et al., 2004; I. Pettersson, Ahlstrom, et al., 2007), helping users to overcome initial ambivalence.

With an increasing focus on researching and understanding the experience of the people who use equipment after stroke, there is now a more nuanced and in-depth understanding from literature of the ambivalence which people can go through about using their equipment and

that equipment can take on meanings for this group which can change as they come to terms with their stroke recovery.

## **2.6 Equipment provision services in New Zealand**

To be eligible for publicly funded equipment in New Zealand, an assessment with a therapist to assess disability-related need is required. The therapist then recommends the most appropriate and cost effective equipment (if one is required) to a government contracted service who manage the Ministry of Health budget for funding equipment (Ministry of Health, 2015a). Strategies to manage limited budgets include; bulk purchasing commonly requested equipment items, contracting with preferred providers for optimal rates, refurbishing items for re-use, and creating prioritisation systems. This is similar to processes used in many other developed countries (Andrich & Caracciolo, 2007; Wessels, De Witte, Weiss-Lamrou, Demers, & Wijlhuizen, 1998).

In New Zealand, different processes are used for people expected to require equipment for less than six months (deemed to be a short term need, and administered through local DHB services) compared to those anticipated to require equipment for longer than six months (which is administered by agencies responsible for large regions) (Ministry of Health, 2014a). Equipment can also be obtained without any health service involvement, as it can be privately purchased, inherited from family members, found somewhere, or received as a gift (Hagblom-Kronlof & Sonn, 2007), which further creates difficulties when working out who has what equipment and to what end.

Healthcare providers often make their recommendations about formal care and equipment concurrently (Agree & Freedman, 2000; Roelands et al., 2006) and policy on equipment and care in New Zealand often links these two strategies. Consequentially it can be difficult to separate out the costs of equipment from other services. For instance, while Disability Support Services in New Zealand can provide information that the combined costs of environmental support services (housing and equipment) was NZD \$122 million for 2011 – 2012 (Ministry of Health, 2012a), it does not appear possible for this service to report separate costs for equipment for stroke specific equipment.

There are two contracted services which manage Ministry of Health funding for equipment, housing and vehicle modifications in New Zealand. Enable New Zealand serves

approximately 62% of the population and Accessable are the company which serves Auckland and Northland. They are both governed by the same Ministry of Health protocols for funding. Enable New Zealand report that for the financial year June 2013 – June 2014 the total spending on equipment (excluding housing and vehicle modifications) was approximately NZD \$18 million (Enable New Zealand, 2014). Assuming that Accessable had a similar rate of spending, this indicates that total spending on adaptive equipment in New Zealand in June 2013 – June 2014 was approximately NZD \$29 million and funding in this area has not significantly increased in recent years.

The Equipment and Modification services handbook, which provides guidelines for the eligibility and assessment processes for people who are eligible for Ministry of Health support for equipment, states that:

Before equipment can be recommended as the most appropriate solution to meet the person's needs, the Equipment and Modification Service Assessor needs to identify: the availability and viability of a range of options including support packages (paid support services and unpaid natural supports from others) to meet the person's disability related needs; the person's essential need for, and their ability to benefit from, the proposed equipment; the implication of the proposed equipment not being provided and how this might affect the person's need for support and/or impact on carer stress; the most appropriate and cost-effective solution to meet the person's disability related needs when all other factors have been taken into account. Cost effective equipment is the most economic and suitable item to meet the person's essential needs related to their disability. (Ministry of Health, 2014a, p. 11)

The Disability Support Services Strategic Plan 2010–2014 outlines the overall purchasing strategy and actions for providing disability support services to eligible New Zealanders (Ministry of Health, 2012a). Equipment can be considered to support an individual or their primary carer, to manage one or more of the following everyday tasks: eating and drinking, personal hygiene, getting dressed, transferring from their bed or chair, getting in and out of and around their home, preparation of food and drinks, if they live alone or are by themselves for much of the day. Mobility equipment such as a walking frame or wheelchair may be provided when a person is unable to manage getting around in their home. Funding is not available for mobility equipment if someone can mobilise without an aid in their home but has difficulty getting out in their community, although equipment can be provided to enable access to a vehicle parked near a private home (Ministry of Health, 2014a).

Informally, clinicians interpret this to mean that funding is available to support a person get to their letterbox. The only exceptions to this are where people are engaging in full time work (more than 30 hours per week), full time study or volunteer work (more than 20 hours per week where they have been in position for at least 8 weeks and likely to remain so for 12 months). These situations would rarely be applicable for someone who is retired or has had a moderate to severe stroke.

Simple devices like toilet seats are bought in bulk and are readily available while more complex and expensive equipment require greater depth of assessment and paperwork. Some inexpensive devices like urinal bottles or walking sticks come under a threshold for funding which means that even if they are recommended by a therapist, they cannot be funded and the person with stroke will need to buy these items privately (Ministry of Health, 2014a). This can create tensions as people with disabilities question why similarly important items, from their perspective, are funded differently. Indeed, dissatisfaction with equipment services or delays in equipment assessment is common in relation to such funding issues in the UK and the USA (Cowan & Turner-Smith, 1999; Reisinger & Ripat, 2014).

Ripat and Booth (2005) concluded, following consultation with equipment users, funders and equipment prescribers, that an ideal equipment provision system should include users and their support people, standardised measures and non-standardised assessments and processes for matching a user's profile with the activities that they need to or wish to pursue, and their financial situation. However, Ripat and Booth (2005) did not outline divergences between the competing agendas of these three groups, where tensions may occur, which is an area of interest for this thesis.

Characteristics of therapists appear to have a bearing on the ways in which they provide their service. Krantz et al. (2011) conducted a survey using the Matching Person and Technology model as a theoretical framework with 278 prescribers of wheelchairs in Sweden (response rate = 76.4%), where therapists who had more clinical experience were more likely to consider how their client's lifestyle would be influenced by new equipment as well as have a greater appreciation for cost impact.

There are two powerful and often competing, priorities when it comes to the design and delivery of equipment services: the rationing of limited public health funding and adhering to

the concept of client-centred practice. Developing client-centred practice for equipment provision has been heavily endorsed by research on use of equipment (Hedberg-Kristensson & Iwarsson, 2013; Scherer, 2014) and client satisfaction with disability services (Daly, Kellehear, & Gliksman, 1997; Mirza & Hammel, 2009; Reisinger & Ripat, 2014) as well as by disability rights advocates (Disabled Persons Assembly New Zealand, 2012; Franits, 2005). Therapists are obligated by their code of ethics to respect autonomy and practice in a client-centred manner (Occupational Therapy Board of New Zealand, 2004; Physiotherapy Board of New Zealand, 2011). However, distinguishing between client identified needs, wants and rights remains a challenge when such therapists are also expected to outline need and risk in relation to eligibility criteria (McCreadie & Tinker, 2005).

Eligibility criteria work effectively for people who present with straightforward conditions and concerns, however:

It is increasingly recognised that standard, routinely provided services cannot cater for fluctuating or unpredictable needs and can be as institutionalising as the institutional care that community care policies seek to avoid. (Thornton, 1993, p. 339)

Recently, Scherer (2014), one of the foremost researchers in this area, reflected that, despite an increasing bank of available equipment, there appeared to be a trend in policy and funding for equipment where a one-size fits all approach was increasing in prevalence, due to economic constraints. She claimed that satisfaction with service and equipment was less important to funders than client improvement in functional performance. Her other concern has been that, in the face of increasing regulation and documentation, the potential to develop person-centred services remains underdeveloped or is even becoming less of a priority. She also highlighted that therapists provide a service, rather than just a product, and has re-emphasised how vital it is to provide users with options. When bureaucracy (for example, paperwork and administration communication) associated with equipment provision takes up a lot of time, this represents a threat to the whole healthcare system meeting its objectives, given that therapists in stroke rehabilitation are recommended to spend up to 80% of their time working directly with clients (Dawson et al., 2013).

## 2.7 Theoretical models of equipment assessment

There are several models which offer guidance on equipment provision and this section covers the better known ones including: the Matching Person and Technology model (Scherer & Craddock, 2002), the Human Activity Assistive Technology model (Cook & Polgar, 2015b), and the more recently developed Assistive Technology Assessment model (Federici, Scherer, & Borsci, 2014). Terminology varies, but essentially, most theoretical models underpinning equipment provision are transactional and focus on the complexity of the equipment, the skills and abilities of the user, the activities for which the equipment will be used and the context in which the user expects to live (Cook & Polgar, 2015b; Lenker & Paquet, 2003). There have also been recommendations about evaluation and training, providing the equipment, education about the equipment and an element of co-ordination (Ripat & Booth, 2005) and that assistive technology provision models are complex due to them needing to be able to evaluate outcomes as well as systems' factors (Hersh & Johnson, 2008).

Initially based on a grounded theory study with 10 people with physical disabilities, Scherer and Craddock (2002) developed the Matching Person and Technology model for assessment of equipment provision with a suite of related instruments. This model proposes assessing three primary areas; the environment or 'milieu' affecting how equipment is used, the preferences of the equipment user and the functions required for the equipment. The original model was updated in 2007 (Scherer et al., 2007) and its recent iterations have strengthened its association with the classification terminology of the ICF (Scherer et al., 2010). Although helpfully focussing on the importance of personal factors and assessing disposition of potential users of equipment, the Matching Person and Technology model remains descriptive rather than predictive about who is most likely to use equipment and the matching process suggests that there is a potential ideal solution eventually, when this may not be the case (Lenker & Paquet, 2003).

The Human Activity Assistive Technology model was the first to conceptualise assistive technology provision specifically and it has been recently revised (Cook & Polgar, 2015b). This model's core concepts are very similar to those in the Matching Person and Technology model in that it is focussed on the person, the activity to be completed, aspects of the assistive



technology being provided and the context in which the interaction between these three factors takes place. This model is similar to the Matching Person and Technology model in that it is primarily descriptive (Lenker, 2003). This model's relatively straightforward and consistent core concepts and inter-relationships is one of the reasons why it has informed research design in this area in the last 20 years, however clearer definitions of assistive technology system outcomes is required to strengthen the validity of this model (Giesbrecht, 2013).

The most recent comprehensive review of the models developed for assistive technology provision was completed by Bernd et al. (2009). These authors searched one database (Medline) between 2003 and 2007 and while this is a relatively limited search, models of assistive technology provision are a recent development. Their search reported on the findings of 16 articles, nine of which were literature reviews and none of which employed an experimental design. The most cited model identified was the Matching Person and Technology model (Scherer, 2002). These authors concluded that this field is under-researched and what does exist is weak in terms of providing guidance for best clinical practice (Bernd et al., 2009).

Most recently, a new model has been proposed, entitled the Assistive Technology Assessment Process (Federici et al., 2014), combining principles from both the Matching Person and Technology and the ICF. This model advocates for the consistent presence of a psychologist as part of the equipment selection process to ensure personal factors are considered. In fact, the authors of this model advocate for employment of a 'psycho-technologist' to lead a team of other professionals when matching equipment to peoples' needs, wants and rights. Given that the current resourcing situation for equipment provision in New Zealand is that demand exceeds supply (Ministry of Health, 2015a), this is unlikely to be a model that would be considered in its current format in this country. In addition, this model assumes users are active at identifying their needs and seeking equipment options. This is often not the case in the earlier phases of recovery after stroke, where people encounter equipment as a consequence of being in hospital and around therapists and others using equipment (S. Sim et al., 2014).

Despite their iterative development and use in research, theoretical models specific to assistive technology have not gained traction in clinical practice (Friederich et al., 2010) and

these models continue to be criticised as too reliant on the medical model as their underlying philosophy (Hersh & Johnson, 2008). As stated by Ripat and Booth (2005), ‘No preferred method has emerged as the method of choice in the field of AT service delivery; each method needs to consider the unique social, financial and political environments in which it exists’ (p. 1462). Arguably, the financial and political environment has a greater impact on equipment provision than is currently recognised in the literature (Hammell, 2006; Layton, 2015). While the focus on the needs, context and abilities of the equipment user is vital, the impact of the healthcare system, the relationship between the user of the equipment and their equipment provider and the influence the personal and professional values of the therapists are not the focus and therefore not described within these models. The importance of these elements to the decision making process in equipment provision is becoming increasingly acknowledged (Maywald & Stanley, 2014).

## **2.8 Equipment provision and ethical reasoning**

This section serves as an overview of key ethical ideas as they are applied to research in healthcare and equipment provision. Ethics is defined as the study of morality in relation to human conduct and values (Jindal-Snape & Hannah, 2014). For this thesis, the moral rules which were under exploration related to those used during equipment provision after stroke. Applying rational ethical principles to the study of health service provision is complex (Canning, 2005; Seedhouse, 1995) though for almost all decision making undertaken by therapists there is some degree of moral reasoning involved (Haynes, Devereaux, & Guyatt, 2002; Seedhouse, 2002). As outlined by I. Edwards, Braunack-Mayer, and Jones (2005) in relation to ethical reasoning in clinical decision making for physiotherapists:

When faced with ethical problems or scenarios in clinical practice, the alternatives to ethical reasoning are, in one direction, that we merely follow rules or codes of behaviour without being able or willing to apply them to clients’ specific or extraordinary circumstances, while in the other, we primarily go by our own personal beliefs or values which, if un-reflected upon or unchallenged, could at times also be our prejudices. (p. 229)

Managing resources for equipment provision has been cited as an area of ethical concern for occupational therapists in particular (Barnitt, 1998). Discussion of ethics in the allied health professions is subtly different to those discussed in traditional medical practice, which

often is dominated by issues around life or death decision making (Barnitt, 1998; Hansson, 2007). One of the most cited frameworks for ethical reasoning in healthcare was established by Beauchamp and Childress (2013) and is known as principlism. This ethical framework is comprised of a series of moral norms, the most general and comprehensive of which Beauchamp and Childress call 'moral principles'. Beauchamp and Childress (2013) proposed that there are four key principles in biomedical ethics: including 1) non-maleficence (to avoid causing harm to others), 2) beneficence (to benefit others, sometimes by weighing up potential for benefit versus harm of an action), 3) respect for autonomy (to support the freedom of choice), and 4) justice (to consider fairness towards individuals and society as a whole). However, Beauchamp and Childress (2013) have also identified four core behavioural norms: veracity, privacy, confidentiality, and, importantly for this thesis, fidelity (to be honest and trustworthy). Fidelity is of particular relevance in relation to how therapists strive to be trustworthy to both their clients and to the health service that employs them.

It has been argued by Cook and Polgar (2015b) that fidelity, where loyalty and solidarity with a client are prioritised in the relationship, is one of the ethical areas which most often causes of conflict for healthcare practitioners, when what a client wants is at odds with the wishes of family members or what the healthcare system can provide. Alternative approaches include feminist relational ethics (MacDonald, 2007) and other care based ethics, which emphasise the uniqueness of a situation, one's sense of personal responsibility, and the application of intuition to guide moral reasoning. This can be related to a justice based code of ethics where equity and societal fairness pre-dominate thinking (Jindal-Snape & Hannah, 2014). As described by Braveman, Starfield, & Geiger (2001), equitable process relates to a system wide intention to actively reduce health disparities between social groups with differing levels of advantage. A care-based, relational approach to ethics results in a fluid interpretation of autonomy in particular. Offering choice about the extent to which someone is autonomous, for example, may result in the person preferring to have assistance rather than doing an activity by themselves. This sort of outcome can be challenging for a health service which often supports people to achieve their own maximum levels of autonomy with minimum external supports and cost (Harris, 2007).

Therapists are generally risk averse when working with clients in a hospital setting, encouraging their clients to be cautious with exploring their abilities while in hospital. In part

this might be due to a sense of moral responsibility to avoid people coming to harm while on hospital property (Hansson, 2007). This professional attitude can shift when a person goes home, when expectations can increase for the client to take more responsibility judging their own level of risk with any one particular activity (Siemonsma et al., 2014). This extends to decisions about when and how to use prescribed equipment. Risk assessment tools abound (Perell et al., 2001), and while awareness of risk of injury is vital, it can also be a reason why therapists and their clients come into conflict. Hunt and Ells (2011) offer a useful construct about relational autonomy, where the decisional autonomy of a client is shaped by relationships and situations. Using this approach, therapists can discuss relative benefits and disadvantages of choices such as where and how to use equipment, without compromising either their professional and organisational imperative to promote safety, or the client's wishes to explore their body and abilities after stroke. This negotiated autonomy has wide reaching ethical implications, where therapists are responsible to the health system they are employed by, as well as being professionally accountable to society for their use of public resources and, individually, to the client they are directly working with.

There is scant research directly linking concepts about human rights to rehabilitation, although Siegert, Ward, and Playford (2010) presented an argument that human rights principles could and should inform an ethical framework in rehabilitation. Human rights can be defined as: 'moral norms than can be translated into specific rules such as laws that protect core features of human functioning' (Siegert et al., 2010, p. 966). In terms of equipment provision, human rights issues apply when discussions occur regarding the activities or areas of life which are enabled as a result of equipment provision or 'disabled' by lack of provision. These include tangible outcomes like living in one's own home and being able to shower and eat. Other human rights enshrined by the UNCRPD relate to supporting social participation and inclusion for people with disabilities (United Nations, 2007).

Allocation of resources has been cited as a common source of moral distress among nurses and for those working in more economically deprived areas (Berney et al., 2005). However, less is understood about moral distress among therapists (Mukherjee, Brashler, Savage, & Kirschner, 2009). Moral distress has been defined as:

The stress experienced when there is a conflict between individuals' values and the situation in which they find themselves ... rehabilitation professionals

continuously grapple with the concepts of hope, prognostic uncertainty, personal values, disability stigma and resilience, all of which can contribute to moral distress. (Mukherjee et al., 2009, p. 457)

Clinical decision making, which leads to recommendations for equipment, often consists of a collection of ideas about a client's situation, their abilities and goals, containing moral judgments and value laden thinking (Greenhalgh et al., 2008; S. White & Stancombe, 2003). Arguably, as weighing up individual need in relation to what is available through publicly financed health services is part of the art of clinical reasoning (Unsworth, 2004), moral distress may be potentially unavoidable in the working life of a therapist. Another issue to note regarding equipment provision and stroke is that some therapists believe that equipment limits the restoration of normal movement (Tyson & Rogerson, 2009) and these therapists can become ideologically torn between safe and speedy mobilisation of a client and their potential for physiological recovery.

### **Assuming economic responsibility**

Economic responsibility is often present as a moral responsibility in the public health sector. In New Zealand, the Ministry of Health's Disability Support Services Strategic Plan 2010–2014 (Ministry of Health, 2012a) outlined the overall purchasing strategy and actions for providing disability support services to eligible people. The most recent update on this policy was in 2015, which reiterated previous goals and added that in relation to environmental support services (a term encompassing housing and equipment provision), a priority is to 'ensure equipment and modification service providers follow moderation processes to ensure assessors are prescribing best value for money solutions for disabled people' (Ministry of Health, 2015b, p. 18). This exemplifies an increasing trend in healthcare planning internationally, where all services and products are required to have greater clarity about cost effectiveness (Harris & Sprigle, 2003).

Economic evaluation in health care resource allocation is frequently cited as important but rarely reported (Williams & Bryan, 2007). Chiatti and Iwarsson (2014) have extended the debate in this area to recommend that economic responsibility is a growing part of practice. These authors posit that three questions need to be considered when therapists make publicly funded recommendations; '1) Will X be more effective than Y?, 2) Will X be more costly than

Y? and, 3) Will X be more cost-effective than Y?' (p. 323). To address these questions adequately, the onus is placed on therapists to learn about and maintain their knowledge on the cost of items and how to integrate cost effectiveness in their report writing and discussions with users of equipment and funders.

Gelderblom, de Witte, and Andrich (2002) distinguish between two key concepts when discussing cost analysis and equipment: The first is 'cost', which is the use of resources, while the second is 'expenditure', pertaining to the flow of money. Andrich et al. (1998), Italian researchers, developed a tool called the SIVA<sup>8</sup> Cost Analysis Instrument which can 'instil an attitude of informed, responsible and efficient use of resources' (p. 99), though this is in its early stages of testing. In an evaluation of this tool across 31 equipment provision programmes in Italy, it was reported to lead to less carer assistance than usual practice and therefore greater cost saving over a five year period (Andrich & Caracciolo, 2007). Nonetheless, given that other researchers have been critical of the extent to which equipment can substitute formal care (Agree et al., 2005), this finding needs to be viewed cautiously.

### **Distributive justice**

For the most part, equipment provision is not an immediate life-saving resource and is therefore debated about in a different way to life saving resource allocation (Stein, 2002). When considering just resource distribution, two key theories about how value is attributed are relevant: egalitarianism and utilitarianism. The notion of egalitarianism favours equality and proponents contend that we are all of equal worth, whereas utilitarianism prioritises relative benefit rather than comparing needs or differences in disability (Stein, 2002). Utilitarianism has been interpreted as discriminatory against people with disability, as people who take this approach can view those with lower utility-generating ability as less worthy of support (Sen, 1992). So, taking a utilitarian approach to planning health service funding allocation could, for example, result in more money being allocated to maximising outcomes for people who are less disabled and minimising extra spending for people who are more disabled and therefore less likely to substantively benefit from dollars spent. However, Levack (2009) has argued that utilitarianism does not necessarily result in less resource allocation for more dependent people provided that the full costs and benefits of any health

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<sup>8</sup> Italian term not further defined within the article

funding allocation is included in any such economic evaluation, and provided that 'benefit' is based on experiences reported by people with disabilities rather than calculated based on the assumptions of non-disabled ethicists or economists.

Sen (1992) is a leading proponent of the idea that, for disability services, rather than advocating for equal resource allocation across individuals, increasing capability is where services should be focussed. Capabilities can include the ability to move oneself, take part in one's preferred routine and in one's community. The ability to participate in one's community is acknowledged as vital (United Nations, 2007) but the means to support this is limited due to lack of discretionary money within budgets for equipment (Bowe, 1995). Other studies which included users and prescribers reported that safety was perceived as a priority for equipment funding over participation-related goals (Ripat & Booth, 2005). Other theorists favour the idea that resources should be distributed to enable all people to achieve an agreed upon normal (i.e. minimum standard) range of function (Daniels, 1990). This idea appears to be the basis for the model of resource allocation preferred by the Ministry of Health in New Zealand, who place a funding limitation on equipment based on the location of activities (for example, limiting purchase of equipment which is only required for use outside of a person's home). Daniels (1998) advocates that healthcare services bear a special, moral responsibility when it comes to distributing resources, in order to preserve opportunities to take part in society. To defend this approach, Daniels (1998) cites Rawls' theory of justice (Rawls, 1971). Both a capabilities approach and theories of justice advocate for the protection of opportunity for people with disabilities.

Whilst responding to public demand for person-centred care, health professionals can also experience pressure from financial restrictions imposed on the healthcare systems. For example, a study of general practice doctors' (GPs) in the UK accounts of clinical decision making found that while GPs frequently identified strongly as client advocates, they experienced role tensions in relation to other professional responsibilities such as budget management (I. Jones et al., 2004). In a separate study, Berney et al. (2005) illustrated how GPs' personal values and their relationships with different clients influenced decisions they made regarding the urgency of referrals (for example, deciding that someone who was working should take higher priority on a waiting list than someone who was not). The GPs in this study often resented being the people who had to explain rationing decisions, despite them

agreeing that their involvement in such resource management was necessary. These concepts are in line with other research which highlights that the way strategies and criteria for resource allocation are applied is influenced by the interaction between a health service provider and a client as well as the health service providers' own set of personal values (Johansson, Borell, & Lilja, 2009; McKinlay, Potter, & Feldman, 1996) and that to state otherwise risks leaving such factors influential but unacknowledged (Bornstein & Emler, 2008; Valerie A. Wright-St Clair & Newcombe, 2014).

Johansson et al. (2009) studied the moral reasoning of occupational therapists when applying for housing modifications on behalf of their clients, and concluded that therapists typically act as translators of a person's difficulties into a language and format understood by the healthcare system, enabling them to qualify for a service or product. In order to do this effectively, the therapist needs to understand their clients' values and priorities as well as the terminology which the service funder favours. Indeed, the New Zealand occupational therapy Code of Ethics confirmed that available resources are a consideration when it comes to outcomes for their clients and that advising the client and their family about resource shortfalls is part of ethical conduct:

Occupational therapists shall prioritise the allocation of available resources to achieve the best possible outcome for consumers. Occupational therapists shall: 1) use a coherent, robust, and transparent rationale to prioritise the allocation of service and resources and 2) advise key personnel (e.g., managers, other service providers, consumers, and their family/whānau) when resources are insufficient to allow for safe and adequate service provision. (Occupational Therapy Board of New Zealand, 2004, p. 4)

While this section has focussed on the ethical difficulties inherent in therapist assessment of the needs of others, totally user-focussed resource allocation is also not without its complications. Menzel, Dolan, Richardson, and Olsen (2002) interrogated a common philosophical assumption: that disabled people rate their health-related quality of life more highly than people without disabilities imagining themselves with the same disability. Menzel et al. (2002) concluded that the health-related quality of life scores elicited from people who are disabled are influenced by an altered understanding of health to the norm, adjustment to circumstance, lowered expectations and heightened stoicism and they concluded that such practice is morally questionable. This view is compatible with arguments proposed by Sen



(1992), where the ability of people with disabilities to have unfulfilled wishes can be hindered by their adaptation to life with disability, therefore they can under-report about their needs. In addition, self-determination is debatable when peoples are frail, cognitively impaired or have experienced long term marginalisation for any reason (Zwijssen, Niemeijer, & Hertogh, 2011). Menzel et al. (2002) advocated for a non-client representative (often their therapist) perspective as well in these situations, to ensure that ‘lowered expectations and entrenched deprivation do not disadvantage people with disabilities when it comes to health service provision’ (p. 2157).

A question relating to the principle of justice is: What is adequate? This relates both to therapists’ view of the extent they should be advocating for clients and what is fair to expect from the provision system for their clients (Cook & Polgar, 2015a; Peterson & Murray, 2006). Thus, a best practice approach to equipment service design would include consideration of client, funding agency, and societal resources (Peterson & Murray, 2006). While it may not be feasible to imagine a truly socialist health care service, many bio-ethicists would endorse that by having therapists consider equity issues in their positions of power, they can transcend systemic influences to treat everyone as intrinsically valuable, so that a ‘socialist attitude is a constant possibility’ (Seedhouse, 1997, p. 184). In contrast, social model of disability theorists maintain that current distribution of resources themes are intrinsically linked to a capitalist ideology which is unlikely to change in the near future (Terzi, 2004). An Australian researcher, Natasha Layton, has advocated that occupational therapists need to be more aware of how policy and healthcare service priorities are set and how they influence clinical practice, describing the tensions that exist between the priorities of one’s employer, often focussed on throughput of clients within a service and cost efficiency and the wants and rights of one’s client, where engagement and respecting their individuality is paramount (Layton, 2014).

### **Structural competency and politicisation of therapists**

There is a need for an evolving ethical framework for therapists, as it appears that there is a lack of relevance between current models of ethical reasoning and the broader operational frameworks within which therapists work. Taff, Bakhshi, and Babulal (2014) argued that the need for such a framework is to ‘1) achieve balance between science-driven and holistic elements, 2) operate within larger contexts on problems brought on by socio-political and

natural determinants of health, and 3) maintain an ethical identity across all arenas of practice' (p. 320). This model resonates with the interests in this thesis. The authors trace the historical roots of occupational therapy over the last 100 years, where, for the first half of the 21<sup>st</sup> century, a person with disability was the agent of their own recovery. Following World War II, a structuralist approach emerged, where medical advances re-conceptualised someone with a disability as a sum of his or her body functions and impairments. Despite discussion within the profession about person-centred practice (Yerxa, 1967), Taff et al. (2014) argued that occupational therapy has been overly influenced by structuralist thinking which encourages quantitative measurement. They propose that greater links between occupational therapy ethical frameworks and human rights models are required - an argument endorsed by Hammell (2008) who stated that the future of occupational therapy will be secure when 'occupational rights [are] recognised as a political issue and the profession's confinement within health-care services end[s]' (p. 61).

Increasingly, allied health researchers are critical about the levels of structural competency exhibited by therapists (Layton, 2015). Metzl and Hansen (2014) define structural competency as the ability to work out the influence of social and institutional factors on inequalities and a commitment to highlighting and changing these underlying reasons for inequality. Hammell (2015) contends that occupational therapists in particular have focussed on developing research to measure individuals' abilities rather than challenge the policies and attitudes which lead to structural inequality, citing inadequate mobility equipment and inequitable access as an example. Concern about the importance, but lack of information about, therapist's role in the political structure of their working environment is one which has led to this thesis.

There are ethical codes of conduct for most registered therapists (Peterson & Murray, 2006) as well as a specific one for equipment provision by Rehabilitation Engineering and Assistive Technology Society of North America (RESNA, 2014). This latter code endorses health professionals who prescribe equipment adhering to ethical principles, namely that they advocate for people with disabilities in order to enable participation, that they take a role in co-ordination of the agencies required for this to happen, and that they provide information in a way that people can make informed choices about how they use equipment.

### **Gatekeepers and advocates**

There appears to be a balancing act in the decision making process therapists go through when considering whether they are advocating for clients or gatekeeping resources for the health service (Cook & Polgar, 2015a; Hammel, 2003; Peterson & Murray, 2006). Where therapists prioritise intervention that is client focussed, individualised and tailored, decision making about recommendations for resource allocation for their clients becomes increasingly complex. Indeed for therapists, work-related burnout is often linked to lack of control over the care they are providing (Bailey, 1990; Foye, Kirschner, Wagner, Stocking, & Siegler, 2002). Given tightening eligibility criteria to access equipment, it is probable that this particular stressor is going to increase.

Establishing best practice for equipment provision is an ongoing challenge. The four categories identified by Angelo et al. (1997), in order of importance, were 1) to be client-centred, 2) to conduct a thorough assessment 3) to have a team based approach and 4) to consider and access funding. This study concluded that funding should be considered after the other factors, but was, nonetheless, an important consideration. There is very little known about how therapists experience their role of being and becoming resource co-ordinators and whether they perceive themselves skilled and interested in this role. Even though priorities for a satisfying working life change over a therapist's career, the most satisfying aspect of working is client care and the most stressful part reported is often paperwork (Bailey, 1990; Freda, 1992). In addition, keeping up to date with technical changes with equipment and funding structure alterations can be particularly challenging when demand for direct clinical output threatens training opportunities (M. Jones, Morris, & Mueller, 2010).

Ferguson-Pell et al. (2005), in their development of wheelchair seating standards, suggested that the two core responsibilities of therapists in equipment provision were to understand all clinical and personal facets of a client and to be able to describe all the possible equipment solutions which could work for them. These researchers take the position that there probably always will be a difference between a clinically-optimal equipment solution and one which is achievable within funding availability, regardless of the model of service delivery used (Ferguson-Pell et al., 2005).

McCreadie and Tinker (2005) identified three tensions that arise when older people

come to terms with using equipment: 1) a dissonance between what a therapist recommended as a need and what the client perceived as a need, 2) a high value expressed by the older person to remaining in their own home, and 3) a presumption that equipment can substitute for physical assistance. Exploring therapists' perception of themselves as both advocates and gatekeepers is an important debate, given the tension already outlined between these principles (Barbara & Curtin, 2008; Barbara & Whiteford, 2005). In Australia, occupational therapists have recently been challenged to re-consider their role in government funded equipment schemes (Barbara & Whiteford, 2005; Layton, 2015). Similarly, Hammell (2013) has claimed that occupational therapists, have become: 'slavish adherents to procedural "red tape" ... accountable to employers rather than to clients' (p.176). This view of occupational therapy is incompatible with how the profession describes its priorities as being client-centred (Kjellberg, Kahlin, Haglund, & Taylor, 2011) and this discordance therefore needs to be critically examined.

It is not uncommon for therapists and users' priorities to differ in relation to equipment use (McDonald, Surtees, & Wirz, 2007), where users and therapists often imagine equipment being used in different ways to each other, with these different visions then impacting on how each group talks about equipment (Cushman & Scherer, 1996). Rehabilitation staff can be focussed on concrete functional outcomes whereas people with stroke are more interested in abstract goals related to re-discovering or rebuilding their identity (Bendz, 2003). When therapists value therapeutic relationship building, they are also more likely to have positive regard for their clients and reported that they would follow up concerns about their clients (Taylor, Lee, Kielhofner, & Ketkar, 2009).

A recent observational study of equipment use demonstrated that the procedures used by therapists and the degree of follow-up provided had a significant effect on equipment abandonment rates ( $p = .0005$  and  $p = .002$  respectively), emphasising the importance of both these elements (Federici & Borsci, 2016). There is increasing attention paid to the effect service delivery and therapist interactions have on abandonment rates and decisions about who is appropriate to receive training on equipment use (Mortenson, Clarke, & Best, 2012). Training in the use of equipment is often considered best practice although some researchers have in the past argued that this recommendation is not well evidenced (Neville-Jan, Piersol, Kielhofner, & Davis, 1992). Training for equipment usually takes place in a hospital or

rehabilitation unit (Hass et al., 1996) rather than in a persons' home and that training process is often poorly described (Maywald & Stanley, 2014). Given that ability to recall training on equipment is a key factor predicting non-use (Wielandt et al., 2006) this warrants further attention.

Therapists can see their role as bridging the gap between hospital and home (Wottrich, Von Koch, & Tham, 2007) and while therapists often recount holistic aims like encouraging client led problem solving, an audit by Tyson and Turner (2000) of people with stroke revealed that clients felt therapists often had low expectations of them. These authors concluded that while the home environment and care needs were regularly assessed, there was less focus on domestic skill development post stroke and that social activities were rarely considered (Tyson & Turner, 2000). Possibly the lack of funding which is available for equipment for activities outside the home stymies these conversations between therapists and clients. Differences in the approach taken by therapists to equipment provision before, during and after discharge from hospital to home warrants further investigation.

### **Shared decision making**

The first point on the Code of Ethics for occupational therapists in New Zealand recommends that occupational therapists should be respectful of the autonomy of their clients and the role their families play and that they should actively 'share power and decision making wherever practically possible' (Occupational Therapy Board of New Zealand, 2004, p. 1). Therapists enable decision making with (or for) their clients when they recommend or give options to them: each approach elicits different responses (Toerien, Shaw, & Reuber, 2013). Shared decision making, where clients and therapists collaborate on how interventions are provided, is commonly cited as a best practice standard in healthcare internationally (Barratt, 2008; Stacey et al., 2014). It is defined by Barry and Edgman-Levitan (2012) as a process inherent to applying the principle of client-centred care, where:

An optimal decision may be reached for a client at a fateful health crossroads ... both parties share information: the clinician offers options and describes their risks and benefits, and the client expresses his or her preferences and values. Each participant is thus armed with a better understanding of the relevant factors and shares responsibility in the decision about how to proceed. (p. 780)

Despite this endorsement of shared decision making, there are many reasons why it has not been adopted by therapists, including that shared decision making presumes a client has some interest and ability to take part in decision making and time and energy available to see this through (Roelands et al., 2004). Charles, Gafni, and Whelan (1997) were among the first to describe distinct models of how interactions between health professionals and clients occur, ranging from paternalistic (where the therapist is driven primarily by the principle of beneficence and makes decisions on behalf of clients) to consumerist informative (where clients make decisions without involvement from therapists once they have been given information), to shared decision making (where the process is seen as interactive). According to a systematic review about use of shared decision making principles, Gravel, Légaré, and Graham (2006) reported that the most cited barriers were time constraints, lack of applicability due to client characteristics and a perception that clients did not want this approach. These authors also noted that this approach was motivated by health professional beliefs that it would result in better outcomes for their client and the healthcare system.

While most research on shared decision making has been carried out with single disciplines, Hofstede et al. (2013) completed qualitative analysis with multi-disciplinary team members and service users about shared decision making for people with sciatica. They reported that healthcare professionals and clients reported barriers related to the organisational context including lack of trust and communication between healthcare professionals and lack of visibility of key personnel. These findings corroborate the idea discussed earlier in this chapter that therapists are held individually accountable for decisions arising from the system of care in which they work (Berney et al., 2005; Reisinger & Ripat, 2014). In a recent ethnographic study on decision making by physiotherapists on an acute stroke ward in the UK (McGlinchey & Davenport, 2015), prioritisation of resources was a consideration when making recommendations for future treatment for clients and the extent to which clients participated in decision making about treatment varied. This speaks to decision making relating to clinical and non-clinical features, which is in line with other studies considering allocation of clinical resources like hospital stays and admission to rehabilitation services (Foster & Tilse, 2003).

Most therapists agree that providing choice to the people they work with is important. What is less clear is how, when and where therapists offer this choice, or how they enable

people with disabilities to have some or all of the control during the assessment and provision of services (F. Jones, Mandy, & Partridge, 2000; I. Jones et al., 2004). Listing options is one way shared decision making can be applied, as opposed to recommending a course of action, but this technique also relies on therapists relinquishing some authority for recommendations (Toerien et al., 2013).

Shared decision making is not without its conflicts with other theories in client-centred care (Makoul & Clayman, 2006) and it can be seen as incompatible with some interpretations of evidence-based practice (Barratt, 2008). This approach is often most associated with younger, educated and more cognitively intact client groups (De Haes, 2006; Moreau et al., 2012). Shared decision making has also been found to lack an explicitly inter-professional approach and while current models appear theoretically sound, the process is often not specific (Stacey, Légaré, Pouliot, Kryworuchko, & Dunn, 2010) and cultural influences have been under-researched (Charles, Gafni, Whelan, & O'Brien, 2006).

Moreau et al. (2012) conducted focus groups with a broad range of people including university students, people living in a retirement village and local community members to investigate if people's attitudes to shared decision making varied by age, health-promotion activism or residential status. Their findings confirmed that older populations often preferred a more paternalistic approach and one of the main tenets of shared decision making, in their opinion, was 'finding common ground' (p. 210) where the expertise of both the client and the physician could be acknowledged. Health professional skill and interest was required in order to accurately judge a client's preference and ability for shared decision making (Kon, 2010), and challenges arise when people would prefer a health professional made a choice for them (Johansson, 2013). Bright, Kayes, Worrall, and McPherson (2014) conducted a concept analysis with 31 articles on the concept of engagement in rehabilitation and reported that there are two ways engagement can be conceptualised: as a process and as a state. They concluded that their findings contradicted common rhetoric from therapists, where engagement could be seen as primarily related to the client and their motivation. These authors recommend that there is a need to clarify the role of therapists in stimulating engagement with their clients.

In summary, engaging people in shared decision making about equipment selection and use is influenced by the ability and interest of the clients as well as therapists' personal and

professional characteristics, values, and their knowledge and ability to access resources to enable client choice.

## **2.9 Summary**

The importance of equipment for enabling a good life after stroke has been established in this literature review. National and international policy guiding healthcare systems which provide equipment have been outlined and contentious issues related to equity of stroke rehabilitation and equipment provision services have been detailed. From the literature reviewed, it appears that the most likely benefits arising from equipment use are: 1) increased sense of safety (Agree & Freedman, 2011; Gitlin et al., 2006; McMillen & Soderberg, 2002; Resnik et al., 2009; Robison et al., 2009; Sainty et al., 2009; Samuelsson & Wressle, 2014), 2) greater sense of control and confidence (Agree & Freedman, 2011; Bendz, 2003; Pallesen et al., 2013; Resnik et al., 2009; Samuelsson & Wressle, 2014; R. Smith, 1995; Tyson & Rogerson, 2009), 3) increased capacity to take part in enjoyable and meaningful activities (Agree & Freedman, 2011; Copolillo, Collins, Randall, & Cash, 2001; Sainty et al., 2009; Samuelsson & Wressle, 2014; Scherer & Glueckauf, 2005; van Wijk et al., 2006), and 4) greater support for people who are formal or informal carers of people with stroke (Agree et al., 2005; Mountain, 2004; Roelands et al., 2004).

This chapter provides a basis for establishing standards for best practice regarding equipment provision. This includes issues related to: 1) communication required during equipment provision and training needs to be both written and verbal (Garber et al., 2002; Hoffmann & McKenna, 2004; Schemm & Gitlin, 1998), 2) thorough assessment and training in equipment use promotes uptake and satisfaction with equipment provision services (Hocking, 2000; Hoffmann & McKenna, 2004; Logan et al., 2012; Mountain, 2004; Neville-Jan et al., 1992), 3) the need for efficient delivery and quality of equipment (Cowan & Turner-Smith, 1999; Federici & Borsci, 2016; Greer, Brasure, & Wilt, 2012; Mountain, 2004), 4) that equipment options as offered as part of an assessment for equipment (Hedberg-Kristensson & Iwarsson, 2013; Kon, 2010; Moreau et al., 2012; Peoples et al., 2011) and 5) a strong endorsement from literature in this area to promote involvement of equipment users in decisions about equipment (Cowan & Judge, 2014; Ministry of Health, 2015b; Ripat & Booth, 2005; Samuelsson & Wressle, 2008; Scherer et al., 2011; Schraner et al., 2008; Wessels et al.,



2004). When people feel that they have had their individual needs and preferences considered, they are more likely to express satisfaction with a service (Martin et al., 2011).

This chapter also highlights that the actual assessment process used by therapists for equipment provision is unclear (Maywald & Stanley, 2014) and questions remain about what equipment is actually distributed to people after stroke and what is accomplished as a result (Cook & Polgar, 2015a). There are three key areas where further investigation is required: 1) the cost benefits of providing equipment in terms of reducing impairments and promoting activity and participation for people after stroke, 2) the experience of the equipment users and therapist involved in equipment provision services, and 3) how tension between competing issues related to equipment provision are resolved (for example, prioritising clients' needs, preferences, and dispositions regarding equipment versus the policy and budgetary needs of the healthcare system). There remains little information on the cost of equipment for people with specific diseases, such as stroke, despite its widespread use and predicted increasing demand (Andrich & Caracciolo, 2007; Gosman-Hedstrom, Claesson, & Blomstrand, 2002). In fact, research on equipment provision has been criticised for having an absence of specificity regarding devices, health professional groups, and conditions (Auger et al., 2008; Dudgeon et al., 2008; Garber et al., 2002; Lenker, 2005). This issue is addressed in this thesis by focusing on a defined population (people with stroke) and a clearly delimited range of equipment.

Overall, there is a paucity of information about how people with stroke receive and use adaptive equipment and how people from different backgrounds interact with adaptive equipment and equipment providers. Provision of adaptive equipment is a routine part of practice for therapists, yet there is limited understanding about what influences their reasoning in this area. In Chapter 3, I describe the methods developed to address these gaps in knowledge before presenting the thesis results.

## **Chapter 3. Methodology and methods**

### **3.1 Chapter outline**

This chapter describes how literature from the fields of both mixed methods and grounded theory were used to address the study methods in this thesis. I outline the philosophical roots of these methods before illustrating how ethical principles were adhered to in this study. Finally, the different sampling strategies, data collection methods and analysis techniques which were used are described.

### **3.2 Overview of methods**

This thesis is a mixed methods study and I used explanatory sequential mixed methods (Creswell, Klassen, Plano Clark, & Smith, 2011; Johnstone, 2004) to develop a theoretical understanding of equipment use and equipment services for people with stroke. In explanatory sequential mixed methods each stage of data collection happens in sequence, and each set of results expands on and is used to explain earlier findings. Data collection and analysis for this study occurred in three phases. Phase 1 was largely quantitative, involving a population-based survey of people who had been admitted to hospital with stroke to explore their experiences of equipment prescription and equipment use. Phase 2 consisted of qualitative analysis of interviews with a subgroup of the survey respondents in order to explore their perspectives with equipment use after stroke in more depth. Phase 3 followed up with a qualitative investigation of the experiences of therapists (occupational therapists and physiotherapists) who were involved in equipment prescription.

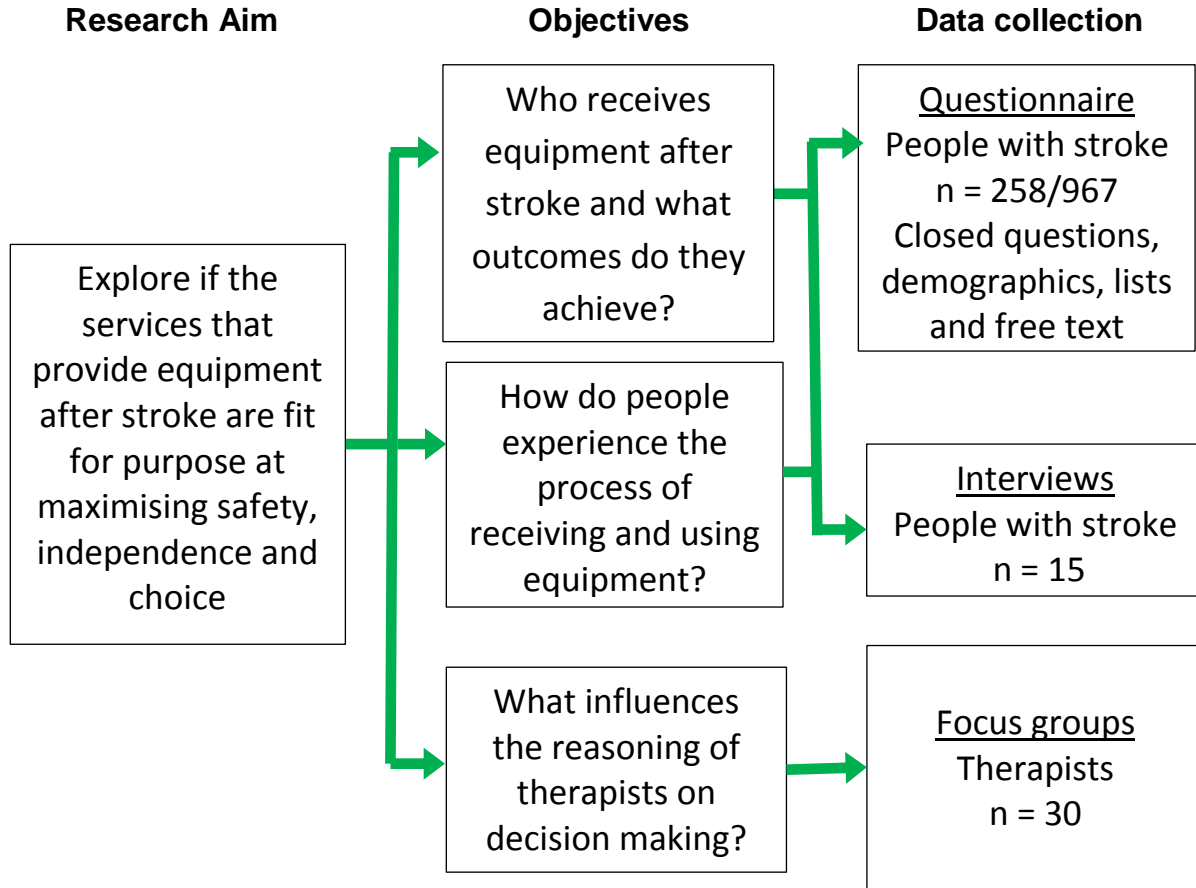
The quantitative data from Phase 1 were analysed using descriptive statistics and regression analysis. Phase 1 also included some text-based answers to open-ended questions, which were analysed using basic thematic analysis (Braun & Clarke, 2013). The qualitative data in Phase 2 and 3 were analysed using principles from grounded theory, based on constructivist grounded theory principles outlined by Charmaz (2006). While some authors claim that grounded theory can be used to analyse quantitative data (Glaser, 1999), in this study grounded theory techniques were applied to the qualitative data only and the framework for the overall research design was sequential explanatory mixed methods. As such, this study used a version of grounded theory known as ‘GT-lite’ (Braun & Clarke, 2013), using the

coding strategies and concept development approaches advocated by grounded theorists alongside other methods.

Overall, I took what is known as a 'quan→QUAL' approach to mixed methods research, where the quantitative work preceded and informed the more dominant qualitative work (Onwuegbuzie & Leech, 2007). While mixed methods design can place a greater or equal emphasis on the quantitative component (Creswell & Plano Clark, 2011) in the case of this research there was an greater focus on the qualitative phases as these data were more useful when building theory and when developing a contextualised understanding in relation to my research aim. This type of study design has also been called a quantitative preliminary design (Morgan, 1998), where the initial quantitative data is used to identify and purposefully select the most relevant cases for qualitative analysis. Put another way:

Qualitative dominant mixed methods research is the type of mixed research in which one relies on a qualitative, constructivist-poststructuralist-critical view of the research process, while concurrently recognising that the addition of quantitative data and approaches are likely to benefit most research projects. (Johnson, Onwuegbuzie, & Turner, 2007, p.124)

The research aims and objectives of this this study, and their relationship to the phases of data collection, are outlined in Figure 2.



*Figure 2 Relationship of data collection and objectives: Overview*

### Mixed methods research

Anthropologists and sociologists have been using mixed research since the early 20<sup>th</sup> century, long before the term mixed methods was coined (Johnson et al., 2007). Researchers have been explicit in their use of mixed methods since the late 1950s, when they began exploring multiple sources of information to validate psychological traits and they called this process triangulation (Campbell & Fiske, 1959). The nature and use of data triangulation was developed further by Denzin (1978) where he proposed that triangulation could be within methods (different types of qualitative or quantitative data) or between methods (where both qualitative and quantitative could be used). Denzin (1978) contended that limitations of either quantitative or qualitative data could be overcome only by using between methods triangulation. Likewise, Patton, an early leading qualitative researcher, proposed that intentionally designed methodological mixes offered advantages over qualitative or

quantitative methods used in isolation (Patton, 1980).

Mixed methods theories began to be published in earnest in the late 1980s by researchers from different disciplines with a focus on how different data sets could complement each other (Creswell & Plano Clark, 2011; Morse, 2003; Teddlie & Tashakkori, 2009). For example, where quantitative data could objectively illustrate whether an intervention worked or not, qualitative methods could produce data to help explain why an intervention did or did not work. Development of mixed methods evolved further as ideological debate among academics about different paradigms in the 1980s resolved to some extent (Johnson et al., 2007), when qualitative research came to be viewed as making a useful contribution to knowledge generation.

Johnson et al. (2007) compiled an account of recent history of mixed methods and an online discussion with leaders in the field, presenting the following as the most agreed upon definition of mixed methods:

Mixed methods research combines elements of qualitative and quantitative research approaches (e.g., use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purposes of breadth and depth of understanding and corroboration. (p.123)

More recently, Ostlund et al. (2011) endorsed the desirability of mixed methods research (to complement the limitations of either quantitative or qualitative) and reviewed trends in mixed methods research design. They employed a systematic approach to locate 168 articles from three large databases (Psychinfo, CINAHL and Medline) between 1999 and September 2009. They identified that parallel data analysis of quantitative and qualitative data was the most common structure used, though sequential data analysis frameworks (such as the one used in this thesis) were gaining popularity.

Mixing research methods relates to how both quantitative and qualitative methods are used to address a research aim. Different methods can come from different epistemological perspectives and value different ways of recognising knowledge and have different positions on what can be known (Morgan, 1998). Qualitative methods provide depth and detail on phenomena, while acknowledging there is a subjective or constructed nature to 'truth'. Quantitative methods focus on determining generalisability and value objectivity in data

collection and analysis. In other words, different methods suit different questions (Sackett & Wennberg, 1997).

One advantage of mixed methods is that a breadth and depth of understanding on a topic can be achieved more effectively than when using either quantitative or qualitative methods alone (Creswell & Plano Clark, 2011; Johnson et al., 2007; Teddlie & Tashakkori, 2009). The research questions best suited to mixed methods studies are when one data source appears insufficient and where generating theory is a primary goal, rather than testing an existing hypothesis (Creswell & Plano Clark, 2011; Johnson et al., 2007). Mixed methods research can enable a researcher to see things from multiple perspectives, allowing a more complete representation of a situation to be depicted (Bryman, Becker, & Sempik, 2008), for instance, in the case of this research, about how equipment after stroke is provided from multiple perspectives.

As all methods have limitations, combining methods can help to reduce the impact of limitations of individual methods (Creswell & Plano Clark, 2011) and therefore leave less unanswered questions at the completion of a study. Mixed methods can enable a researcher to address a range of questions – including, as in the case of this thesis, ‘why’ (for example, why do people use equipment after stroke?) as well as ‘who’ (for example, who uses equipment after stroke) and ‘how’ (for example, how can the process of equipment provision be maximised). I therefore chose mixed methods for this research to create a meaningful and systemic appraisal of a situation as complex as equipment use after stroke.

The flexibility of mixed methods research has also resulted in some criticism. Some have stated that mixing methodologies with different paradigmatic perspectives is impossible as their epistemological differences are fundamentally incompatible (Greene & Caracelli, 1997). For example, theorists who advocate that qualitative research provides a necessary counterpoint to the dominance of quantitative research argue that mixed-methods as a methodology is cleverly worded post-positivism, (Giddings & Grant, 2007). Giddings (2006) has suggested that mixed methods theory has developed as a result of pandering to the economic pressures of research funding, and that by being combined ever increasingly with quantitative methods, qualitative research as an academic discipline is at risk of losing the depth and breadth of philosophical debate that has been hard won by qualitative researchers.

However, while I accept these concerns, I am more convinced by theorists like Patton (2002a) who, despite being a strong proponent of the value of qualitative research for decades, has joined the growing call for focusing on choosing methods which will most effectively address research questions.

Nevertheless, while the usability of mixed methods certainly appeals, there is also room for scepticism of its current popularity. There is a comparatively new field of experts and terminology emerging (Cooper, Glaesser, Gomm, & Hammersley, 2012) in which claims about innovation are presented as the main advantage of mixed methods (Sandelowski, 2014; Sandelowski, Voils, Leeman, & Crandell, 2012). Any claim based primarily on novelty needs to be treated with some caution. Indeed, there is an ever burgeoning list of frameworks for mixed methods design (Creswell & Plano Clark, 2011; Teddlie & Yu, 2007) using different terminology, which is at odds with the purpose of a typology enabling common language and understanding about process (Teddlie & Tashakkori, 2009). While typologies are useful for learning what mixed methods is and how to do it, they can be restrictive when projects need to be changed due to larger datasets or logistical challenges (Guest, 2013).

In arguing for the value of mixed methods, there is a risk of characterising qualitative research as purely inductive and quantitative research as deductive. Such a move simplifies a situation where there is iterative cycling between inductive and deductive reasoning, integral in all research designs (Mills, Bonner, & Francis, 2008; Onwuegbuzie & Leech, 2005). In fact, Sandelowski (2014) argues that the current interest in mixed methods represents a re-branding of a long standing mixing of methodology inherent in all empirical inquiry.

### **Selection of mixed methods research for this thesis**

It can be difficult for those working in the health sector in general to find acceptable and relevant evidence when there is often a need to understand multiple perspectives (Barratt, 2008) with most quantitative or qualitative research designs representing only one perspective. As mixed methods approaches enable integration of different perspectives, they can therefore meet the needs of healthcare sector research (Sale, Lohfeld, & Brazil, 2002).

While traditionally research into health outcomes has used quantitative methods to investigate cost and effectiveness of health service provision, such methods are not well suited to address more complex aspects of service provision such as client perceptions of care and

the culture of the health workforce (Curry, Nembhard, & Bradley, 2009). Qualitative methodology offers a way of illuminating complex processes in healthcare service by understanding user and provider experiences (Bradley, Curry, & Devers, 2007). However, there are challenges with designing effective ways to measure client satisfaction with healthcare provision, which is a consideration for this study. How people experience health service provision can be highly subjective (Ford, Bach, & Fottler, 1997), so combining methods to account for such subjectivity can enable a deeper understanding. Some well-established health research methods used to elicit satisfaction lend themselves easily to mixed methods research, such as surveys which can include the ability to collect qualitative data, in the form of free text responses from open questions (Andres, 2012).

The value of capturing qualitative data about the experience of life after stroke and other conditions is gaining increasing acknowledgement, offering a previously untold perspective on involvement with stroke related services (Clarke, 2003; McKeivitt, Redfern, Mold, & Wolfe, 2004). In stroke rehabilitation, the use of mixed methods has gained recognition as a means of understanding such a heterogeneous condition, where complexity warrants multiple perspectives (Clarke, 2003). For the purposes of this study, with people after stroke, quantitative research elicited general information about how participants perceived the use of equipment and satisfaction with services that provided equipment. Qualitative methods informed nuanced examples of importance to people with stroke (Taule & Raheim, 2014).

Adaptive equipment as a subject of enquiry presents some particular challenges when trying to use conventional health science research approaches. For instance, the outcomes of equipment use are diverse and are influenced by a number of other rehabilitation interventions (Gelderblom & de Witte, 2002). This makes selection of a primary outcome variable difficult in quantitative studies on this topic. Randomised control trials on the effects of adaptive equipment use are complicated by an inability to blind the equipment user or provider, by ethical issues around not providing equipment to a control group, as well as difficulties unpicking the impact of equipment from other rehabilitation interventions (Anttila et al., 2012). Epidemiological studies, alternatively, depend upon the extent to which confounding variables can actually be identified and large population-based surveys which focus on the equipment used provide little in-depth information about personal perspectives (Hoenig et al., 2007).



Mixed methods have been proposed as a way of addressing many of the challenges inherent to research about equipment use (Hoenig et al., 2007). In particular, a mixed methods approach can provide information on real-life dilemmas regarding adaptive equipment use, and detail the interaction between the person with a disability, their equipment, and their social and physical environment (Da Silva et al., 2014; Johnston, Currie, Drynan, Stainton, & Jongbloed, 2014; Scherer & Lane, 1997). For example, a longitudinal study examining equipment use among 76 to 86 year olds in Sweden reported that mixed methods was an effective approach which created a 'more nuanced picture of use and users of assistive devices in everyday life' (Hagblom-Kronlof & Sonn, 2007, p. 343). This thesis similarly considers users' perspectives alongside description of equipment provision services, though this thesis is focussed on people who have had a stroke rather than an exclusively older population. Much of the existing research on equipment use after stroke has involved cross-sectional questionnaires (Cornman et al., 2005; Freedman et al., 2006). There is value, however, in researchers also exploring qualitative aspects of use and non-use of equipment and the relationship between the perceived effort required to use equipment and actual use (Cornman et al., 2005). These are issues which are explored in more detail in this thesis.

### **Grounded theory**

In addition to mixed methods research, this thesis draws heavily on grounded theory methodology. The premise of grounded theory is that all theory is inductively reasoned from data, rather than being constructed prior to data collection and exploration (Glaser & Strauss, 1967; M. Kenny & Fourie, 2014) and as an approach it is well suited to the development of theory (Chiovitti & Piran, 2003).

The original proponents of grounded theory were Barney Glaser and Anselm Strauss in their text 'The Discovery of Grounded Theory' (1967). At that time, their vision was ground breaking as the prevailing research perspective was positivism, where only objective data was considered scientific and valid (Birks, Chapman, & Francis, 2006; M. Kenny & Fourie, 2014). The views of the original proponents of grounded theory have since diverged (Melia, 1996) with the pivotal difference, according to Glaser (2008), being that Glaserian grounded theory is based on theory emerging from data, rather than forcing theory from data. Key areas of quality (and controversy) in the development of grounded theory by different theorists have

included differences in data sampling, the use of creativity during analysis, the application of researcher reflexivity, and the place of past literature in the analysis of new data (Cutcliffe, 2000; Heath & Cowley, 2004).

Strauss and Corbin (2014) reported that their version of grounded theory has been adapted as a result of ongoing academic debate over a 35 years period, whereas Glaser claims that they have developed a quite separate methodology (Cooney, 2010). While qualitative methods have dominated heavily when it comes to finding instances grounded theory studies, the original proponents of this theory argued that it is relevant to all types of data (Glaser & Strauss, 1967) and there has been an some recognition of the applicability of this approach to quantitative observational data (Benoliel, 1996), such as data generated by surveys.

Most recently, a student of Strauss, Charmaz (2006) offers her interpretation of how grounded theory can be conceived and she aligned this approach squarely with constructivism. Prior to this explicit constructivist application of grounded theory, results in grounded theory studies were described as being 'discovered'. Using Charmaz's approach to grounded theory, findings are perceived as co-created between participants and researchers (Charmaz, 2006), which in turn highlights that researchers' roles and pre-suppositions need to be clarified before and during data analysis and theory formation (Mills et al., 2008). Charmaz also acknowledged the flexibility of grounded theory principles in supporting analysis in studies which do not purport to be pure grounded theory research and in the value of having different types of data as required for analysis (Charmaz, 2006).

### **Use of grounded theory strategies**

I have drawn primarily on perspectives offered by Charmaz (2006) in the development of grounded theory methods used in this thesis. Grounded theory methods such as the use of data coding, theoretical sampling, data saturation, constant comparative coding, and development of theory (Charmaz, 2006) were all used in the qualitative phases of this research, to explore the participants' beliefs and experiences.

One key point of difference between the approaches to grounded theory advocated by different theorists is the place of prior knowledge in the development of theory. This prior knowledge can come from the researchers' own expertise, personal experience, or from existing literature on a given topic. Strauss and Corbin (1997) and Charmaz (2006)

acknowledged the value in understanding some existing theory about a topic prior to looking at new data, provided that any development of subsequent, substantive theory is embedded in the emerging data. This is in contrast to Glaserian grounded theory (Glaser, 2007) where a purely atheoretical stance is encouraged, as Glaser was concerned that learning about existing theories on a topic would adversely affect sensitivity to the emerging data. Glaserian grounded theory requires an ‘un-knowing’ of the topic, meaning that a researcher is supposed to come to a subject naïve to its history and without assumptions regarding the potential results of the study, allowing all results to emerge from the participants’ accounts (Chiovitti & Piran, 2003; Guba & Lincoln, 1994).

Given that my thesis involved early theory development and exploratory testing of a hypothesis about potential group allocation in the analysis of survey data, a Glaserian grounded theory approach was not possible. Moreover, the study design as a whole, being mixed methods research, did not lend itself in its entirety to a typical grounded theory methodology. Nonetheless, even the early quantitative phase of this study (survey data from Phase 1) incorporated considerable inductive methods, rather than being solely (or even primarily) deductive in nature. As such, the grounded theory components in the subsequent phases of the study (Phase 2 and 3) can be considered consistent with the methods used in this earlier phase of data collection and analysis (Suddaby, 2006). In this way, grounded theory methods can be seen to fit with the overarching approach of sequential explanatory mixed-methods. I also took guidance from the guidance of Charmaz (2006) on issues such as prior reading, with background literature searching used to develop core areas of interest, which was relevant as these were required to develop the survey in Phase 1 of the study.

### **3.3 Philosophical and methodological considerations**

#### **Epistemological considerations**

Epistemology refers to the theory of knowledge, addressing what can be considered as legitimate knowledge and how such knowledge is created or discovered (S. M. Carter & Little, 2007; Crotty, 1998; Guba & Lincoln, 1994). An epistemological stance is sometimes known as a paradigm (Feilzer, 2010), although this term can have other meanings (Morgan, 2007). Choosing an epistemology places boundaries around how a researcher conceptualises the nature of their research and the way in which their results can be understood (Madill,

Jordan, & Shirley, 2000). Making one's epistemological view explicit is often (though not always) considered an important step in qualitative research design in particular as there are philosophical assumptions embedded in the processes used when I collected, analysed and interpreted data. While epistemological viewpoints are not objectively provable (Guba & Lincoln, 1994), it was important for me to be aware of my own position regarding epistemology in order to understand the nature of my assumed reality. Epistemology helps researchers to plan and adjust methodological decisions, which in turn guides and justifies methods employed to address a research question (S. M. Carter & Little, 2007).

Broadly speaking, there are two epistemological positions which relate to this thesis: 1) positivism/post-positivism, where there is thought to be one singular truth which can be known and verified, and 2) constructivism, where there are many possible truths to uncover as the 'truth' is conditional and changeable (Creswell & Plano Clark, 2011; Morse, 2003). There is much academic debate about paradigmatic conflict when it comes to mixed methods research (Greene & Caracelli, 1997). Though the design of this study has been influenced by positivism and constructivism, neither can fully address the aim of this thesis, therefore pragmatism has been adopted as the overarching approach (Morgan, 2007).

Pragmatism as a philosophy arose in the United States of America at the beginning of the 20<sup>th</sup> Century, with John Dewey as one of its main proponents (Flower & Murphey, 1997), and this school of thought is based on the concept that theories and ideas are only useful insofar as they solve agreed upon problems. In a manner of speaking, pragmatism is a post-epistemological philosophy (Morgan, 2007) which sits well with the contemporary perspectives on mixed methods research as the focus is on research process and finding ways for shared understanding of issues rather than epistemological divides (Creswell et al., 2011). Pragmatism accepts that it can at times be useful to assume the existence of a single, observable reality, while at other times assuming the co-existence of multiple, socially-constructed realities can be practical (Creswell & Plano Clark, 2011; Morgan, 2007). What is deemed more important when taking a pragmatic approach is what will best address a particular research question. Pragmatism has been identified as the most suitable over-arching approach for mixed methods research (Teddlie & Tashakkori, 2009) because: 1) pragmatism is philosophically consistent with the intent of mixed methods, providing a practical framework for mixed methods, and 2) pragmatism as an approach is less concerned with

metaphysical issues, such as reality and truth, and more concerned with what works (Morgan, 2007). When using a pragmatic approach, both objective and subjective worldviews can be incorporated together (Johnson & Onwuegbuzie, 2004; Tashakkori & Teddlie, 2006), thereby offering an opportunity to blend worldviews as a research question requires, rather than follow one specific approach (Olsen, 2004).

Another advantage of pragmatism for this research is that it is compatible with grounded theory methodology (Bryant, 2009; Hall & Callery, 2001; Weber, 2010). Constructivist grounded theory holds that reality is dependent on humans making meaning (Charmaz, 2006), a process which is in turn dependent on human interaction with the world and with other humans (Bettis & Gregson, 2001). When applying constructivism to qualitative analysis the researcher aims to understand complex human phenomena, where the values and beliefs that people hold are believed to be constructed and fluid. All constructions are valid to the person who expresses them and they are often bound to the time of experience. Indeed, Charmaz (2008b) has reported that her constructivist perspective fits with earlier work by Strauss, who was predominantly pragmatic in his philosophical orientation:

Constructivist grounded theory loosens grounded theory from its positivist roots, moves it into interpretive inquiry and preserves and enhances its pragmatist heritage. (Charmaz, 2008b, p. 133)

Both constructivism and pragmatism endorse the idea that truth and reality are ever changing over time and both reject reductionism and prioritise eclecticism (Johnson & Onwuegbuzie, 2004). To that end, guidelines for data collection techniques, analysis and reporting developed by Strauss and Corbin (1997) and Charmaz (2006) were used to guide data collection, analysis, and interpretation of the qualitative aspects of this thesis in Phase 2 and Phase 3.

### **The role of the researcher**

For the purposes of this research, the researcher and those taking part in research were inextricably seen as linked and that findings were co-created as a result of interaction between the researcher and the researched, rather than uncovered by the researcher (Charmaz, 2006; Guba & Lincoln, 1994). As a result, there was a need for active development of reflexivity and awareness on behalf of the researcher:

If we fail to be critically aware and to know ourselves then we are in danger of undermining the validity of our work. Our findings, rather than being firmly grounded in people's accounts, may merely be a reflection of our own unconscious biases, stirred by the research. (Bannister, Burman, Parker, Taylor, & Tindall, 1994, p. 150)

How the researcher influences decisions is an important consideration throughout the design and implementation in all mixed methods and grounded theory research (Cutcliffe, 2000). Charmaz (2004) argued that, as researchers, it not actually possible to be completely naïve to a topic or to bracket our pre-suppositions (a feature of many phenomenological methods (LeVasseur, 2003)), but that researchers can, through reflective activities, make prior knowledge an explicit part of the research process. In particular, reflexivity is important when someone without a disability interviews, and thereby seeks to represent the views of, people who have disabilities (Manderson, Bennett, & Andajani-Sutjahjo, 2006). Therefore, I take the perspective that results are co-created by me as a researcher along with those taking part in the research, through interpretation and abductive reasoning (Chiovitti & Piran, 2003; Guba & Lincoln, 1994).

I acknowledge that I bring to this study my life experience as an occupational therapist, health researcher and able bodied European female, which was the lens through which I have viewed and analysed the data. Further, I have worked as an occupational therapist in a variety of settings for 14 years and I have a personal set of ideals about politics and society which is generally left wing. Assessing for and providing equipment has played a significant role in my working life and organising equipment trials with clients and completing applications for equipment funding has taken up a considerable part of the hours the tax payer has funded me to work in the public healthcare system. I have therefore reflected regularly in my working life about how equipment is provided, how it could be provided and how it should be provided. These experiences have provided the impetus and motivation for this research. I am relatively well informed about some of the challenges and opportunities at the front line of an equipment service and I feel strongly enough about these issues to pursue the answers to the questions which confront me regularly. My personal experience with this topic is also a challenge as I have needed to be clear with myself and my supervisors that I have had pre-understandings and presumptions about this clinical process and how it affects users of equipment. Acknowledging my pre-understandings has been the first step in managing these

presumptions throughout the research process and this thesis (Chew-Graham, May, & Perry, 2002).

### **3.4 Ethical considerations**

This research received ethics approval from the Northern Health and Disability Ethics Committee in New Zealand 13/NTA/31 [See Appendix B]. This study was subject to full review by a committee as the stroke population was classified as vulnerable, with some participants expected to have problems with cognition and communication, requiring a comprehensive ethics consultation process. This is a common consideration when researching older people (Atwal & Caldwell, 2005) and those with neurological impairment (Levine et al., 2004). That said, the obligation to protect and support vulnerable populations should be met in such a way that these (often under-researched) groups are not deprived of the opportunity to participate in research (Bernat, 2008; Hurst, 2008).

#### **Risk management with vulnerable populations**

The principles of planning and maintaining a sound ethical protocol overlap with rigorous analysis and reporting processes already outlined in this chapter, including taking a reflexive approach with analysis to ensure a participant's voice and perspective is maintained as honestly as possible. While it is acknowledged that social science holds the potential for understanding and remediating many complex issues, there has been concern about the potential harm posed by the pursuit of social research (Haggerty, 2004). Although discussing equipment use does not appear, initially, to be an obviously sensitive subject, similar studies on this topic have reported that participants disclosed neglect or abuse by caregivers (Garber et al., 2002). This risk was particularly relevant for the qualitative interview data collection stage during Phase 2.

Other examples of this kind of ethical quandary include when participants are going through a crisis (related or unrelated to the research topic) unbeknownst to the researcher or tensions arise because of the dual role held by researchers who are also health professionals (Robertson & Hale, 2011). Such issues were dealt with during this study by using supervision to debrief and by providing participants with information about health advocacy and support services for stroke in the community.

### **Consent and people with stroke**

Consent is perceived as signalling a contract of mutual understanding between two autonomous individuals, however this concept can become complicated when researching people who have had a stroke (Demarquay et al., 2004; Mangset, Forde, Nessa, Berge, & Wyller, 2008). Using significant others to assist with consent is an accepted way of enabling a broad range of people with stroke to contribute to research (Kunkel et al., 2015) and means that those with cognitive and communication difficulties can be included (Sneeuw, Aaronson, De Haan, & Limburg, 1997). The cognitive problems associated with stroke can make it difficult to make decisions about taking part in research (Schulz, Wasserman, & Ostwald, 2006) and for this reason consent was treated as an ongoing process (Penn, Frankel, Watermeyer, & Müller, 2009; Richards & Schwartz, 2002) which was relevant before, during and after data collection has occurred rather than a one-off discrete event where a participant signed the consent form.

In New Zealand, the Privacy Act (Ministry of Justice, 1993) prioritises the following in relation to the use of health related information: 1) only collect information that is needed, 2) tell the people concerned what will be done with their information, 3) be considerate once the information has been collected, 4) allow for the information to be corrected if it turns out to be incorrect and 5) use the information only for the purpose it was collected. These recommendations were adhered to throughout this thesis.

### **Cultural sensitivity**

The main concerns for many indigenous peoples in research are about respect for their rights, control over research processes and reciprocity within research relationships to ensure that equitable benefits are realised within indigenous groups (Henderson, Simmons, Bourke, & Muir, 2002). Māori in New Zealand have identified similar issues and these concerns can be aligned with the principles of the Treaty of Waitangi (Harwood, 2010; Hudson & Russell, 2009), a founding document in New Zealand (signed in 1840) which outlines the relationship and obligations between the British Crown and Māori people (Barrett & Connolly-Stone, 1998). This treaty enshrines Māori with the right to participation, protection and partnership. Designing and practicing research methods which were culturally appropriate and which respected the intention of this treaty were considered highly important in this thesis.



Consultation occurred prior to ethics application with Ngai Tahu, a Māori tribe with whom the University of Otago has an enduring relationship (See Appendix C) and consultation with their representatives was accepted at Canterbury DHB and Southern DHB as they are a local tribe in those areas. Consultation with Māori research groups also occurred at other recruitment sites in Wellington, Hutt Valley and Waikato (See Appendix C). The Whānau Care Services<sup>9</sup> contact details in Wellington, as requested, were added to the Capital and Coast DHB information sheets (See Appendices D and E). A local report on the numbers of Māori participants recruited and specific issues recruiting or retaining Māori will be submitted at the completion of this thesis in 2016, along with a copy of the final study report. A researcher with experience of Kaupapa Māori research process, where Māori philosophy is paramount (Bishop, 1999), was consulted during the development of this research proposal and she was involved as a cultural advisor for its duration. This Māori researcher provided input into questionnaire design in Phase 1 and I met with her regularly during analysis, particularly when analysing qualitative data from Phase 2 where I had interviewed Māori. This consultative process increased the validity of findings in terms of ensuring cultural relevance and accuracy (S. Walker, Eketone, & Gibbs, 2006). Further validity measures are described in Chapter 7.

### **3.5 Phase 1: Survey of experiences of people with stroke**

#### **Survey design**

This study began with administering a mailed questionnaire to people who had been admitted to hospital with a diagnosis of stroke between 1 January and 31 December 2012. The objective of collecting data using a questionnaire was to describe the characteristics of the people with stroke who use publicly-funded equipment, the type of equipment they use, what outcomes are achieved by them using this equipment, and to estimate the annual cost of adaptive equipment prescription for people with stroke. A secondary aim was to examine if the odds of receiving equipment differed by ethnicity, while accounting for a range of related factors.

Questionnaires are a common method of collecting (mostly) quantitative data about health service user attitudes and experiences (Clarke & Gladman, 1995; Oppenheim, 2000;

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<sup>9</sup> Family support services for Māori accessing hospital services

Singer & Presser, 2008) from a sample of people in order to generate statistics which can be generalised to a larger population (Andres, 2012). All questionnaires have the limitation of being a self-report tool in that the respondents report subjectively on their experiences, with this response being limited further by recall bias, rather than a being a truly objective measure (Mukherjee et al., 2009). While mail questionnaires are a cost efficient way of gathering data from large groups and can preserve anonymity more so than telephone interviews or face to face methods, there are challenges with this data collection method. These include problems with response rates, response quality (Eaden, Mayberry, & Mayberry, 1999) and constraints on the design of the survey itself in terms of constructing written questions to meet the objectives of a survey (Aday, 1996).

### **Questionnaire development**

The questionnaire was developed to collect demographic data and self-reported information on equipment use, satisfaction with equipment, and satisfaction with the services that had provided the equipment. Satisfaction with a service can be conceptualised as a value judgment that clients place on experiences of interactions with health professionals (Kane, Maciejewski, & Finch, 1997). It was never my aim to rigorously assess the psychometric properties of the questionnaire. However, in line with similar questionnaire-based studies on equipment use (Samuelsson & Wressle, 2014), features from previously validated questionnaires were considered when designing the questionnaire. For example, the format of the outcome measure the Quebec User Evaluation of Satisfaction with Assistive Technology (discussed in Chapter 2) was used, where satisfaction rating with equipment is placed before satisfaction with aspects of equipment provision service (Demers et al., 2002).

Expert review is acknowledged as an important feature of questionnaire development (Groves et al., 2009). Initial development of the questionnaire used in this study involved consultation with other therapists and people familiar with providing or using equipment. As part of the process of obtaining ethics consent with the Health and Disability Ethics Committee (Appendix B), a scientific peer review was completed. This involved an independent senior researcher at the University of Otago reviewing the whole study design, which resulted in a favourable outcome (Appendix D). Suggestions about the length of the questionnaire and clarification about core questions were made during this review and the

questionnaire was changed accordingly at this stage.

The draft questionnaire was also reviewed by the End-User consultation committee, from the Burwood Academy of Independent Living in Christchurch, New Zealand (Appendix E). The committee is comprised of people with disabilities, who consider the needs of end users of disability-related research when evaluating a proposed research method and potential usefulness (Bourke et al., 2012). This group's aim is to improve consultation between lay end-users of health and disability services and researchers. This type of consultation can increase the relevance of research to end-users, reduce errors in questionnaire responses, and address moral issues related to the involvement of people with disabilities in research on disability (Hammell, 2010).

Peer-review and consumer input are also important because survey design and language use in a questionnaire can affect response rates (Leung, 2001) and response quality (Aday, 1996). Factors such as the length of the questionnaire, the order of questions and the use of visual aids were considered when designing and piloting this questionnaire. There is a risk of errors when participants rely on memory to answer questions (Eaden et al., 1999) which is increased significantly in the stroke population. As outlined by Tourangeau, Rips, and Rasinski (2000) other common problems in questionnaire design include grammatical ambiguity, excessive complexity, faulty presupposition (making inaccurate presumptions), inclusion of vague concepts and unfamiliar terms. For the stroke population, the ability to comprehend questions and navigate the questionnaire as easily as possible were particularly important.

Statistics New Zealand (1995) has recommended five steps for the development of a robust questionnaire which were followed. Step 1 required the articulation of the precise information needs. Collecting demographic information about who uses what equipment after stroke has already been highlighted, as well as exploring expected outcomes of equipment use in daily life. In addition, core information needs included; the most valued items of equipment to people with stroke and why they were important, eliciting perceptions of being a user of equipment provision services, including how decisions were made about equipment provision and satisfaction of users with specific aspects of equipment provision process, according to best practice standards developed from the literature.

At step 2 the needs of the group who would respond to a questionnaire were considered (Statistics New Zealand, 1995), in this case, people who have had a stroke. Common side effects of stroke include difficulty with reading, writing and articulating, with right-side cerebral stroke increasing the risk of visual scanning difficulty and the incidence of ignoring stimuli on one side when completing activities (neglect issues) (Jehkonen et al., 2001). Adapting research methodologies to represent people with communication difficulties is paramount in research with this group (Lloyd, Gatherer, & Kalsy, 2006). Having a potentially large group who cannot respond reduces the generalisability of survey results as well as denying some people who use equipment the right to participate in this research. Recruiting participants with stroke to take part in research can be a challenge (Schulz et al., 2006), however, having an appropriately designed questionnaire increases the likelihood of response (Leung, 2001). It was assumed that family or other support people may be required to support some stroke survivors to complete the questionnaire. Older participants are often willing to criticise wider issues in the health service but are reluctant to be critical of individual specific personal interactions and experiences (Owens & Batchelor, 1996) or fearful that criticised services will be removed rather than improved (Atwal & Caldwell, 2005). As the risk of stroke is positively associated with aging (Feigin et al., 2009), this was another factor to consider during design of the questionnaire, participant information sheets and consent forms for people with stroke (Appendices F,G and H).

Step 3 involved writing questions that met the information needs of the questionnaire (Statistics New Zealand, 1995). There are two basic types of question used in surveys. Closed questions give a set number of options which are quick, easy to code at analysis, and minimise discrimination against people who may have literacy difficulties (Leung, 2001). Open questions, on the other hand, have the advantage of enabling respondents to discuss ideas using their own words and therefore allows for a wider range of possible responses (Leung, 2001). They are useful when opinions are required or the range of possible responses is not well developed (Groves et al., 2009). Both types of questions were used in this questionnaire.

In addition to the style of questions developed, there are some other important considerations about how questions should be designed. For instance, Groves et al.(2009) reported that there are three standards which need to be addressed when designing questions:

1. Content - are the questions asking the right things?
2. Cognitive demand - do respondents understand questions?
3. Usability standards - can respondents complete the questionnaire easily?

These issues relate to content development, mode of delivery and presentation (Peat, 2001) of the questionnaire and were vital to consider at this stage, as detailed in Steps 4 and 5 in the guide by Statistics New Zealand (1995). Therefore, the next two sections of this chapter relate to the evaluation of questions and formatting of the questionnaire.

### **Questionnaire content and mode of administration**

The questionnaire was developed to capture information about a balance of attributes, beliefs and behaviours related to equipment use. The content of the questionnaire explored the most salient outcomes expected as a result of equipment use, as identified by the literature review presented in Chapter 2. Based on this prior reading it was determined that it was most important to explore the relationships between equipment use and one's sense of personal control, participation in meaningful activities, safety for self and others, and self-confidence. The questionnaire was also designed to explore the participants' views on equipment provision, focusing on accepted aspects of best practice, also discussed in Chapter 2. These areas of best practice included:

1. Adequate written and verbal instruction.
2. Thorough assessment and training.
3. Efficient delivery and quality of equipment.
4. Involvement of equipment users in decisions around the trial of equipment.
5. Selection of equipment options.

Questions 4 and 5 from this list related to participants' experiences of having their values and preferences elicited and how (or if) they were presented with equipment options. Information about the type of equipment provided and the current extent equipment use was sought and respondents were asked to identify their equipment from a predetermined list. The list was based on cataloguing common adaptive equipment as defined in Chapter 2 and related predominantly to mobility and self-care activities. The list was also influenced by my prior

work experience as an occupational therapist, including selection of terms which I thought respondents would be most likely to understand. See Appendix H for a copy of the questionnaire.

The questionnaire was structured to lead from short and factual questions, for example, whether or not someone assisted the respondent to complete the questionnaire, to questions that required more reflection and subjective judgement, like asking about their experience of receiving equipment through the health service. Participants were encouraged to relate their own experience of equipment and the procurement process through free text prompts. Finally, all participants who had received publicly funded equipment were asked to consent for me to contact their equipment funder to ascertain the estimated cost of their publicly funded equipment. Questions about demographic details were sought at the end of the questionnaire to ensure the easiest questions were asked when respondents were most likely to be fatigued.

Because aphasia is a common consequence of stroke (Engelter et al., 2006) recommendations on written communication for people with aphasia were considered. This group may have had different experiences with equipment provision services so maximising their ability to participate was important. Examples of presentation styles that enhance accessibility for people with aphasia used in this study included; using a large, clear font of 14 point, non-serif format, providing white space between blocks of text and having extra pages to accommodate these requirements (T. A. Rose, Worrall, Hickson, & Hoffmann, 2012).

While graphics can increase accessibility for people with aphasia (T. A. Rose, Worrall, Hickson, & Hoffmann, 2011) the content of this questionnaire did not lend itself to having full pictorial representations, though visuals of typical equipment were presented on the cover of the questionnaire. Respondents could choose to take part using a support person to communicate for them, which can introduce complications both from an ethical point of view and in terms of interpretation of the data, but on balance this is the only way to collect information from some people with severe language and cognitive difficulties, who would otherwise have been excluded from the research (Lofgren, Nyberg, Mattsson, & Gustafson, 1999; Sneeuw et al., 1997).

Participants' level of health literacy was also a consideration in questionnaire design. Until recently, most health literature has been created using advertising and document design

principles (Buxton, 1999) and the way health literature is written is often not accessible for people with aphasia (Dalemans, Wade, van den Heuvel, & de Witte, 2009). Vocabulary and syntax were simplified to improve readability (Brennan, Worrall, & McKenna, 2005). The possibility that some participants would need to write with their non-dominant hand is common after stroke and as this technique requires more attention to hand movement (Hoshiyama & Kakigi, 1999), it was likely to increase fatigue and potentially limit the level of detail expressed in the free-text responses.

Other important considerations specific to the stroke population which were factored into the design of this questionnaire included possible impairments in visual scanning, fatigue, and concentration. Likewise, pre-stroke literacy levels and the potential for participants to have English as a second language were likely to affect both the response rate to the questionnaire and the quality of information gathered (Aday, 1996; Boynton, Wood, & Greenhalgh, 2004). In order to address potential problems with literacy, all potential respondents were also given the option to complete the questionnaire by telephone. An option to complete the questionnaire online was also offered. While these strategies introduce variation to the data collection process (Collins, 2003) they enhance accessibility to take part in research for vulnerable populations thus increasing the potential generalisability of the findings (Groves et al., 2009; Leung, 2001; Statistics New Zealand, 1995).

### **Piloting the questionnaire and cognitive interviewing**

Two phases of piloting were undertaken to assess the acceptability and face validity of the questionnaire for people with stroke. Firstly, two equipment users were invited to provide feedback via email in relation to their experience of completing a draft version of the questionnaire. They were asked to comment on ease and flow of questions, relevance of questions and comprehensiveness of options for answers. Secondly, three additional people who had a stroke at least 18 months prior participated in cognitive interviews on their experience of completing the questionnaire, and the questionnaire was again revised. Cognitive interviewing is a strategy in questionnaire design used to evaluate coverage of the intended concepts and inconsistencies between the researcher and respondent interpretation of individual questions (Collins, 2003; Drennan, 2003). During cognitive interviewing, attention is paid to how respondents mentally process and respond to questions. It is a helpful step in

minimising invalid findings which can occur when respondents interpret questions in different ways than intended, resulting in incomparable responses (Collins, 2003). In this study, there was a high risk of misinterpretation of survey questions given the age, health status, and communication impairments associated with this group.

Two key techniques guide cognitive interviewing; thinking aloud and probing (Priede & Farrall, 2011). Thinking aloud involves asking respondents to verbalise their thought process as they consider each question. Probing involves asking specific questions about what participants were thinking as they answer questions (Priede & Farrall, 2011). Probing runs the risk of enabling the interviewer to focus on areas of interest to them, whereas thinking aloud is more open-ended and thus thought to be more user-led. However, a study comparing the effect of using each style of interviewing found the differences between them, in terms of impact on revision of a questionnaire, were minimal (Priede & Farrall, 2011). Thus, probing was chosen as the main way of guiding cognitive interviews in this study to reduce cognitive burden for participants (DeWalt, Rothrock, Yount, & Stone, 2007). While cognitive interviewing has been criticised as discriminating against those less eloquent or cognitively able (Drennan, 2003), it does provide an opportunity to systematically review the content of questionnaires, usually using a list of prompts as a guide (Collins, 2003; DeWalt et al., 2007; Drennan, 2003). See Appendix I for a copy of the cognitive interview guide used when refining the questionnaire.

The cognitive interviews influenced the use of terminology in the questionnaire. For example, 'electric' was added to the description of 'wheelchair with motor' as respondents referred to it with this term, despite therapists tending to use the term 'motorised' or 'power'. For some questions respondents were required to recall complex events over time such as describing their engagement with specific therapist disciplines. People with stroke struggled to differentiate between different allied health disciplines, so these questions were reformatted to avoid reference to specific job titles. Questions relating to satisfaction with rehabilitation services had the words 'in general' added as asking about specific healthcare interactions also appeared to be more confusing than was helpful. No confidential data was kept about the people who took part in cognitive interviewing and their responses did not count towards data collected for this study. This process, where questions were developed by researchers and people with lived experience of a phenomenon of interest, and then finally



evaluated with respondents similar to the target population, is comparable to other studies using questionnaires to explore equipment use (Krantz, Persson, Lindgren, & Bolin, 2011).

### **Participant recruitment**

The primary goal of recruitment for this phase of was to elicit as high a response rate as possible from people who had a stroke in 2012 who use or used adaptive equipment after their stroke. As it was not possible to specifically identify this population through any district health board (DHB) database, the inclusion and exclusion criteria were designed to target people admitted to hospital with stroke who were most likely to also have used adaptive equipment after stroke. Recruiting in this way enabled collection of descriptive data from people who had a stroke who used equipment and information from people with stroke who did not use equipment, allowing comparative analysis between these two groups which is described later in this chapter. So both people with equipment and without equipment could and did respond to this questionnaire. Participants were recruited from five DHBs in New Zealand: Capital & Coast DHB, Canterbury DHB, Waikato DHB, Hutt Valley DHB, and Southern DHB. Combined, these DHBs serve approximately 39% of New Zealand's population (serving 1.7 million of 4.4 million in New Zealand in 2012) and four of the five largest urban areas in New Zealand are situated within these five DHBs (Statistics New Zealand, 2013c).

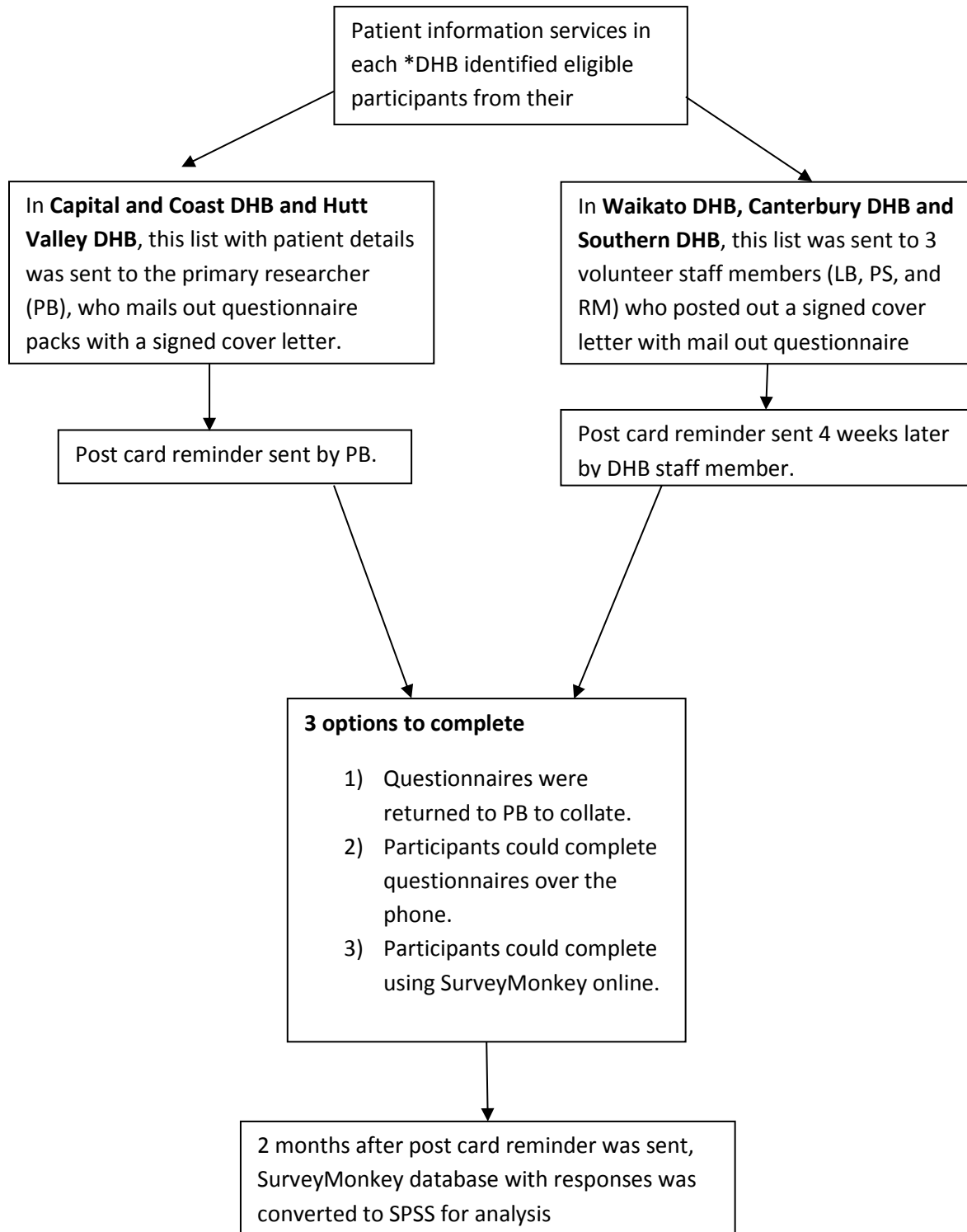
Participants were eligible to be included in the survey if they met the following criteria: 1) stroke was recorded as a primary reason for admission to hospital between 1 January and 31 December 2012, 2) they were over 16 at the time of admission, 3) they were alive at time of mail out and, 4) they had stayed in hospital for longer than seven days. No restriction was applied for the upper age limit for participants. As the data was collected between May and October in 2013, most participants had their stroke between six to eighteen months prior to receiving their questionnaire. This time period was important to ensure that participants had their stroke recently enough so they could recall how they had interacted with equipment and equipment provision services. Ideally, participants were eligible if they had a reasonable level of English, though fluency was not a requirement and participants could be assisted during the questionnaire or the subsequent interviews by family members or interpreters (if they so wished), so that a breadth of cultural perspectives could be captured during recruitment.

One source of potential bias was that there was no systematic way of identifying people who had used adaptive equipment before contacting them. Any recruitment strategy available either had the potential to recruit a large number of people who had never needed adaptive equipment after stroke or fail to recruit people who had a stroke and been equipment users. To target people who were most likely to have equipment (people with moderate to severe stroke (Okoro et al., 2010)), one of the inclusion criteria was that potential participants had stayed in hospital longer than seven days after a stroke. Alternative recruitment strategies (such as targeting stroke-specific community services, some of whom kept lists of referrals) were discounted as these strategies could not be replicated across all five sites. Only including people with stroke who had attended inpatient rehabilitation was also discounted as this would have resulted in different recruitment patterns across the five DHBs, as each had different criteria for admission to rehabilitation and therefore would have missed potentially eligible participants who had been treated on general medical wards.

To develop a strategy for targeting people who met criteria for inclusion, a meeting with the decision support unit with Capital and Coast DHB was arranged. An initial search strategy was tested using the inclusion criteria and ICD-10 codes developed to categorise stroke. Using ICD-10 codes alone was not ideal for identifying people in the population for this study as, along with being dependent on the coder's accuracy at time of recording, these codes did not capture whether people had passed away at the time of, or since, their stroke, so this needed to be checked separately (where possible) using real-time hospital records at the time of mail out. However, ICD-10 codes have been found to have high sensitivity for coding stroke (92% sensitivity; 95% confidence interval 88% to 95%) (Kokotailo & Hill, 2005) and are used by the Stroke Foundation in New Zealand to collate data on stroke incidence. Furthermore, these codes were used at all five DHB sites. Following discussion with the decision support unit at Capital and Coast DHB, the decision was made to use the ICD-10 codes recorded at discharge rather than admission to hospital, as this increased the likely accuracy of the coding. This search was completed across all five DHBs by information management personnel and the lists generated were sent to either me (where appropriate) or a recruitment support person who was a local DHB staff member. See Appendix J for list of ICD-10 codes used.

**Data collection**

Collaboration with health professionals from other DHBs was essential in order to access health care records and facilitate mail out of the questionnaire. I was able to access health records myself in two DHBs by gaining special staff status. At three other DHBs, a DHB staff member was required to access client information and sign mail-outs on my behalf, and I remotely provided support to these recruitment aides. These health professionals were an occupational therapist in both Canterbury DHB and Southern DHB and with a clinical nurse specialist for stroke in Waikato DHB. An 'opt out' option was available for all five DHBs. People who did not wish to take part could ring the nominated person in each DHB or an administrator at the University of Otago, named in the cover letter, and anonymously decline to participate. Where possible, a reason for refusal was recorded. Please see Appendix K for a generic copy of the cover letter which was signed by either me or a recruitment aide at one of the other sites. The process of data collection across all five sites is outlined in Figure 3.



\*DHB = District health board

*Figure 3 Mail out process for questionnaire*

Some logistical issues affected how recruitment for this questionnaire was completed. There were privacy issues, where I could not, as a researcher, access client data without their consent, hence why DHB staff were required to make initial contact about the study in some regions. The DHB staff member who assisted with the administration of questionnaires did this in addition to continuing clinical work with their clients, and therefore they could only commit a small amount of time for the physical mail out of letters. In Canterbury DHB, the research office declined to include the phone number for the DHB staff member for participants to call to anonymously opt out, as this was perceived to represent an unknown cost of their staff members' time. So for this DHB only, an option was added where they could call an administrator at the University of Otago in Wellington. An ethics amendment was submitted and approved for amending the study protocol for this change (See Appendix L for ethics amendment approval).

Low response rates introduce problems with systematic error and reduce the generalisability of surveys (Boynton et al., 2004; P. Edwards et al., 2007; Goyder, 1985). There are, broadly speaking, three different reasons for non-response: 1) failure to deliver the questionnaire, for example, inaccurate address, 2) the invited individual declines or forgets to respond and, 3) the invited individual is unable to participate (Groves et al., 2009). In addition, failing health has been identified contributing to low response among people with stroke (Garber et al., 2002). Response rates in studies involving people with neurological impairments are particularly problematic (P. Edwards et al., 2007), so extensive consideration was given when planning this research to strategies to maximise the response rate.

Where addresses were returned by post as incomplete, names were checked against public records (for example, public phone and address directories). To maximise the response rate further, I needed to encourage potential respondents that the benefits of contributing to the research outweighed the costs, in terms of their time and energy (Dillman, 2000; Manzo & Burke, 2012). To that end, respondents were included in a draw for NZD \$50 grocery voucher. One of the risks in researching equipment use with questionnaires is that those who have publicly funded equipment they do not use, but have not returned, may feel guilty on receipt of such a questionnaire (Neville-Jan et al., 1992). Therefore reassurance was supplied in the participant information sheets that the questionnaire was confidential and that taking part would not affect the participants' healthcare in any way.

Questionnaires from well-known institutions result in higher response rates and so the university crest was included on letterheads and envelopes (Boynton, 2004) as well as on cover letters which were personalised for each respondent. Follow-up reminders about the questionnaire was of particular importance for people with cognitive impairment (Dillman, 2000) and potential participants were prompted one month after they received a questionnaire via a reminder post card. Originally a second reminder was proposed, however this was abandoned following concerns from DHB research staff that this would increase participant frustration. Return postage for completed survey was provided along with the cover letter.

### **Cost information**

To estimate the cost of mobility and personal care equipment to people with stroke, all participants who received publicly funded equipment were asked to give consent for me to contact their Ministry of Health funded equipment provider, Enable New Zealand. Contact was established early in this thesis with Enable New Zealand, who managed the Ministry of Health budget for adaptive equipment for all geographical locations where people were recruited for this study. Information held by Enable New Zealand was then used to estimate the type and cost of equipment issued to people with stroke in New Zealand in 2012. The cost of publicly funded equipment was estimated by checking the exact items of equipment issued by publicly funded bodies to respondents by contacting Enable New Zealand advisory staff who compiled a list from their database (E. Williams, personal communication, October 9, 2014). The companies which supplied each of these items were contacted (20 suppliers in total) to request information on cost to the public for these items.

### **Data analysis**

Data were collected via paper surveys and telephone and entered manually into an online survey platform, SurveyMonkey. Two participants entered their responses online and all other entries were checked and entered by me. The SurveyMonkey interface minimised the risk of data entry errors because the layout mirrored that of the paper surveys. Prior to analysis, data cleaning occurred, noting instances of ambiguous responses and item non-response. These errors were dealt with by telephoning participants, where possible, to clarify their responses. Data were then downloaded to IBM Statistical Package for the Social Sciences (SPSS) (2013), Version 21, for analysis and a codebook was developed with easily

identifiable labels for all variables.

All data from Likert style scales in the questionnaire were treated as ordinal data. As analysis progressed some codes were collapsed, marking a compromise between analysis process and accuracy of core data. For example, self-reported health status had six response options, which was designed to maximise variation, however for analysis these were collapsed to three categories: ‘excellent or very good’, ‘good or fair’ and ‘poor or very poor’.

As over 80% of respondents were New Zealand European and as non-New Zealand European participants represented small numbers of people from a wide range of other ethnicities, all those identifying as non-New Zealand Europeans were grouped together in order to detect differences between these two groups. Furthermore, for the purposes of statistical analysis, those who were European but did not self-identity as New Zealand European (for example, British) were pragmatically grouped as New Zealand European, as it was assumed that their experiences with the equipment provision services were likely to be similar to New Zealand Europeans. Where people selected New Zealand European and one other ethnicity, they were categorised as non-New Zealand European, which is an approach endorsed by Statistics New Zealand (Statistics New Zealand, 2005).

### Descriptive analysis

Descriptive statistics were compiled, including the mean, range and standard deviation for continuous variables and frequency for categorical variables. Where appropriate, graphs were created with Microsoft Excel to illustrate the spread of data responses. The demographic characteristics of people with stroke who had equipment and those who did not use equipment were compared, including proportions and confidence intervals calculated using Fishers’ exact method. The costs gathered were also described descriptively.

Participant demographic information including gender, ethnicity, social living situation, time since most recent stroke were analysed descriptively. Microsoft Excel was used for descriptive analysis and SPSS version 21 was the statistical software package used for inferential analysis. Logistic regression was used to address an *a priori* question of ‘does ethnicity predict who is more likely to have equipment after stroke?’, while accounting for other demographic factors including age, gender, ethnic background and social situation. The binary outcome was whether or not someone had received equipment following their stroke.

### Logistic regression

In order to determine whether ethnicity influences the likelihood of people receiving equipment after stroke, multi-variate logistic regression analysis was used, accounting for age, social status, and health status. Logistic regression was chosen as it is a recommended approach to modelling when the outcome variable is categorical (Hosmer, Lemeshow, & Sturdivant, 2013; Peng, Lee, & Ingersoll, 2002). It has been used successfully when modelling prosthetic use (a comparable field of interest to adaptive equipment) and produced similar result to linear and non-linear methods, with reportedly easier to interpret findings than other methods (Biddiss & Chau, 2008).

Increasing age is a strong predictor of stroke occurrence and increasing stroke-related disability (Anderson et al., 2005). So evaluating whether ethnicity predicted equipment use without considering age could have led to an inaccurate picture as differences may be attributable by age. Social situation also relates to ethnicity, which again needed to be adjusted for in the regression model. Social situation in this survey was categorised on the basis of the level of social support (having family support, living alone or living in residential care). The results from the logistic regression analyses are reported as odds ratios (OR) with 95% confidence intervals in Chapter 4. Odds ratio for this research is the change in odds of a participant being in one of the categories of outcome when the value of a predictor increases by one unit. To prevent 'overfitting' where a model would explain a dataset well but would not be translatable, 10 to 20 case outcomes versus non outcomes are typically required in a dataset for each variable (Pallant, 2010).

### Thematic analysis of free text responses

Six questions elicited free text responses which were each separately analysed using thematic analysis (Braun & Clarke, 2013). Respondents were asked to expand on their answers to a question with predetermined potential responses or they could offer an alternative explanation for their response. One of these opportunities to give more information in their own words was when participants were asked to detail what would likely happen if they did not have equipment (other than the outcomes suggested in the questionnaire). Five questions which encouraged free-text responses related to satisfaction with standards of equipment provision, including:



1. Appropriate assessment for equipment.
2. Satisfactory training on using equipment.
3. Satisfactory quality and delivery of equipment.
4. That people had their views and preferences taken into account.
5. That people had options explained to them.

Text data was imported to a table which was used to highlight preliminary codes before progressing to more interpretative codes (Braun & Clarke, 2006). From the list of initial codes, very early development of themes occurred, while remaining open and curious to the phases of data collection yet to be analysed, which is also consistent with early grounded theory development (Charmaz, 2008a). This data provided valuable information for sampling decisions for the next phase of interviews with people with stroke.

### **3.6 Phase 2: Interviews with people with stroke**

#### **Participant recruitment**

This phase was designed to explore the experiences of people with stroke regarding their use of equipment and provision services. An important aspect of sequential explanatory mixed methods is that one stage builds on the results of the preceding stage (Creswell & Plano Clark, 2011; Tashakkori & Teddlie, 2003). To this end, participants were selected for face to face interviews on the basis of their questionnaire responses and analysis of the results from the survey as a whole. Rather than recruiting a representative sample, participants were selected to establish maximum variation of experience with equipment provision after stroke. While every effort was made ensure the questionnaire was suitable for people with aphasia, it is acknowledged that 30% of people with stroke have aphasia (T. A. Rose et al., 2011) making completion of questionnaires challenging for this group. Therefore, those with more severe aphasia might have already been lost during recruitment before Phase 2 had begun.

Twelve respondents who indicated willingness to participate in interviews were recruited initially, with a further three people recruited after preliminary analysis revealed that further data collection was necessary to reach theoretical saturation (Guest, Bunce, & Johnson, 2006; Mason, 2010). As Māori and Pacific people have strokes at a younger age than European New Zealanders (Feigin et al., 2009), there may be culturally specific issues in

relation to equipment provision (Harwood, 2010) and so these groups were purposively sampled where possible.

Consistent with grounded theory methods (Charmaz, 2006; Mills et al., 2008), the transcripts of the first three interview participants were analysed to identify broad themes without generating theory, in order to select which of the potential remaining participants could best add to the developing ideas. Further participants were then invited based on their likely ability to address discrepancies in the emerging analysis or to provide a different perspective (Charmaz, 2008a). For example, as sampling progressed, it was evident that participants' views in this phase seemed to be mostly critical of the equipment provision process, so further sampling specifically targeted participants who had reported positive or mixed responses in Phase 1. Also, initially more men agreed to be interviewed and so more female participants were actively recruited as data collection progressed.

### **Data collection**

Interviews took place in the participants' homes at a time convenient to them. All interviews were audio recorded by digital recorders and transcribed verbatim by an experienced typist. Interviewee identities were kept anonymous as their interviews were transcribed with pseudonyms. Given that one of the primary criteria for selection for qualitative interviews is that the participant can give a rich, or thick description (Strauss & Corbin, 1997), the communication difficulties often inherent with the stroke population needed to be considered carefully. Factoring in how fatigue impacts on someone's expressive ability (Carlsson, Paterson, Scott-Findlay, Ehnfors, & Ehrenberg, 2007; Pallesen et al., 2013) interviews were scheduled for a time of day that best suited participants in terms of their fatigue.

Furthermore, in order to address problems with cognition and communication, all participants were offered the opportunity to nominate a support person to assist them to take part. This approach has been used successfully with other qualitative studies exploring life after stroke (Mayo et al., 2002; Rutherford et al., 2014). Having another person to help tell one's story is also an important consideration when collecting data from Māori, where interdependence and strengthening of whānau after disability is often seen as a priority (Ratima & Ratima, 2007). Participants with cognitive difficulties were permitted to draw on

their support person to provide prompts when trying to remember issues that they considered important, in line with recommendations for interviewing this group (Pallesen et al., 2013). Where family members were involved, a plan was discussed before the interview to manage their input. It was agreed that family members should only provide prompts when requested by the person with stroke, to keep the discussion focussed on the experience of the person with stroke. While initially it was expected that the narrative supplied by support people would not be used as core data, when conducting analysis on the transcripts it became clear that for a few participants with stroke, some important portions of their interview only made sense when the context provided by the support person was included. Therefore, there was occasional inclusion of the partners' contributions in Chapter 5, where it was warranted. An ethics amendment was requested and approved for support people, where relevant, to give consent for their words to be used in final analysis of qualitative data (Appendix L).

In line with explanatory mixed methods process (Creswell et al., 2011), questions for the interviews were refined and finalised after Phase 1 data had been analysed (see Appendix M for a copy of the interview schedule used). Reference to free text responses given by participants in their questionnaires was made during interviews. As the schedule was semi-structured, prompts were used to follow the areas of interest and importance to the participants (Ritchie, 2009), as well as covering core research questions in the interview schedule. Denzin (2001) refers to a performance aspect inherent in qualitative interviewing, which facilitates elucidation of experience and meaning.

As Robertson & Hale (2011) noted in a study about researchers who were also health professionals, there are important differences in the nature of the interviewing process compared to assessing people as a health professional, with active listening endorsed as a core skill. I endeavoured to remain open to being surprised by what the participants described, which is vital when undertaking research where the topic is well known to the interviewer (Gramstad et al., 2014). A clear lead into the end of a qualitative interview was important, to reduce the risk of a participant sharing interesting and relevant information after the recorder has been turned off (Braun & Clarke, 2013) and so I signalled the upcoming end of an interview while allowing for more points to be made or prioritisation of comments.

## **Data analysis**

In line with grounded theory methods (Becker, 1993), data analysis occurred concurrently with data collection. NVivo 10 (QSR International Pty Ltd, 2012) software was used to help organise and manage the interview data. Field notes were also generated immediately after each interview in order to begin analysis and consider further selection criteria depending on early themes. The transcripts were then read line by line with a code assigned to a word, phrase or paragraph (Bradley et al., 2007), resulting in over 200 initial codes. At this stage of coding, all possible meanings and directions for analysis remained open. Constant comparison was used to refine codes, where each code was compared with others at coding level and at the level of text (Charmaz, 2006). The relationships between and within categories emerging from this coding were explored with increasingly higher levels of conceptualisation. These were organised with the use of memo writing and diagrams, which are recommended as part of the abstraction process for themes (Buckley & Waring, 2013). Focussed coding resulted in broad categorising of codes, looking at connections and where data did and did not support further development of categories. Practically, this meant looking at coding using the NVivo programme and then printing off the NVivo code list to see all codes laid out over six pages, using highlighters and notes to re-organise codes.

Assumptions were checked against the raw interview data and re-worded when needed and developing core categories were placed in hierarchies. Some of these clustered hierarchies were clear and consistent early on, for example, that the effort to learn how to use equipment was worthwhile if it enabled getting out of the house. Other categories were developed from initially disparate threads that took longer to understand in relation to each other. Naming core codes becomes more interpretive rather than descriptive at this axial coding level (Charmaz, 2006), capturing the essence of the meaning of equipment and the equipment provision process. Organisation of codes, with supporting quotes, was shared with supervisors at this stage of the analysis where wording, concepts and relationships between ideas were challenged and debated, resulting in refinement of themes. Categories were developed, compared and contrasted in relation to the results of Phase 1 to ascertain links and contradictions, which is consistent with a sequential explanatory mixed methods framework (Creswell et al., 2011).

While grounded theory coding is purported to be purely inductive, there is an argument

to include some deductive elements to the coding process. As the original instigators of grounded theory have developed their guidelines for analysis separately, Glaser has maintained a stance on staying purely inductive (Glaser, 2007), while Strauss & Corbin (1997) have written about the value to having some guidelines and structure around coding process. As part of analysis, noting frequency of themes by primary coder and peer coders contributed to decision making about core themes and subsequent theory building (Maxwell, 2010). Providing a broad sense of frequency of ideas can assist with identifying patterns in qualitative data, for example by use of words like 'seldom' or 'often', can contribute to evaluation of the internal validity of a study, by illustrating how common ideas or experiences were across all participants (Maxwell, 2010; Sandelowski, Voils, & Knafl, 2009).

Quotes are used in grounded theory to illustrate how a phenomenon or category has been observed by the researcher, so that readers can have belief in the result of abstraction (Sandelowski, 1994). For the purposes of this research, sounds that were uttered that did not seem to add value to a quote were removed from transcripts, however speech patterns were not otherwise changed. Also, for studies such as this one, which have participants with different demographic characteristics, it was important to indicate who contributed which quote in order to provide context to the analysis (Sandelowski, 1994).

### **3.7 Phase 3: Focus groups with therapists**

Focus groups were used to address the research objective about exploring the perspectives of therapists who prescribe equipment regarding their role and the influences on their decisions regarding equipment funding. Focus groups work well where research relates to social understandings, context and culture (Kitzinger, 1994; Liamputtong, 2011) and can be used to unearth the thinking patterns of a group (DeWalt et al., 2007). Focus groups have, for instance, been used to elicit occupational therapy opinion on best practice in equipment prescription in Australia (Angelo et al., 1997) and America (Ripat & Booth, 2005). The advantage of this mode of data collection over others lies in the ability of focus groups to maximise interactions that occur between group members (Seale, McCreadie, Turner-Smith, & Tinker, 2002). Participants in focus groups can find the experience more stimulating than other structured modes of data collection (Bristol & Fern, 1996) and focus groups can offer a more naturalistic form of data collection than interviews as conversations between participants

create opportunity for connecting ideas (Wellings, Branigan, & Mitchell, 2000).

### **Participant recruitment**

Therapists were invited to participate in a focus group if they were working as accredited equipment assessors and were either an occupational therapist or a physiotherapist, and they had current or previous experience working with people with stroke. Participants were recruited from two DHBs – Capital & Coast DHB and Hutt Valley DHB. Four professional advisors (one each for physiotherapy and occupational therapy in each DHB) agreed to support recruitment for this study, identifying that this topic was of interest and relevance to their professional groups. The therapists were invited to take part in focus groups by their professional advisors who e-mailed potential therapists who met inclusion criteria. Professional advisors assisted with booking rooms in the respective hospitals to optimise ease of therapists attending.

There was a focus on recruiting therapists with a wide range of experience, including experienced and newly qualified therapists. It has previously been noted that newly qualified practitioners are likely to avoid sensitive issues and discuss process in an under-confident manner, whereas expert therapists are more likely to be conversational when discussing process and more willing to discuss sensitive issues (Mitchell & Unsworth, 2005). However, it was assumed that newly qualified practitioners were likely to have different roles and perspectives regarding equipment prescription so their input was considered valuable to this research. All focus group participants received a participant information sheet and signed a consent form (Appendix N) prior to taking part. There was an opportunity to ask questions and to have a support person present at meetings if desired.

### **Data collection**

I collected data during six focus groups, the smallest having four participants and the largest comprised of seven, in line with recommendations to keep focus groups to less than eight participants so that all groups members can contribute (Krueger & Casey, 2009). Meetings were audio recorded with digital recorders and transcribed verbatim by either a qualified typist or I transcribed them. Participants were divided into groups based on experience (with separate groups for new graduate and experienced therapists) and professional background (with separate groups for physiotherapists and occupational

therapists). These steps were taken because group members are often influenced by their relative status to other members of the group as well as by accepted local norms (Hollander, 2004; Liamputtong, 2011). Also, as advised by Krueger and Casey (2009), where it is reasonable to assume that different groups have different collective experiences of a phenomenon, homogeneity within groups is encouraged in order to contrast these experiences. No managers were present in any groups.

Focus groups were semi-structured, where broad open-ended questions were developed into an initial schedule to guide data collection (see Appendix O for focus group schedule). I incorporated the ideas and issues which had arisen in Phases 1 and 2 into the design and running of the focus groups. This process happened in a planned way, where specific examples and questions were included in the focus group schedule and also in an opportunistic way, where focus group participants brought up issues that were complemented or contradicted by comments from users of equipment. Therapists' clinical reasoning process for equipment prescription for people with stroke was explored as well as their perspective on the factors that contributed to their decision making in this area. Their opinions on the challenges and gaps within the current processes for equipment prescription were recorded and the focus group schedule was adjusted as data collection progressed. Demographic characteristics of the therapist participants were also collected (see Appendix P for data collection tool).

The focus group schedule of questions was kept purposefully open, bringing up broad topics and then allowing group members to offer their own ideas with the intention that they would inspire and reflect on each other's contributions, as a less structured interview schedule enables more organic conversations (P. Kidd & Parshall, 2000). I recorded notes directly after each group and the interview schedule was reviewed in conjunction with these field notes and amended for future groups as some topics elicited strong opinions whereas others were of little or no consequence to group members.

When providing prompts to participants during the focus groups, I balanced neutral responses to comments (for example, 'okay') with more encouraging ones, designed to enhance the quality of data provided (for example, 'that's really interesting, tell me more'). I used phrases such as 'think back to' to link the focus of the group with context that therapists

were directly familiar with, starting by asking them to provide me with the first words that came to mind when I mentioned the term 'adaptive equipment'. I used words I believed participants would use when talking about these issues and also noted the terms they preferred as they talked. I focussed on evoking conversation rather than asking direct or complex questions. While many of the skills inherent to qualitative interviewing also apply to moderating focus groups, there is an additional need to be a levelling presence to enable group members to consider different perspectives without pressure (J. Sim, 1998) and moderation of a focus group needs to maximise the depth of information shared (Liamputtong, 2011). Information sharing can be encouraged or hindered by the interactive component of groups, where participants are sharing ideas in a forum where they may feel judged. For example, when new graduate participants expressed controversial views or appeared uncomfortable, I took a supportive approach, reminding them there were no wrong answers.

During focus groups, I was mindful that my appearance and attitude could have a bearing on the nature of the discussion that arose (Wellings et al., 2000). Some group members were known to me, some knew of me, and all participants were aware that I was an occupational therapist. This was both an opportunity and a risk to be managed. Rapport is important in making focus group members feel comfortable enough to share their honest thoughts with the group and the facilitator (Braun & Clarke, 2013) and a researcher who was perceived to know little or nothing of the participants' world would have possibly met with less enthusiasm. However, my background as an occupational therapist also meant that the potential for me to impose my own established ideas on the line of questioning and responses was a threat to validity. This was managed by me keeping reflective diary records about the focus groups and on my contribution to them, debriefing with supervisors between groups, and with peer coding completed by my supervisors. Providing food at focus groups was important, as sharing food can facilitate a non-threatening beginning to communication (Krueger & Casey, 2009), so morning or afternoon tea with snacks were offered prior to the meetings.

### **Data analysis**

Data collection and analysis in Phase 3 followed a similar format to Phase 2 in that this followed the principles of grounded theory. Similarly, analysis of the Phase 3 data also



involved constant comparative coding, an iterative approach to increasingly more conceptual coding progressing from line by line coding to axial and theoretical coding (Charmaz, 2006), memo-ing and diagramming (Charmaz, 2008a). In addition, due to the substantial amount of data generated from these six focus groups, two complementary processes were incorporated into the analysis: fragmenting and connecting (Dey, 1993).

Fragmenting consisted of separating and labelling components of each focus group using line by line analysis and constant comparative coding. Connecting was the process of constructing meaning from the meticulously labelled codes, where the parts were interpreted as a whole (Boeije, Duijnste, & Grypdonck, 2003). The recommendations by Charmaz (2006) on axial coding and theoretical coding became more pertinent at this stage of analysis, where patterns, similarities and contradictions were explored. The importance placed on equipment as part of the practice and professional identity of therapists was explored and questions about whether ethnicity and culture affected decision making with equipment provision were posed. Situations where it appeared that dual roles or inconsistencies were acknowledged were scrutinised.

### **3.8 Synthesis of data from the three phases of study**

The aim of combining data from these three interlinked phases of study was to produce a clearer understanding of how the equipment provision system for stroke currently operates in New Zealand and whether it is fit for purpose. In the following chapters, the results from Phase 1, 2, and 3 are presented individually in Chapters 4, 5, and 6 respectively, with the final 'connecting' stage of analysis (Dey, 1993) presented in Chapter 7, as is appropriate for a sequential explanatory mixed methods study (Creswell & Plano Clark, 2011). In this final stage of analysis, the relationships between the equipment user and provider perspectives were merged together and presented in relation to the core processes underpinning equipment use and provision after stroke. Furthermore, theoretical sensitivity in the development of this summary has been enhanced by the inclusion of information from the funding body about current status and future directions of the policy and structure of publicly funded equipment.

The processes by which data has been synthesised to form theory in mixed methods studies has often not been made explicit (Creswell et al., 2011; Eaves, 2001). However, in this chapter, the recursive development of codes, clusters of ideas and theory development has

been clarified. This was necessary as mixed methods research needs to not only compare results against each other, but also present a synthesised summary including relevant debate between different strands of data collection (Bryman, 2007).

Theoretical concepts which emerged throughout the study were collected, and the overall relationships between them examined. Each method was sufficiently developed for its purpose (O'Cathain, Murphy, & Nicholl, 2008) and rival explanations for all findings were explored during analysis and when drawing together all perspectives at the final stage, thereby ascertaining validity by 'examining sources of invalidity' (Kvale, 1996, p. 241). Early results were held loosely in terms of confidence until further sources reinforced or invalidated them, for example, the value of mobility equipment indicated by the initial questionnaire data was strengthened and contextualised with subsequent waves of data collection.

In terms of this thesis, one starting point for the integration of phases of the study as a whole centred on the processes for participant sampling. In mixed methods research, a number of different approaches to sampling have been recommended (Yoshikawa, Weisner, Kalil, & Way, 2008) and in this research, sequential sampling was used. This approach advocates that information from one sample and wave of data collection is used to help select participants for the next sample (Teddlie & Tashakkori, 2009). Due to the application of grounded theory to the design and analysis of the second and third phases of this study, principles inherent to grounded theory sampling, such as purposeful and theoretical sampling, were also considered important (Charmaz, 2008a). For purposes of demonstrating how data collection was integrated across the three phases of this study, the following is an overview of the inter-relationship between sampling in different phases of this research.

In Phase 1 (the survey), participants were adults with a primary diagnosis of stroke, who had been discharged from hospital after a minimum stay of seven days over a one year period. Efforts were made to recruit all people who met the inclusion criteria from five DHBs. In Phase 2 (interviews with people after stroke), purposeful sampling was used to identify and recruit key informants from those who responded to the initial population-based survey. Preliminary analysis of data from Phase 1 influenced the selection of characteristics for purposeful sampling in Phase 2. These included: 1) selecting participants to represent a range of core demographic characteristics including typical and atypical age, ethnicity, social

situation and health status, to maximise variation (Patton, 2002b), 2) selecting participants who expressed extremes of satisfaction and dissatisfaction with the equipment provision service, plus those who were ambivalent, and 3) consideration of free-text responses from the questionnaire to select people most likely to produce information-rich interviews (McCreadie & Tinker, 2005; Patton, 2002a).

Emerging findings from the first eight interviews in Phase 2 then informed the recruitment of further participants to this phase of the study. Recruitment for Phase 2 ceased when theoretical saturation was reached, as is consistent with grounded theory (Charmaz, 2006). Results from Phases 1 and 2 were discussed during the focus groups in Phase 3, to prompt discussion and debate about issues important to users of equipment. Determining adequate sample size in qualitative research is ultimately a matter of judgment and experience in evaluating the quality of the information collected against the uses to which it will be put (Sandelowski, 1995). For the purposes of this study, the quality of the data collected at the end of six focus groups was deemed sufficient to develop a thick and rich description of the process of equipment prescription after stroke, from the perspective of those issuing the equipment.

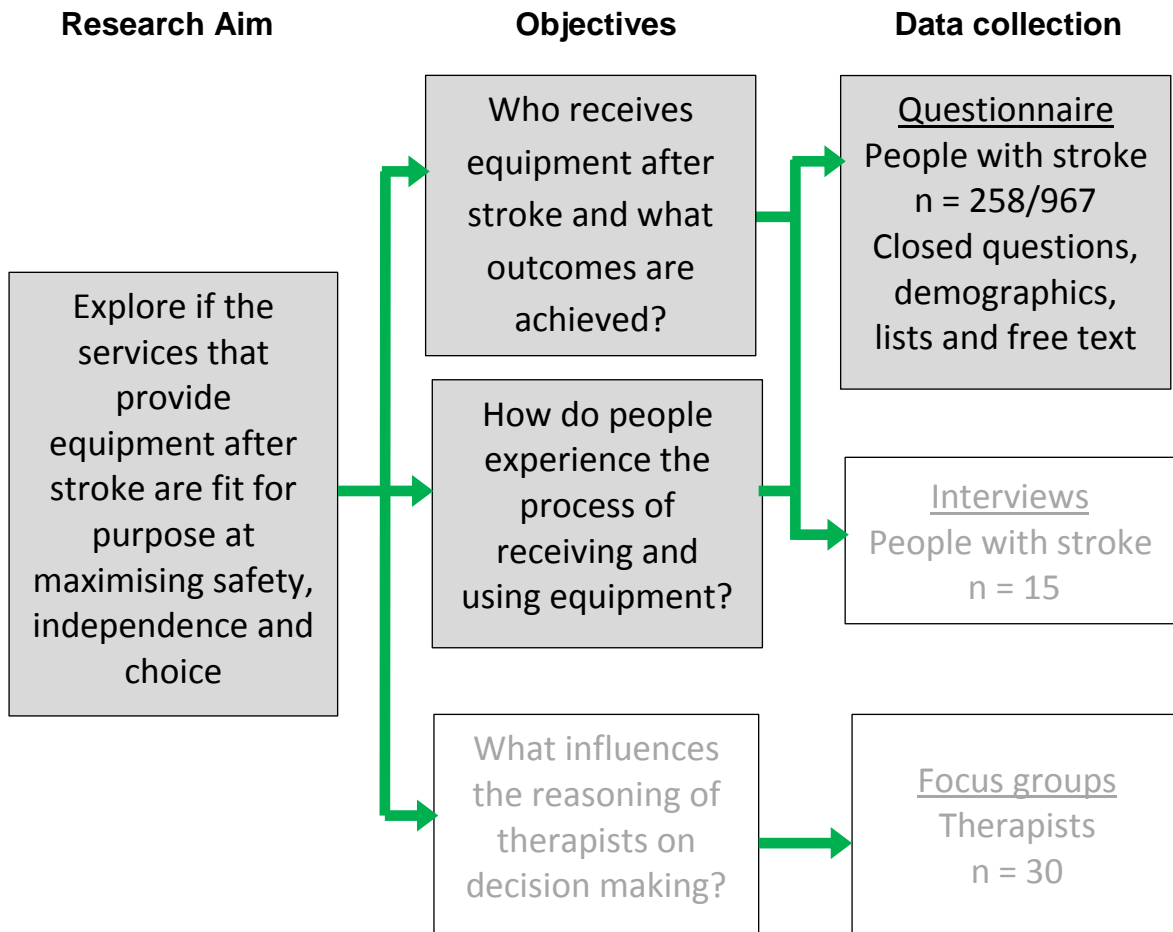
### **3.9 Summary**

Sequential explanatory mixed methods was used to develop the research design for this thesis, in conjunction with grounded theory principles. These methods were underpinned by a pragmatist philosophical approach and the rigour associated with the application of the methods have been described in this chapter and will be evident throughout the remaining chapters where the results are described.

## Chapter 4. Phase 1: Questionnaire results

### 4.1 Chapter outline

This chapter presents the results of Phase 1, from data collected via a questionnaire sent to people who had a stroke in 2012. The questionnaire design, recruitment strategy, data collection and data analysis were detailed in Chapter 3. All of the continuous or categorical results, including secondary analyses such as logistic regression, are presented prior to the analysis of the free text responses from the questionnaire. The aims and objectives which are addressed in this chapter are emphasised by grey boxes in Figure 4.



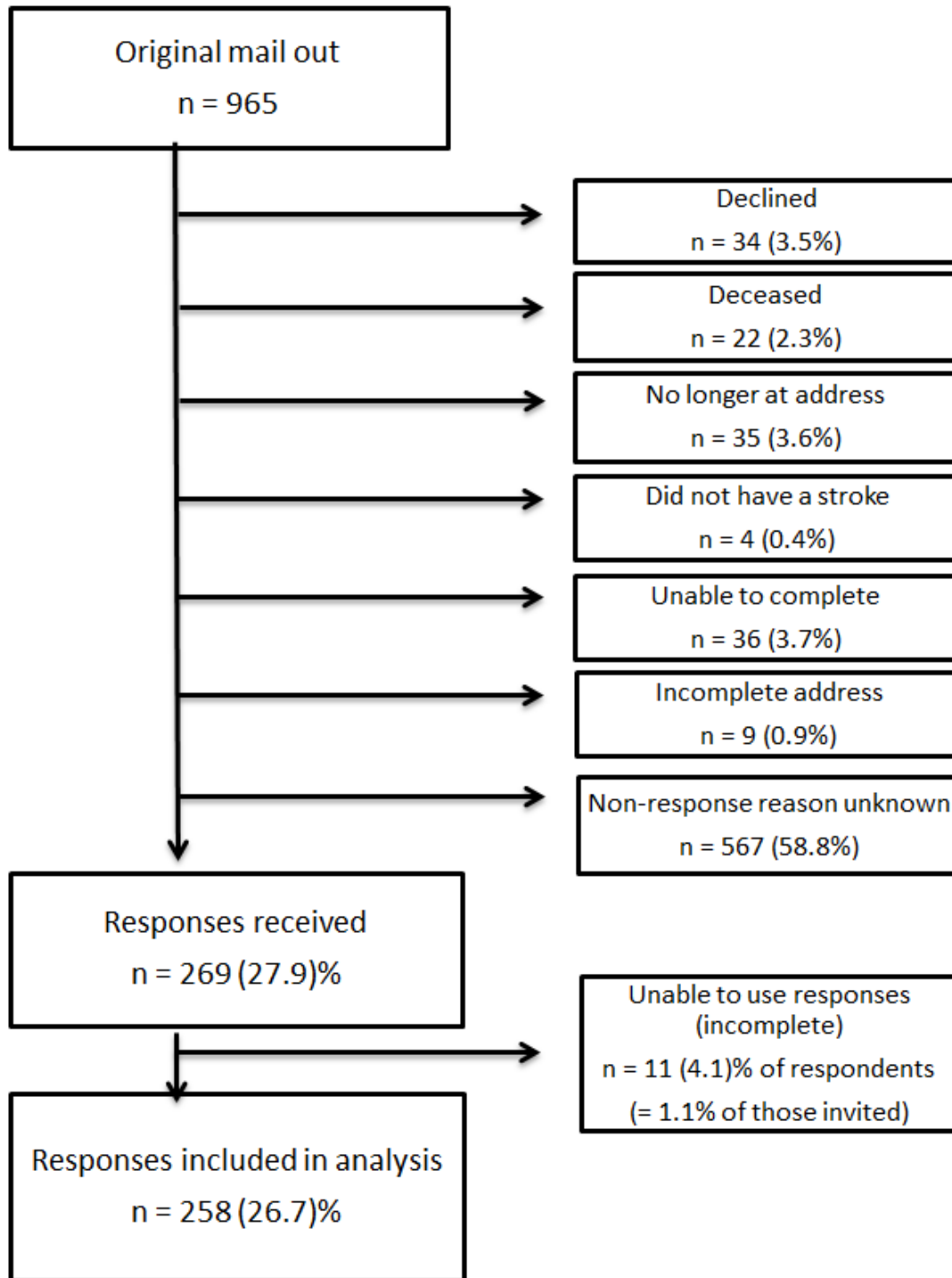
*Figure 4 Relationship of data collection and objectives: Phase 1*

## 4.2 Description of participants

### Response rate

In total, 965 adults were identified who had been admitted to hospital for more than 7 days between 1 January and 31 December 2012, and were sent an invite to participate. Two hundred and sixty nine responses were received, 11 of which were insufficiently complete to permit inclusion, so the final response rate was 26.7% (258/965). Reasons for non-response (where known) are outlined in Figure 5. Due to limited access to DHB databases and the third party distribution process of questionnaires for some DHBs (as outlined in Chapter 3), I was unable to ascertain the characteristics of non-respondents for the purposes of comparison to respondents.

There are other reporting decisions to be aware of when reading these results. While 258 responses were analysed, the denominator changed for each question, depending on two things; whether a respondent answered a question and whether the respondent had been prescribed equipment or not. So, for equipment use questions I only included people in the analysis if they had or have had equipment. Additionally, respondents missing an answer to a particular question were excluded from analysis of that question.



*Figure 5 Summary of response and non-response*

Fifty eight percent (567/965) of the invited population did not respond and did not provide a reason for not responding. However, a non-response reason was known for 14.5% of invitees. These non-response reasons were logged by me when family members, recruitment aides at DHBs or care staff contacted me. Reasons for declining included not having the time, ill-health of the potential respondent and lack of interest in stroke related research.

For the purpose of describing the groups who responded to this questionnaire, those who had equipment at some stage (5.8 %, 15/258) had their responses grouped with those who indicated that they had equipment at the time of the questionnaire (62.4%, 161/258). This decision was taken considering the core research aim about understanding equipment use and equipment provision services, where those who had equipment at some stage would be in a position to comment fairly on these issues. So the group of participants who were considered to have, or have had equipment was 68.1% (176/258).

Descriptive statistics for sociodemographic and clinical characteristics for people after stroke with and without equipment are presented in Table 4.1. Most participants had experienced more than one stroke, with the two groups including a similar number of people with first time stroke. The mean age for people with stroke issued with equipment was 75.8 years while the mean age for people with stroke without equipment was 71.8 years, so the group without equipment was slightly younger. Likewise, people with stroke with equipment were reported to have overall poorer health status, were less likely to be employed and were more likely to be living in residential care. Based on these demographic comparisons people with stroke who are issued with equipment have greater needs with regards to health, disability and care than those without equipment. Further demographic features are described in Table 4-1.

**Table 4-1 Demographic comparisons: People with stroke with and without equipment**

Demographic variable	With equipment n = 176			Without equipment n = 82		
Age						
Mean	75.9			71.8		
Minimum / Maximum	37 – 97			50 – 91		
Standard Deviation	10.9yrs			9.4yrs		
	%	n	95% CI	%	n	95% CI
Gender						
Male	45.5%	(80/176)	37.95% - 53.12%	65.9%	(54/82)	54.55% - 75.97%
Female	54.5%	(96/176)	46.88% - 62.05%	34.1%	(28/82)	24.03% - 45.45%
Ethnicity						
New Zealand European	88.6%	(156/176)	83.00% - 92.92%	90.1%	(73/81)	81.46% - 95.64%
Non-New Zealand European	11.4%	(20/176)	7.08% - 17.00%	9.9 %	(8/81)	4.36% - 18.54%
Self-reported health status						
Excellent or very good	16.3%	(28/172)	11.10% - 22.66%	27.5%	(22/80)	18.10% - 38.62%
Good or fair	76.7%	(132/172)	69.71% - 82.84%	68.8%	(55/80)	57.41% - 78.65%
Poor or very poor	7%	(12/172)	3.66% - 11.87%	3.8%	(3/80)	0.78% - 10.57%



Demographic variable	With equipment n = 176			Without equipment n = 82		
<b>Social status</b>						
Lives with family or partner	53.7%	(94/175)	46.03% - 61.27%	60%	(48/80)	48.44% - 70.80%
Lives alone	32.6%	(57/175)	25.69% - 40.05%	36.3%	(29/80)	25.79% - 47.76%
Residential care	12.6%	(22/175)	8.05% - 18.41%	1.3%	(1/80)	0.03% - 6.77%
Other	1.1%	(2/175)	0.14% - 4.07%	2.5%	(2/80)	0.30% - 8.74%
<b>More than one stroke</b>						
Yes	38.2%	(65/170)	30.90% - 45.99%	32.1%	(26/81)	22.15% - 43.40%
No	61.8%	(105/170)	54.01% - 69.10%	67.9%	(55/81)	56.60% - 77.85%
<b>Employment status</b>						
Retired	82.4%	(140/170)	75.78% - 87.77%	75.9%	(60/79)	65.02% - 84.86%
Unemployed	10.6%	(18/170)	6.40% - 16.22%	2.5%	(2/79)	0.31% - 8.85%
Employed (part or full-time)	5.9%	(10/170)	2.86% - 10.55%	17.7%	(14/79)	10.04% - 27.94%
Homemaker	0.2%	(2/170)	0.14% - 4.19%	3.8%	(3/79)	0.79% - 10.70%

Demographic variable	With equipment n = 176			Without equipment n = 82		
Highest education level						
Post high school training	21.2%	(36/170)	15.29% - 28.09%	13.4%	(11/82)	6.89% - 22.74%
High School	65.9%	(112/170)	58.23% - 72.97%	81.7 %	(67/82)	71.63% - 89.38%
Primary School	12.9%	(22/170)	8.29% - 18.94%	4.9%	(4/82)	1.34% - 12.02%
Use of community services +						
No	30.1%	(52/173)	23.05% - 37.08%	81.5%	(66/81)	71.30% - 89.25%
Yes	69.9 %	(121/173)	61.73% - 75.89%	18.5%	(15/81)	10.75% - 28.70%
Rural/Urban						
Rural	14.9%	(26/175)	9.94% - 21.01%	27.2%	(22/81)	17.87% - 38.19%
Urban	85.1%	(149/175)	78.99% - 90.06%	72.8%	(59/81)	61.81% - 82.13%
Community service card holder*						
Yes	62.8%	(108/172)	54.08% - 68.95%	50.6%	(41/81)	39.27% - 61.92%
No	37.2%	(64/172)	29.43% - 44.17%	49.4%	(40/81)	38.08% - 60.73%

+ Refers to paid carer, home help, district nurse visits, meals on wheels or residential respite

\*Refers to people who are on a low to middle income who receive a card which entitles them to discounted healthcare and other social services

### 4.3 Equipment received and outcomes achieved

The majority of respondents (43.6%, 113/252) had their stroke between 12 and 18 months prior to completing the survey, with the next largest group being 6 to 12 months post-stroke (31.6%, 82/252). Despite inclusion criteria that participants had their stroke at least 6 months ago, 9.7% (25/252) of respondents reported that they had their most recent stroke in the 6 months preceding receiving the questionnaire. This indicated that they had possibly had another stroke following the stroke hospitalisation event for which they were selected into the study. These people were still included for analysis as, according to their DHB records, they had also had a stroke in 2012. Over 28% of people (69/245) indicated that they had a support person help them to complete the questionnaire. The spread of respondents by DHB is depicted in Table 4-2. There were two respondents who lived outside the five DHBs surveyed. This may be because they had their stroke while still within a target DHB and then had moved.

**Table 4-2 District health board where participants were treated after stroke in 2012**

DHB	Response percent	Response count
Canterbury DHB	34.9%	(90/258)
Waikato DHB	23.6%	(61/258)
Capital and Coast DHB	15.5%	(40/258)
Southern DHB	15.4%	(39/258)
Hutt Valley DHB	10.1%	(26/258)
Other DHB	0.8%	(2/258)

DHB = District health board

Most participants had equipment at some stage in their recovery from stroke (68.2%, 176/ 258). Some participants reported having had equipment from before their most recent stroke (26.5%, 43/162) and a quarter of people with equipment relied on someone else to help them to use it (25%, 40/160). The most important item of equipment was usually provided by a public hospital or the health service (78.1%, 125/160) while to a lesser extent people had

purchased their most valued items themselves (16%, 35/160). The frequency of common types of equipment which was used by people with stroke is depicted in Table 4-3, where 155 respondents chose one or more items from a list. As a person could have more than one piece of equipment, the percentages reported are for each individual type of equipment.

**Table 4-3 Types of equipment in households used by people with stroke**

Answer options	Response percent	Response count
Walking stick	47.7%	(74/155)
Shower stool	47.1%	(73/155)
Walking frame + wheels and seat	39.4%	(61/155)
Toilet seat	27.1%	(42/155)
Toilet frame	21.9%	(34/155)
Wheelchair	20.0%	(31/155)
Commode	15.5%	(24/155)
Pick up stick	14.8%	(23/155)
Walking frame + seat	14.8%	(23/155)
Kitchen stool	14.2%	(22/155)
Bed lever	8.4%	(13/155)
Seat raisers	5.1%	(8/155)
Stool in bedroom/bathroom	2.6%	(4/155)
Lifting belts	1.9%	(3/155)
Kitchen trolley	1.9%	(3/155)
Other item (eligible) *	8.4%	(13/155)
Other item (ineligible) **	4.5%	(7/155)

\* When exploring items listed as 'other' handrails or orthoses were excluded for this research (4.5%, 7/155).

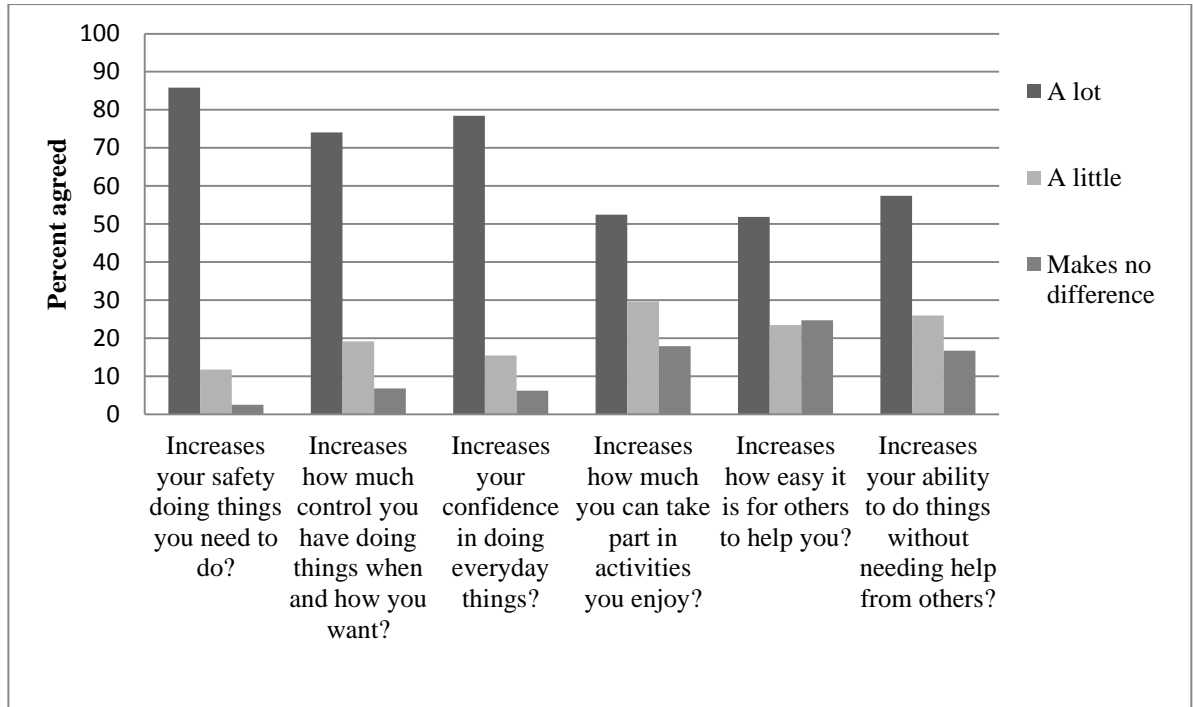
\*\*Included items were dressing aids (1.3%, 2/155), lift chairs (1.3%, 2/155), kitchen aids (1.3%, 2/155), electric bed (0.6%, 1/155), hoist (0.6%, 1/155), crutches (0.6%, 1/155), bath-board (0.6%, 1/155), slide across shower seat (0.6%, 1/155), urinal bottle (0.6%, 1/155) and a bidet (0.6%, 1/155).

**Most valued equipment**

Participants were asked which single piece of equipment was the most valuable to them. The majority placed highest value on equipment that enabled them to mobilise, either by walking or using a wheelchair (71.4%, 115/176). Bathing equipment was also highly valued (9.3%, 15/176), as were toileting items (6.8%, 11/176). Valued equipment was used every hour by some participants (24.2%, 39/161), but more participants indicated they used their most valued equipment daily (56.5%, 91/161). Some participants used their most valued equipment item only a few times a week (16.1%, 26/161) while few participants used these pieces of equipment less than once a week (3.1%, 5/161).

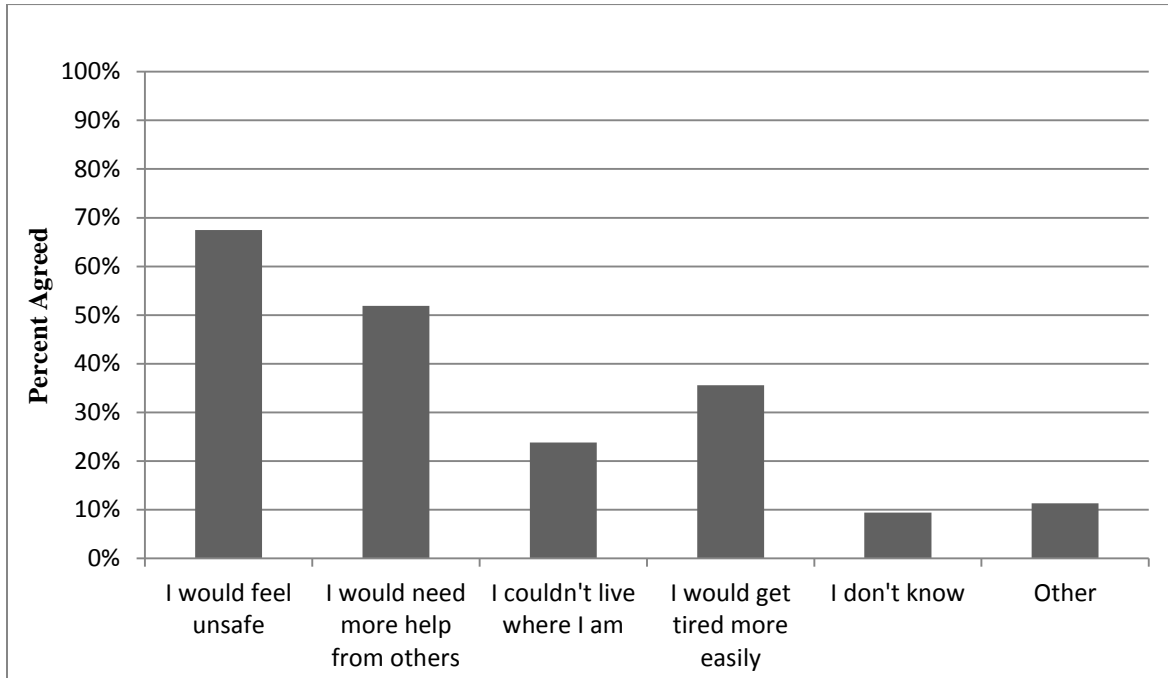
**Outcome of equipment use**

Most participants reported that they felt 'a lot' safer as a result of having and using their equipment (85.8%, 139/162). They also reported that equipment increased their confidence and control 'a lot'. Participants also reported favourably on outcomes such as having an increased sense of confidence (78%, 127/162) and control (74%, 120/162) due to having equipment. The responses were favourable, but less overwhelmingly so, when asked if equipment meant that they could take part in activities that they enjoyed a lot (52%, 85/162). Of note, very few people across all potential outcomes reported that the equipment made no difference. See Figure 6 for more details.



**Figure 6 Outcomes reported from using equipment**

When asked why their equipment was important to them, most people reported that they would feel unsafe without their equipment, (67.5%, 108/160) or that they would require more help from others (51.9%, 83/160) (see Figure 7). The majority of people who had equipment were either very satisfied with the items they had (66%, 107/162) or reasonably satisfied (30.9%, 50/162). Only one participant was very dissatisfied and a small proportion reported they could not comment either way (1.9%, 3/162).



\*Other = Free text responses, data on these is reported later

***Figure 7 Expected outcome if people with stroke did not have their equipment***

In the questionnaire, participants were invited to write about what they imagined would happen if they did not have their equipment. The free text responses to this question were often conceptually tied to the response-constrained Likert-style questions which preceded this question. At this early stage of theme development, analysis showed that equipment enabled participants with stroke to complete activities important to them. The areas of life which equipment impacted on positively were in relation to managing day to day life in their immediate environment, getting out into the world and reducing isolation as well as living with less fear. Many of the comments in this section were based on imagining living without the equipment that they had been given and participants imagined that they would lose physical fitness, sustain injuries and be more socially isolated. Quotes illustrating these ideas are provided in Table 4-6.



**Table 4-4 Reasons why equipment was important: Early analysis**

Managing day to day life
<p>‘Kitchen trolley, I use this to carry items around the house/outside as I have use of one arm only. I use this trolley for everyday items, pills, food, tea, phones. As I only have the full use of one arm only, this is invaluable!!’</p> <p>‘I can use it (stroller) in kitchen to do veges. I can wheel round to couch, then I can walk to toilet with my stick. I also can get into bed at night.’</p> <p>‘I would have difficulty transporting food from kitchen to living room.’</p>
Getting out into the world and reducing isolation
<p>‘Would become bedridden, confined to one room and stuck in bed all day.’</p> <p>‘I would be frustrated, feel more dependent, couldn't go outside or get around rest-home/hospital when I wanted.’</p> <p>‘Lack of social contact and shopping excursions, doctor visits, other medical visits for appointments, outdoor excursions, reduced independence.’</p>
Live with less fear (of falling, injury, tiredness, pain)
<p>‘There is possibility of falls during the night owing to my unstable balance and distance to the toilet.’</p> <p>‘Without the stick I would not feel secure when walking outside, e.g. on pavements, boarding buses etc. I do not normally use the stick indoors.’</p> <p>‘Sense of balance is poor even though I have an exercise programme I do.’</p>

#### **4.4 Who is more likely to receive equipment after stroke?**

Logistic regression was used to address the *a priori* question of whether ethnicity predicts who was more likely to have equipment after stroke, while accounting for other demographic variables. The hypothesis tested using this model was that people who were non-New Zealand European were less likely to receive equipment after stroke than New Zealand Europeans. The absence or presence of equipment was treated as a binary outcome and confounding factors that were included were age, social status and health status. Justification for including these confounding factors was provided in Chapter 2 and Chapter 3.

Only 10 participants were missing data on the key variables of interest. Therefore 248 cases (96%) were eligible to run the model out of a potential 258 cases. As all predictor variables in the model were categorical, the odds ratio is the odds of outcome in that level of the exposure variable (for example, ‘lives alone’) compared to the select reference group (‘lives with family’). Reference groups were selected based on either the largest subset in a variable group, or least at risk subset in each group, as is the rule of thumb for this type of analysis. The reference groups are highlighted in bold on Table 4-5.

**Table 4-5 Logistic regression analysis for equipment receipt after stroke**

Variable	(p value)	OR	95% CI for EXP(B)	
			Lower	Upper
Ethnicity				
<b>New Zealand European</b>	<b>.900</b>	<b>1.05</b>		
Non-New Zealand European	.484	.71	0.27	1.87
Health status				
<b>Excellent/Very good</b>	<b>.175</b>			
Good/Fair	.064	.52	0.26	1.04
Poor/Very poor	.370	.51	0.16	2.24
Age bands				
<b>71 - 80</b>	<b>.115</b>			
50 and younger	.692	0.61	0.05	6.92
51 - 60	.675	0.80	0.27	2.32
61 - 70	.546	1.24	0.61	2.53
81 - 90	.032	0.42	0.19	0.93
91 and older	.117	0.18	0.02	1.54
Social situation				
<b>Lives with family</b>	<b>.161</b>			
Lives alone	.524	1.22	0.66	2.25
Other living situation	.952	0.93	0.07	11.62
Lives in care	.037	0.11	0.01	0.88

CI = Confidence interval

OR = Odds ratio

The p-value on the first line in each section (for example 0.115 for age group) gives an overall test as to whether the odds of equipment receipt differ significantly by that variable. Confidence intervals can change depending on which reference group is selected. However, the p-value is not affected by the reference group selection. There is, therefore, no statistically significant difference between the odds of receiving equipment for people who were New Zealand European versus non-New Zealand European. While initially it appeared that being between the ages of 81 and 90 or living in care statistically predicted the likelihood of someone receiving equipment after stroke, given the wide 95% confidence intervals in this model, the null hypothesis cannot be rejected.

#### **4.5 Equipment provision process**

Thirty one percent of respondents (48/152) reported having received written information about the equipment they had received though more people reported receiving an actual demonstration of equipment 59.7% (92/154), either alongside the written information or instead of it. Respondents were asked to rate three standards of effective equipment provision: assessment of equipment needs, training in use of equipment, and quality and delivery of equipment. Participants reported high levels of satisfaction with all three standards, but particularly in relation to quality and delivery of equipment, as can be seen in Table 4-6.

**Table 4-6 Satisfaction with assessment, training and quality and delivery of equipment**

Standard	Excellent	Good	Fair	Poor	No opinion
Assessment	44.2% (69/156)	35.9% (56/156)	14.1% (22/156)	1.3% (2/156)	4.5% (7/156)
Training	35.9% (56/156)	36.5% (57/156)	9.0% (14/156)	4.5% (7/156)	22/156 (14.1%)
Quality and Delivery	49% (76/155)	36.8% (57/155)	8.4% (13/155)	2.6% (4/155)	3.2% (5/155)

When asked if they had equipment options explained to them, 41.7% (65/156) reported that this had ‘absolutely’ happened, 30.8% (48/156) reported that this had ‘mostly’ happened during equipment assessment and provision and 12.2% (65/156) reported that this had happened ‘a little’. Only 9% (14/156) reported that they had not had any options explained to them while 6.4% (10/156) did not know whether this had occurred or not. In rating whether their views and preferences were taken into account, participants reported that they ‘absolutely’ (45.5%, 71/156) or ‘mostly’ (32.7%, 51/156) had their views and preferences taken into account. For those who reported that their views and preferences had only been elicited ‘a little’ (8.3%, 13/156) or ‘not at all’ (5.1%, 8/156) during equipment assessment, free text responses further illuminated whether experiencing choice was important or desired by participants and are discussed later in this chapter.

In addition to the response-constrained Likert-style questions, participants were also invited to provide free text responses to questions about aspect of the processes of equipment provision in the public health sector, using their own words. Analysis of data on these free text responses suggested that to be effective, equipment provision services needed to offer guidance on equipment choice, rather than just choice. Tailored instruction on the process of acquiring and using equipment was also considered an important component. Underpinning this early theory development appeared to be two key concepts: 1) that ownership of decision

making was affected by the person with stroke's ability and interest to take part in decision making and 2) that a trusting working relationship between the clients and the prescribing therapist was required for shared decision making to be successful and effective.

In terms of needing guidance on choice of equipment, some participants reported that they did not and could not know what was available and what would be suitable for them. As a result, they relied on people other than therapists to advise them on equipment:

I had no knowledge of the health industry and no idea about all the equipment available that stroke people need. I got more help from a friend with only one arm about equipment (Male, 81 years).

One participant, while willing to be guided by her therapist regarding what equipment was required as she herself did not know, had quite specific requests about the look and utility of her kitchen trolley:

I had no views/preferences as I was unaware of what I'd require apart from the trolley; I had requested light, white and ease of use (Female, 72 years).

The ambivalence expressed about certain pieces of equipment contrasted with a clear sense of priority in relation to the kitchen trolley for this equipment user. For some participants, the equipment possibilities appeared strikingly obvious from the outset, whereas others recounted consenting to whatever the therapist recommended, feeling that they had a lot of other, more important, things to worry about in the immediate aftermath of their stroke. This interest and ability to think about what equipment they needed often developed as their recovery progressed, as reported by one participant:

After my stroke I had no idea about what I would need but as time went on it became more obvious that some things would be more useful (Male, 63 years).

Recalling who did what from earlier days post stroke was a challenge for some participants, with one person describing that the 'hospital' had decided what equipment would be required for them and that they had agreed. People trusted hospital staff, particularly when someone was going through as traumatic an illness as a stroke, and as a result they were willing to agree with whatever the hospital staff decided they needed:

I think the hospital decided it [the equipment] was necessary and I would

agree with that (Male, 87 years).

Another participant described how, after she was discharged from hospital to a rest home instead of her home, she had been given some photographs of different walking frames for her to look at and consider. While this could give her an idea of what she could possibly use, the physiotherapist also added that she had a recommendation for which would work best for her:

The physio lady said 'I'll send you the photos of several but I think I know which one is best for you' (Female, 84 years).

This example is about how a physiotherapist gave choices, while also providing direction and advice based on and her experience with equipment prescription. Finally, participants acknowledged that their therapists were required to balance explaining how to use equipment with encouraging people to use them:

It's a balance game between the therapists explaining and demonstrating how to use a piece of equipment, and also in part being the encourager (Female, 69 years).

While it was not clear why the therapist was encouraging this participant to use their equipment, what is interesting is that the person with stroke noticed that there were multiple roles occurring for the therapist during the equipment provision process. Further examples of quotes supporting these emerging ideas are provided in Appendix Q.

#### **4.6 Cost of equipment**

One hundred and sixty one people reported having equipment at the time of the questionnaire. Of these, 145 gave consent for me to access their Ministry of Health records to work out what equipment they had been issued. A list with respondents' names, dates of birth and addresses was sent to an administrator at Enable New Zealand as a password protected document, along with proof of consent from participants for me to access this information. This administrator searched records for an 18 month period from January 2012 to June 2013 (inclusive) and returned an Excel spreadsheet where 45 people had no record of equipment issued for that time period and for the remaining 100, varying equipment lists were supplied. This timeframe was chosen to include costs which related to people who may have had their

stroke in November or December 2012 but who had not received equipment until later on. The companies who supplied the items recorded by Enable New Zealand (n = 20) were approached to request the costs for each item of equipment issued. These costs did not include goods and services tax or freight, but were still greater than the actual costs which Enable New Zealand purchased these items for. The true cost was not released to me due to commercial sensitivity as equipment companies give substantial discounts to Enable New Zealand in order to be a preferred provider of equipment. The costs which were available are outlined in Table 4-7.

When the cost of re-issued equipment was removed, the cost of new equipment funded by the Ministry of Health for this sample of people with stroke was NZD \$71,040. Approximately 26.7% of potential respondents who had a stroke in 2012 from five DHBs returned this questionnaire. Assuming that NZD \$71,040 was spent by the Ministry of Health on new equipment for 26.7% of the stroke population of five DHBs, and knowing that the population of these five DHBs represents 39% of all people with stroke resulting in hospitalisation in 2012, the cost of new equipment to all people with stroke in 2012 in New Zealand can be broadly estimated as NZD \$1.2 million annually (excluding goods and services tax, freight, assessment costs associated with equipment, costs of reissuing equipment, and costs of management of this funding at a government level).

Approximately NZD \$29 million was spent by the Ministry of Health on equipment in New Zealand in 2013 – 2014 and given that funding has not increased significantly in recent years, this figure is likely to be similar to spending in 2012, when people in this research received their equipment. Therefore, the cost of equipment given to people with stroke represents 4% of spending for Ministry of Health funded equipment. However, considering that the predicted cost of all stroke care in New Zealand in 2015 is likely to be NZD \$700 million (Stroke Foundation of New Zealand, 2010), the cost of new equipment is less than .2% of spending.



**Table 4-7 Costs of equipment to people who sustained a stroke in 2012**

Cost category	Total cost NZD
Cost of all equipment supplied to people for whom data on equipment was available (n = 100), including new and reissued equipment	\$161,563
Cost of new equipment only for this sample (n = 100)	\$71,040
Estimate cost of new equipment for all survey respondents in 5 DHBs (n = 258, 26.7% of the eligible people with stroke in the 5 DHBs; 176 of whom had equipment and 100 of whom data on equipment could be identified)	\$125,070
Estimated total cost of all new equipment for people with stroke in 5 DHBs (39% of New Zealand population)	\$468,427
Estimated total cost of all new equipment for all people in New Zealand who sustained a stroke in 2012 (100% of New Zealand population with stroke)	\$1,201,095

DHB = District health board

#### 4.7 Summary

This chapter has focussed on the description of people with stroke who received equipment after stroke compared to those who did not. The findings in this chapter described who is more likely to receive equipment after stroke and outlined the experience of the equipment prescription service from the perspective of the users. Publicly funded equipment for mobility was most commonly reported by people after stroke and these items were most often cited as the most valued pieces of equipment. People who have received equipment valued their mobility items most highly and there was a high degree of utility of equipment where it was issued. The perception of safety, with related increases in control and confidence, were the most frequently reported outcomes resulting from equipment use and taking part in activities that people enjoyed was least reported. No one demographic factor clearly increased the likelihood of being issued equipment after stroke. Analysis of free text

data contributed insight into the reasons behind satisfaction ratings with standards of equipment provision. These reasons related to therapists providing guidance on choices of equipment and tailored instruction. These preliminary themes from are explored further in Chapter 5, in relation to data from qualitative interviews with 15 equipment users.

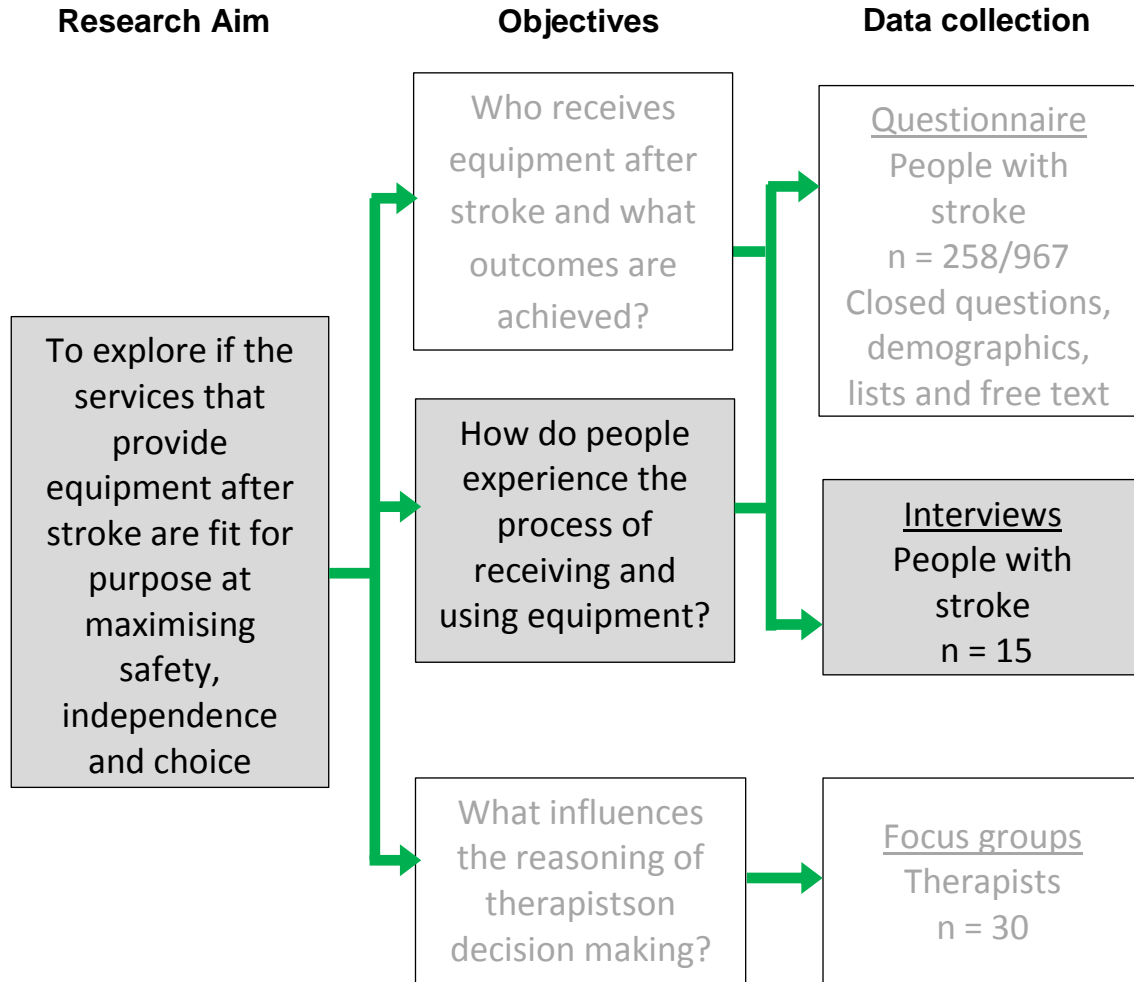
## **Chapter 5. Phase 2: Qualitative interviews with people with stroke**

### **5.1 Chapter outline**

In this chapter, I outline the demographic characteristics of 15 purposefully-sampled people with stroke who took part in qualitative interviews. The selection process and recruitment for this subset of questionnaire respondents were outlined in Chapter 3, along with data collection and analysis strategies. Analysis of these data produced a description of the ways in which equipment was issued and used by people with stroke. The themes which arose from analysis are introduced and explained in this chapter.

### **5.2 Relationship of results to the overall research**

The relationship of this phase of data collection to the aims and objectives of this whole study is summarised in Figure 8. The results presented in this chapter relate to preliminary theme development based on free text analysis in Chapter 4. This early analysis produced the idea that equipment provision services needed to offer guidance on equipment choice and tailored instruction on the process of acquiring and using equipment. There were two concepts underpinning this idea: 1) that ownership of decision making was affected by the person with stroke's ability and interest to take part in decision making and 2) a trusting working relationship between people with stroke and their prescribing therapist was required for shared decision making to be effective. These ideas were considered during collection of data for this chapter and are reflected upon at the end of this chapter, illustrating the iterative development of theory in this thesis.



*Figure 8 Relationship of data collection and objectives: Phase 2*

### 5.3 Description of interview participants

Table 5-1 outlines the demographic features of the 15 people who were interviewed, the types of equipment they used, as well as whether they indicated satisfaction or dissatisfaction with equipment provision process. Two of the participants lived in a hospital level care facility, three lived in rural settings and one lived in Housing New Zealand<sup>10</sup> accommodation. The mean age of people taking part in the qualitative interviews was 71.4 years and the age range was 49 – 90 years. Twelve participants had self-reported speech difficulties as a result of their stroke and four chose to have their partner present while one person had her daughter present. Interview time ranged from 12 to 44 minutes and took on average 27 minutes.

<sup>10</sup> State housing agency in New Zealand

**Table 5-1 Characteristics of qualitative interview participants**

Pseudonym	Age	Ethnicity	DHB	Social status	Equipment	Indicative attitude about equipment provision*
Jack	66	New Zealand European	Capital and Coast	Lives with wife	Toilet seat, walking stick, chair raisers	Good
Tracy	61	New Zealand European	Capital and Coast	Lived in hospital level care	Hospital bed, hoist, manual wheelchair with specialised back and cushion	Fair
Patries	81	Dutch	Capital and Coast	Lived alone	Crutches, kitchen trolley, chair raisers, showering and toileting equipment	Poor
Choum	80	Cambodian	Hutt Valley	Lived with daughter	Hospital bed, commode chair and manual wheelchair	Good
Doug	89	New Zealand European	Hutt Valley	Lived alone (wife in care)	Walking stick and made some of his own kitchen equipment	Fair
Aroha	58	Māori	Canterbury	Lived with husband	4 pronged walking stick	Poor

Pseudonym	Age	Ethnicity	DHB	Social status	Equipment	Indicative attitude about equipment provision*
Nigel	56	New Zealand European and Māori	Canterbury	Lived alone	Walker also has shower stool and kitchen trolley	Good
Paul	76	New Zealand European	Canterbury	Hospital level care, partner visited a lot	Self-propel wheelchair, bed table, hospital bed and hoist	Poor
Bert	79	New Zealand European	Canterbury	Lived with wife	Crutches and shower stool	Excellent
Josie	49	Māori	Waikato	Lived with partner	Walking stick (quad stick), wheelchair, seat for shower	Poor
Mary	81	New Zealand European	Waikato	Lived in flat on same property as her husband with dementia	Bed lever, walking sticks, shower stool, toilet frame, power chair and riser chair.	Good

Pseudonym	Age	Ethnicity	DHB	Social status	Equipment	Indicative attitude about equipment provision*
Mike	66	New Zealand European	Waikato	Lived with wife	Walking stick, wheelchairs (power and manual), shower seat, specialised toilet equipment and commode	Poor
Jan	58	Māori	Waikato	Lived with husband	Electric chair as well as manual wheelchair and shower and kitchen stool	Excellent
Charles	90	British	Southern	Lived alone	Walker with seat (bought own stick)	Poor
Tess	82	New Zealand European	Southern	Lived alone	Walker and walking stick	Excellent

\*Scores for 'Indicative attitudes toward equipment provision' were derived from reviewing the participants' responses to the Likert scale items in the questionnaire related to satisfaction with service delivery. Along with age, gender, ethnicity, and social situation, these scores were used to purposefully select people with a range of different experiences of equipment provision services

## 5.4 Introduction to themes

Two central themes emerged from the interview data. The revised central themes were named ‘inpatient impressions’ and ‘time and testing’. These themes illustrated that there appeared to be two distinct phases of engagement with equipment and equipment provision services; one phase centred on early engagement with equipment provision services after stroke and a second arose due to ongoing experiences of using equipment in the community.

Each of these two central themes was underpinned by two sub-themes. For inpatient impressions the two sub-themes were ‘trust in health professionals’ and ‘shifting worlds: from hospital to home’. For the central theme ‘time and testing’, the sub-themes were ‘making sense of equipment’ and ‘participation makes equipment worth the effort’. These central themes and sub-themes are illustrated in Table 5-2. Reference is also made to the most pertinent factors which influenced participants’ decision making about equipment at two different stages: immediately after their stroke and while still in hospital and sometime later when the participants had returned home or gone into supported living facilities.

Quotations provided from participants here and in Chapter 6 followed the syntax convention described in Appendix R.



**Table 5-2 Summary of themes from interview participants**

Central themes	Inpatient impressions	Time and testing
Sub-themes	Trust in health professionals	Making sense of equipment
	Shifting worlds: from hospital to home	Participation makes equipment worth the effort
Decision making about equipment is led by:	Health professional's advice and recommendations Desire of people with stroke to improve and to leave hospital	Whether the equipment provided is useful to people with stroke at helping them to stay safe and enabling them get out into their community

## 5.5 Inpatient impressions

### Trust in health professionals

This theme captured the role of trust people with stroke had in therapists in an often confused time. At this early time since sustaining a stroke, people looked to therapists for information about the equipment that was available and guidance on which items that would be most suitable for them to start moving again safely. Participants were often uncertain about their prognosis and their physical abilities at this stage; therefore how therapists communicated with them was vital in establishing trust. Participants described the opportunity to be listened to as highly valuable. Participants who believed that therapists were knowledgeable, competent and had the participants' best interests in the forefront of their minds were more satisfied with the service they received. Those who were dissatisfied felt that therapists did not take the time, or did not have the time, to discuss and understand their needs and goals.

Therapists were typically the first group to talk to people about equipment after a stroke, with this introduction to equipment often being woven through other interactions with them. These other purposes included clinical assessments, therapeutic activities in the hospital and home visits. For example, when being assessed for mobility strength, a therapist may bring a piece of equipment to the client's bedside or try a few different types of equipment in a gym. As such, many participants did not recall equipment assessment and provision as a discrete conversation with a therapist. For many participants, assessment and training for equipment happened implicitly amongst many other new and unfamiliar events while they were in hospital.

One of the ways in which participants discussed sub-optimal relationships with their therapists was when they felt their opinions or questions had not been addressed regarding the maintenance of equipment. Doug outlined his experience of this while he was on the rehabilitation ward. He had brought to the ward manager's attention a wheelchair with a broken footplate which had caused him an injury:

Doug: If they'd listened to me, I wouldn't be in this position now.

Interviewer: How did that feel, not being listened to?

Doug: Terrible. Because the head nurse down there said to me 'what are you complaining about today, old grumpy?' And I thought 'is that the way you speak to a client?' That's what she said to me down there [in the hospital]. And that's the way she treated me - I haven't forgotten that. I don't need that. (Doug, 89 years).

Doug found this comment from this ward manager to be particularly demeaning. For some time after this event, Doug was disinclined to engage with therapists about equipment. This experience affected him more than it may have other people because of his self-perception of being a handyman, someone who knew how to make and fix things. Indeed, following discharge from hospital he had constructed rails for his door out of old vacuum hose.

A contrasting example, where a good relationship with a therapist enabled a positive first experience with equipment, was explained by Aroha. She was encouraged to try out once familiar activities post-stroke in the kitchen at the rehabilitation ward, thereby

realising for herself how hard some everyday movements had become. Aroha described how her occupational therapist had enabled her to work out for herself how the use of her hands was limited when she needed them to balance while standing. Going through this process, including trialling equipment at the same time, while initially shocking for her, eventually resulted in her feeling that she had achieved something worthwhile:

And I had a really good relationship with my OT at [hospital name], who's lovely ... she got me in there [to the kitchen], and taught me how to cook again. And I didn't realise how really hard that is, when you don't have any confidence that you can actually stand up. That you know, how we do, when we just stand up, and we're not leaning on anything, you know. And that suddenly you've got no confidence to stand up, let alone to actually stand and do things with your hands. That was a huge achievement, really (Aroha, 58 years).

The cessation of rehabilitation could adversely affect how people viewed both themselves and their relationships with therapists. Those who had not achieved what they had hoped to achieve could feel abandoned. For example, Paul (76) was a resident in hospital level care as his care needs were too great for his partner to be able to assist him with at home. She visited him every day but they both expressed how disappointed they felt at the end of his this rehabilitation, where 'going into a home' was seen as the last and only resort. Inherent in the conclusion of formal rehabilitation was the implication that he had reached the end of his recover and that he was now 'stuck' with the wheelchair he had been issued:

Paul's partner: He was just too weak. So in the end, they just said 'well sorry, we can't do any more for you, you'll have to go into a home.' And that was it.

Paul: So I'm stuck with the wheelchair, that's where I am (Paul, 76 years).

So, while Paul could and did use his wheelchair to move himself, his perception was that he was stuck with the wheelchair as he had not recovered as he had hoped to. Prior to his stroke, Paul had used his garage shed to develop practical craft projects. He had an affinity for tools and could feel productive through problem solving how to fix items. While in residential care he continued to find different ways to overcome his impairments, sometimes, it would seem, exasperating staff members who were more concerned for his

immediate safety. For example, he tried pulling himself in his wheelchair along the corridor using the rails which were in place for people to lean on when walking. It was unlikely that Paul's therapist had envisioned him using his equipment in this way as it is not the ideal way to use a wheelchair. However, coming up with this idea and trying it out, which was partially effective, was confidence boosting for Paul. He gave another example of how he had tried to translate his previous interests into his living environment after stroke, describing his over-bed table as similar to his 'garage shed' where all things he needed were kept, like his television remote control, his newspaper and his diary.

At the time of planning discharge from hospital for someone with stroke, tensions could run high and disagreements between people with stroke, their families and hospital staff could become evident during the equipment provision process. For example, Mike had a moderately severe stroke and he had worked hard on his rehabilitation. He was 1.9 metres tall and had previously been fit and healthy so his change in functional ability was a significant change for him and his family. When he was close to discharge from hospital, he was issued with a wheelchair which suited his height and weight. However, a wheelchair which suited his physical needs was too heavy for his wife to push. She was much shorter than he, of slight build, and she had carpal tunnel syndrome<sup>11</sup> in both her wrists. Mike could not mobilise any way other than with a wheelchair at the time of discharge from hospital. Mike's wife made her concerns about the wheelchair known to the therapists involved in his rehabilitation but she was initially told that this wheelchair was all that was available.

When Mike's wife and he pursued this issue, threatening to delay discharge by refusing to take him home, the reaction from the therapists changed and an adapted wheelchair was arranged which better suited his wife. Both Mike and his wife perceived that no one was listening initially and that this lack of attention was due to their request relating to tailored accommodations for his wheelchair. Of note, Mike had a long career working as a social worker with youth and this may have influenced his and his wife's confidence in being assertive about what they thought they were entitled to and how the decision making process should have been managed from the health services.

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<sup>11</sup> a painful condition of the hand and fingers at the front of the wrist caused by compression of a major nerve.

Patries had lived on her own prior to her stroke and she had walked with crutches ever since she had a hip operation many years ago. When she was admitted to hospital following her stroke, she was strongly encouraged to use a walking frame by the therapists she met. She perceived this intervention from her therapist as a “rigamarole”<sup>12</sup> as she believed that she was safer walking using her crutches. Engaging with therapists about this point was stressful for her and had made her feel hesitant about returning to hospital again in case the same frustrating conversation ensued. Part of her frustration, similarly to Doug and Mike, was that she did not feel that she had been listened to by the therapists:

Why do you have to push so, to get what you want, my reasons were quite, anybody could understand my reasons for it [not wanting to use a walking frame], because my boys know, and they said ‘if Mum says she won’t use it, she won’t use it’ (laugh). They [Patries’ sons] agreed with me and that was satisfying for me, that I was more stable with crutches, why do you have to go through all that rigamarole? If I got taken away to hospital again, for some reason, I have to go through the same performance again (Patries, 81 years).

The therapists who were remembered as being the most helpful were often those credited with aiding someone to use a different, less cumbersome or visually unpleasant, piece of equipment to that originally allocated to them. People with stroke had the impression that graduating from one piece of equipment to another, for example to a smaller item, was a concrete sign of improvement after stroke. Changing equipment to one which was smaller or less awkward was recognised as an achievement:

We’re totally grateful because she [Josie’s physiotherapist’s name] has put a lot of awesome work into Josie actually being able to walk again. And she has got Josie from the big quad stick, down to this one [single point stick] (Josie’s (49 years) partner).

Similarly to Josie, Paul and his partner were grateful for the work of his occupational therapist for. When measuring for and providing a wheelchair they were impressed with her personal attributes like genuinely appearing to care about Paul and perceived her as nurturing when she encouraged them to give certain equipment a chance. The perception of her taking an individualised interest appeared to enhance Paul’s relationship with her and resulted in them having favourable memories of the equipment provision process:

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<sup>12</sup> Slang meaning confusing or unnecessarily complicated procedures or words

She [the occupational therapist] is actually lovely. She was very helpful, and definitely took Paul under her wing there at the start. Which was great, because otherwise, you know ... it was her idea that we should try and get the wheelchair, and give it a go anyway. And that worked, and they measured him up and everything (Partner of Paul, 76 years).

Other features of trusting relationships with therapists were seen in the importance of follow up from therapists. Mary, for instance, returned home to living in a small unit on the same property as her husband. Mary's husband lived in the main house but he had dementia and she and her family had developed a strategy where she lived in a different building as a way of her coping with her own needs, while still supporting her husband. However, there was a delay in formal care support starting at this vital time just after she left hospital and while she was still working out how she would cope with her post-stroke abilities. Consequently, her main support, therefore, was her adult son who came to assist her with personal care, but having him take on this role was distressing for Mary. This delay and subsequent care arrangement fed into a sense of abandonment by the healthcare system at a vulnerable time and contributed to her feeling like she did not know what to do with her equipment initially:

The main trouble was that there was nobody here when I came back. Nobody came for a week. I couldn't shower myself, or any of that sort of thing, just a break down, I don't know what happened. But they [hospital staff] assured me that the very next morning there would be somebody there, take me to the shower, and do any small thing that needed to be done. It never happened. That was the worst part. [Son's name] used to come, and I'd get into the shower, well he'd get me into the shower and then stand with a towel, well a son should never have to do that for his mother. That was the main difficulty. So they never really told me how to use anything (Mary, 81 years).

This experience, where Mary was not given the expected in-home instruction and carer support to use the equipment she had, fed into a feeling of dissatisfaction with her equipment provision service. The slow speed of communication about equipment after stroke could also adversely affect the relationship with therapists, as discussed in the example of Mike's wife earlier. In Josie's case, she and her partner had experienced a combative time with staff while Josie was in hospital, however, they talked more positively about interactions with her community physiotherapist. The reduced stress in this relationship was attributed by Josie and her partner to the physiotherapist being

consistent with her visits and communication, including her letting Josie and her partner know when she would be absent:

Josie's partner: Where the lady (physiotherapist) that turns up now, has been consistent Josie knows, she'll tell Josie 'look, I'm going on leave, I won't be able to see you for a couple of weeks'. And she makes sure Josie understands that. She's got consistency ... It was very erratic, aye?

Josie: Yeah. And, it was erratic (Josie, 49 years).

In contrast to Josie, Nigel reported having positive experiences with his therapists both in hospital and in his home. He felt that staff put considerable effort into helping him stay positive about his future, and as a result he trusted them when they engaged with him to provide equipment. His positive attitude towards his therapists and his trust in them to set an agenda that would meet his needs encouraged him to try different equipment as they advised. He also wanted to reciprocate their efforts by adhering to advice about equipment when it was offered:

Nothing was ever trouble, you know what I mean? And they always got me to look at the positive side of things rather than - yeah, no, they're just really good, if you know what I mean? (Nigel, 56 years).

Charles, on the other hand, had a different experience of interacting with therapists with regards to equipment instruction, where he appeared to have received minimal training about his walking frame. He recalled having had little to no practice using the frame before being discharged home. Charles had learnt a little about fixing the walking frame serendipitously as it needed to be repaired while he was still in hospital:

Oh they [the therapists] never did anything. That was marvellous, I thought that was terribly funny, that was all part of the rehabilitation at the hospital. They gave me a pusher, a machine, I don't know what it was called. And he [therapist] never taught me anything, I was just given it and one of the brakes didn't work and I complained to one of the nurses she said, 'oh that's typical' and the fellow came grumbling along one day when I was in bed and said 'I gather your machine's brake doesn't work' and then he fixed it. I didn't know how you fix it and he showed me how you fix it and that was very good. So there we are, nobody showed me anything else (Charles, 90 years).

Charles experience of being given a piece of equipment without instruction on where

and how to use it was not uncommon, though the extent to which this was a problematic issue varied among participants. For some, it was patently obvious how to use the equipment they were given and so no instruction was deemed necessary. For example, when Tess was given a toilet seat it was immediately obvious to her what it was for and how it needed to be set up, whereas for others, a lack of guidance on using equipment was distressing. The manner in which equipment was issued to people after stroke could also feel patronising, as if being told what to do rather than feeling consulted. Paries, for example, reported feeling affronted by the manner in which her therapists told her she needed to use her walking frame. When asked what could have made her interactions with therapists about equipment less stressful, Paries responded:

Well ask reasonable, you know, not stand over you, like you have to do what you're told like a wee school girl (Paries, 81 years).

Other compromises which participants were not willing to make have already been mentioned, such as in the case of Mike and his wife when it came to the initial wheelchair that they were issued with in hospital. The interaction Mike and his wife had with the hospital service about getting this wheelchair tailored set an expectation for them that they would need to battle with the health service in the future, while maintaining a positive enough disposition so as to not be disadvantaged. The involvement of the health service around this equipment issue required Mike to think carefully about balancing the kind of things he would challenge about the health service and their recommendations and what he would accept, in the interest of an ongoing relationship with the service providers:

You need to not be too nice or they [the healthcare service] will walk all over you. It's a balance between being nice enough that people want to come and see you, and help you, but also not letting them walk all over you. You have to put your foot down sometimes (Mike, 66 years).

To summarise, the therapists' communication style, attention to personal needs, and consistency of service delivery, were reported as important to making people feel confident to use their equipment after stroke. Hospital staff being attentive and able to listen to their needs was particularly relevant at the time of discharge, when the full extent of their changed abilities became clearer and there were many other agencies and services involved all at the same time. This transition process and how it impacted on equipment



use for people with stroke is illustrated in the next sub-theme.

### **Shifting worlds: From hospital to home**

This sub-theme was developed based on participants' perspectives about choosing and using equipment at the time of transition from hospital to the community, either to their own home or residential care. Some had agreed to whatever equipment was recommended by the therapist in order to do what they believed they had to do to get out of hospital. There were several examples where early decision making about equipment was led by this strong desire to go home. It was also evident to some people that they needed to prove themselves competent with, or at least compliant with, equipment in order to satisfy the therapists who were directing the timing about them leaving hospital. This transition was often a time of stress and excitement during which the ways equipment was perceived could alter rapidly. Equipment could be discarded quickly on return to the community. Sometimes this was because the equipment items were things which people were reluctant to use or something they eventually aimed to learn to live without. Other times it was because further consultation with therapists was required about how to use the equipment safely in an environment other than the hospital.

Because of the inclusion criteria used in this research study, all participants had spent time in a hospital environment following their stroke. This was where they were introduced to equipment after their stroke, though they may have already seen or used some of this equipment in the past. The priorities and structure of the hospital environment affected which equipment was recommended and participants held the view that, above all else, safety was most highly prioritised in this setting. While this is understandable and was welcomed by many who were unsure about their physical capabilities initially, the safety focus in hospital could contribute to them building fears about going home. Therefore, the hospital environment did not always prepare people for life at home, which often required greater risks and problem solving when using equipment than the hospital. For at least two participants, an impression was created by therapists in the hospital that their discharge was contingent on them accepting the recommended equipment:

Well I couldn't get out [of hospital] otherwise, without using that frame thing, you know. So anyway, they said 'but you have to use it' and I said

'I won't use it, I can tell you now, I'm pig headed and I've got my crutches here and I'm much better on my crutches than I am on that jolly walking frame' (Patries, 79 years).

Patries was very motivated about leaving hospital so when therapists talked to her about her needing to use the equipment they had organised in order for this to happen, she reacted with frustration. She felt cornered by hospital staff and she was appreciative that her sons agreed with her when therapists did not. Other participants also expressed a strong desire to leave hospital. Charles, for example, stated that he would have agreed to anything in order to leave the rehabilitation ward:

Interviewer: How did you feel about coming home with it [a walking frame with four wheels], did you mind?

Charles: When you can't move at all, it's wonderful to be home and to be out of that blooming place, hospital is hell (Charles, 90 years).

Charles also stated that he had been persuaded, seemingly against his better judgment, to accept a large orthopaedic chair as the therapists considered that this would be more useful to him. He agreed to have the chair at home despite his misgivings, in part due to his desire to leave hospital, but he was keen to be rid of it soon after returning home, and he was relieved when it was taken away:

Oh, they [therapists] came and tried to persuade me to have various bits of equipment, they wanted me to have an extraordinarily uncomfortable chair, great sort of 'sit up and beg' affair, which I didn't like and I didn't use ... Anyway, now that I've gotten rid of that blooming thing, I'm much happier without it (Charles, 90 years).

It was not uncommon for participants like Charles to find giving back equipment a satisfying experience. Returning equipment appeared to mark the end of one stage of recovery and this process could be viewed with pride even if the return was an exchange, where large and bulky equipment were switched for smaller equipment. In the case of Charles, it was also a time when he could be proven right, he had never thought that the chair was necessary and sending it back soon after discharge reiterated his stance on this. Also, for those who had been persuaded to have equipment by therapists rather than embracing the idea themselves from the beginning, returning the equipment was accompanied with some relief about their home environment beginning to more closely

resemble what it had been like prior to their stroke.

There appeared to be a lack of attention at the time of discharge regarding activities outside the home when it came to planning equipment needs. For example, while Josie reported feeling well set up regarding her home environment, the logistics of getting in and out of the car were not taken into account by therapists in hospital despite this being important to both her and her partner:

But they [hospital therapists] hadn't taken the vehicle into account, for Josie, when they did the assessment. And I don't really feel they took Josie getting in and out of the house into account. Once we were in the house, it was fine ... Cause, I mean Josie still has to go to doctor's appointments, and still needs to be able to get out, and mix with other people. And that's what I felt, once she was home, she was supposed to stay indoors at all times (Josie's (49 years) partner).

In contrast, Bert, a farmer, was surprised and a little nervous when one of his therapists suggested practicing using his equipment in his farm environment. In this situation, compared to Josie's, Bert was reassured by how broadly those supporting him to return home were thinking in terms of his outside mobility. He used a quad bike<sup>13</sup> for longer distances outside and valued having this reviewed by his therapists, despite that it being something he funded himself. The result of that assessment was that he was more confident with certain outdoor tasks:

Yeah, was a physio, wasn't it, she came out, she wanted to know how I was going to get on, on the farm. I said 'well, I've got a quad bike, I can get on and off that, I'm sure.' So I had to show her. And then she wanted to see me get onto my tractors, to feed out hay, we were feeding hay at the time. So, you know, I thought that could be a bit of a tall order. But no, I managed that all right (Bert, 79 years).

The timing of support services for people at home was queried by some participants. I have already discussed Mary's distress at the lack of care provided to her in the first few days at home which resulted in her feeling dissatisfied with the equipment provided to her. Josie's partner's view was that more could have been done prior to discharge from hospital to support the whole family and to reassure them that the areas that they were most concerned about could be addressed using either equipment or other support systems:

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<sup>13</sup> A motorcycle with four large tyres, for off-road use

I think those sort of services need to come in earlier, rather than wait till people get home. They [families] are on an emotional rollercoaster road anyway. Because all those places know, they have a basic idea of what people need, they need to really start setting it up before the person comes home. So the care-giver, is sort of in their mind thinking 'oh hell, look, we've got most things here.' So that part of the emotional ride is just taken care of a little bit. It's not going to be totally taken care of, but just a little bit (Josie's (49 years) partner).

The existence of unwritten rules set by hospital staff about how to use equipment, often related to safety concerns, was alluded to by a number of participants. For Tess, being told constantly to 'slow down' when walking with her frame while in hospital was frustrating, as she perceived herself to be someone who naturally moved quickly. As a result, she was frustrated with being told this by staff when it was not something she thought she could do:

Interviewer: So that [walking frame] gives you a bit of speed?

Tess: Yes it does. I got told 'go slow', 'go slow' from the time I went into hospital. I was born in the fast lane and I just can't go slow (Tess, 82 years).

Similarly, Nigel was clear that there were activities with the equipment he was allowed to do in hospital only when the therapists, or other hospital staff, were present, which meant he could mobilise only at specific times that suited other staff members. However, in contrast to Tess, he was appreciative of this 'rule' as it meant that he became familiar with his walking frame by having to adhere to this. He did not appear to resent this imposition and even suggested that becoming accustomed to the walking frame on the ward was facilitated by the prompting and structure of others being present when he used it:

I had got used to it because I was in hospital, and I wasn't allowed to go anywhere unless I was assisted or walking with the walker, you know that was just in the ward. So I got used to it, having it (Nigel, 56 years).

Some problems with equipment were not apparent until the equipment was used in the home environment. When difficulties occurred some people could find this stressful, or, like Mary, embrace the opportunity to problem-solve how to make it work for them or enlist the support of others in their support circle. Mary, for example, had friends who had

wheelchairs and she was quickly comfortable with the practical elements of using her electric wheelchair:

Mary: Possibly with some people, who have not ever done anything mechanical, they would need a little more instruction. I knew what you did with a wheelchair, when they brought it, I just got on with it.

Interviewer: Were there any options discussed with you about the equipment?

Mary: No. No options.

Interviewer: OK. Was that important?

Mary: Well it [wheelchair] filled the need that you had, so why would you want a better one, if it allowed you to do what you needed to do, I can't really see any reason to want something different, or better (Mary, 81 years).

Mary expressed that she did not feel that discussing wheelchair options was an important part of the process for her. Rather, she quickly saw the benefit of having the first wheelchair she was set up with and preferred to focus on learning to use it rather than discuss alternatives. Alternatively, another participant suggested that neither the person with stroke nor their partner would have known where to start regarding equipment and so they welcomed a more paternalistic approach at that stage of rehabilitation:

They were quite good, the lady did come and have a look at the house, and say 'right, yeah, this is what you need' because we didn't know what Josie needed. So I think she advised us to the best of her training (Josie's (49 years) partner).

This reassurance and encouragement from therapists was, for the most part, seen as necessary in order for people to learn what was available and what could work for them. Furthermore, without guidance at some level from therapists, identifying as someone who now required equipment was a struggle. This development of an altered sense of identity, as Nigel expressed, could initially be difficult, but did get easier over time. Participants became more used to having the equipment and using it in their homes and community, and being seen using it:

Interviewer: How do you feel about having the equipment in your life

long term?

Nigel: I haven't really thought, it won't phase me now, probably at the beginning it would, because it's not me (Nigel, 56).

Nigel feeling that the equipment was initially 'not him' was telling: he was indicating that there was a process he went through to adjust to using the equipment, particularly when he imagined others seeing him with his walking frame outside his home. This walking frame was not part of him but it was now in his life and it was essential if he wanted to move by himself. Time and practice were required for him to be able to assimilate this. In contrast, Mary reported that she had an immediate acceptance of the equipment given to her, a bed rail, when she appeared to require no discussion or much time to get on with using it:

Interviewer: Did they [therapists] discuss with you whether or not you wanted these things? Can you remember?

Mary: No, I think they just made out of their knowledge, 'when you go home, you will need this, and you will need that. One of the main things is that loop on the bed that allows you to turn over. It's marvellous. You wreck your back doing it. But it's marvellous (Mary, 81 years).

So Mary's comment also illustrates how some equipment came with a downside, a cost to be borne in order to use it effectively. In Mary's case it was pain caused by using the bed rail. Overall, she was prepared to tolerate this to be able to turn over in bed without help. Another difficulty mentioned with equipment was when others could remove the equipment, intentionally or not, which would render someone who needed it unable to complete valued activities. Particularly for people who were living in residential care facilities, equipment that could be easily moved could lead to distress when care staff did not realise how vital items were to people who could not move by themselves:

I get frustrated as hell when they [care staff] take that trolley [over bed table] out. Cause it's usually got my phone on it. And that's like my garage bench ... everything I want is on there (Paul, 76 years).

In summary, the transition from hospital to home could be stressful when it came to use of equipment. This transition represented a time of exploration for people coming to terms with many unknowns after stroke. The reality of their new limitations and using

equipment to compensate became more personal and related to adjusting to their previous lives and interests, rather than the context of a hospital ward. For those who returned to their own homes, the shift from having supervision and constant guidance from staff to living alone or with family changed how they perceived the usefulness of their equipment. The transition could be made more or less stressful by how hospital staff focussed on the concerns of people with stroke and their families as well as administrative tasks such as ordering and delivering equipment.

## **5.6 Time and testing**

### **Making sense of equipment**

People spent more time at home, an important feature of their relationship with equipment and provision services was making sense of equipment. Earlier in their recovery process, people with stroke had either gladly or reservedly accepted equipment recommended by the therapists. Once discharged participants spent a period of time learning about their post-stroke body and what could be achieved at home and in local environments. This experimentation provided them with experiences which led them to either accept equipment longer term, led them to request that it was changed or reviewed, or in some cases led to them purchasing different equipment or adapting equipment themselves, in order to meet their own goals. Reviewing their own abilities as they continued to recover from or adapt to the consequences of their stroke was an ongoing process captured in this sub-theme. The meaning and relevance of equipment became more obvious as time went on and as people assessed for themselves where their new, and often still resolving, physical limits were:

I expect my levels of confidence are a little bit diminished. You have to kind of test in terms of knowing what you can do now, and what you can't do, or wasn't as easy to do now, compared to before. So you know, I think that's the biggest thing, is readjusting to, the new normal. But yeah, it's the new normal that your body has, its different limitations to the ones I had before (Aroha, 58 years).

The need to work out what was possible for oneself was repeated by other participants. In Mary's case, the 'framework of what is possible' in terms of her own physical abilities after stroke appeared to be something she had to work out first before incorporating information as she received it from therapists:

I would say be aware of what you can and can't do, and make your own choices within the framework of what is possible. Or what they [therapists] offer you (Mary, 81 years).

For many participants, what had once been a familiar home environment became difficult to get around, with or without adaptive equipment. Participants described how their hallways at home suddenly seemed too long for them to walk, how driveways had become too steep and kitchens too small now that a mobility aid was required when making a cup of tea. There was a rediscovering of one's individual environment while simultaneously learning how best to use one's equipment. Charles spoke about this learning curve when he first used his walking frame on his outside pathway:

My first experience of using the walker which I'd never used before, after I came home from hospital ... So the brake system was an absolute Godsend but I had to use it in jerks, that is to run it a bit forward, then put the brakes on and then catch up with it and this was a bit of a mickey mouse outfit. It took me a day or two to get the hang of the trolley ... it is awfully hard work pushing it up the slope, it's not a big slope, it doesn't look like a slope at all, but actually it is (Charles, 90 years).

Charles, who had never previously noticed that his driveway sloped, attempted this pathway to get to his letterbox and found the exercise so terrifying that he had abandoned hope of using his walking frame to go further than the end of the driveway. There had been no slopes or uneven terrain at all in the hospital environment and so this challenge came as a surprise to him when he returned home. Charles had also imposed some restrictions on himself regarding the distance he would mobilise, due to a fall which had occurred outside on concrete. This had profound ramifications for how he thought about himself and his ability to move. This self-imposed limitation came about after his imagining the possible consequences of having further falls:

I thought, 'uh oh, the last thing I want at this stage is to break a hip', not only because it involves other people ... I didn't want to involve the family and so on and so forth. The problem of putting a pin in my hip and so on. It would have been a damn nuisance to everybody ... So anyway, I realised that was a risk situation and so I didn't want to fall again onto concrete. So yes, I think I've avoided situations like that one [walking too far from home] and that was a situation which I could have avoided ... it's not the moment that matters so much, it's the consequences of the moment (Charles, 90 years).



The choice about how to use equipment, for some people, was multi-faceted and context specific. For Aroha, a wheelchair was needed initially to safely and comfortably get from one place to another. However, when she needed to attend an event at her marae<sup>14</sup>, where her family/whānau would all be present, she decided to use her walking frame as it was important to her to be seen walking and upright in this context. This was more tiring and a greater risk to her being able to attend the family event safely, however, on balance this was her preferred way of being seen and she selected the equipment which facilitated this accordingly:

Aroha: We belong to the local tribe [tribe name], and we have a big event on an annual basis so it was quite a big thing for me to actually like show people that I was actually okay.

Interviewer: Yeah. Did you use the wheelchair for that one?

Aroha: No, I used a trolley [walking frame].

Interviewer: Okay. Did that make a difference to how you felt about going?

Aroha: I think it was better to have the trolley, actually. Because I was propelling it, that I was in control of it, not the other way round.

Interviewer: Yeah, that's interesting.

Aroha: When you're in a wheelchair, you're not really in control of it, are you? And it's not that easy to make a wheelchair go when one arm's not quite the same as the other arm. And in my case my arm's pretty strong. And it can do a lot of things, but certainly it is weaker than it used to be.

Interviewer: There's something interesting about that wanting to be able to walk, being seen to be able to walk, I think.

Aroha: Yeah. Well you can imagine that everybody knew that I'd had a stroke whether I told them or not. Sort of Māori grapevine, what do they call it? The kumara<sup>15</sup> vine. Was you know, whoomph, out there like nobody's business, you know (Aroha, 58 years).

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<sup>14</sup> Meeting house which serves as a communal or sacred place for religious and social purposes for Māori

<sup>15</sup> Māori word for sweet potato

Other examples of adjusting equipment depending on the activity included when Charles created a cord which he fastened to his walking stick so as to enable him to use it when walking in the garden. This cord which he looped around his torso enabled him to be able to stop and complete gardening tasks requiring two hands without having to put the stick down. This enhancement to the original simple equipment was something which Charles was proud of, having come up with the idea himself in reaction to a specific activity need he had identified. Similarly Doug had searched disability shops to find a walking stick attachment which would allow him to access his bowling green without puncturing the lawns and he would show his adaptation to other people as he was pleased that he had found a way to work this out.

People made decisions for themselves about which item would best suit specific activities and, in some situations, adapt the equipment as they saw fit. This was an ongoing process for months and even years after stroke. Nigel observed that bar stools were an easy height for him to get on and off and as a result, he could play pool in the local bar with minimal standing. He could also walk in this environment with his walking stick rather than his bulkier walking frame. The walking stick had the advantage of being more discreet in a social situation such as the pub where, echoing similar sentiments to those expressed by earlier by Aroha when she attended the marae. Aroha had re-evaluated her need for equipment as time went on, particularly with kitchen aids. She noted that initial fear and lack of strength after her stroke had made her conscious about having a solid surface to hold onto when in the kitchen, but as time went on this resolved:

You'd be scared, you know, walking around the kitchen like this, and holding on and all of those things. So I found this chair was comforting, to be able to sit down if I got tired, when I was making things ... and I used it sometimes just to eat my breakfast on. But it really wasn't too long before I was able to think 'oh no, I don't need that now' ... just a transitional aid, I guess, to moving from the not being able to do anything, to having the confidence to know that you could be safe (Aroha, 58 years).

Aroha was not alone in perceiving that using her walking aid was more beneficial to her ongoing recovery than her wheelchair which, theoretically, was safer and conserved more energy. Mike had been trying to avoid using his wheelchair also, but for different reasons. He and his partner believed that it would make him lazy and that his mobility and

his ongoing recovery would then be disadvantaged. Mike and his partner had been influenced in their beliefs about wheelchair use by someone who they described as a wheelchair technician:

Well, if I use the wheelchair to go out and about, I'd be able to get out and about, but I wouldn't be able to get the walking. And I need to do the walking and exercises to get better. So if I had the wheelchair, the power chair, I'd go down the road, I'd go here, go there. And I'd never get any walking in (Mike, 66 years).

Mike made reference to technicians who had visited to adjust his wheelchair who had warned him to not use the wheelchair too much, stating that he had seen other people do this and then they would not progress with their mobility. Mike was judicious about when he used his wheelchair, like for more arduous trips like going to hospital appointments rather than local visits.

There was a distinct moment for some participants when they decided that the benefits of the equipment out-weighed the difficulties they experienced. Paul, for example, reasoned that using the equipment was the only way that he was going to be able to get around. He had been initially resistant to both the recommendation for residential care and all equipment associated with his severe stroke but over time he reasoned that he had no choice but to use the wheelchair if he wanted to have some control over when and where he moved. He essentially became resigned to using the equipment he had been issued and while using it more, he realised with some pleasure that he could control the wheelchair, whereas he could not control his body in the same way:

But I thought now, I got to sort of thinking, 'now, what options have I got?' I got this wheelchair that I've got to wheel myself around in, cause I got to wheel the wheels, which I quite like, because I'm in charge. And then I said to myself, this is the only way of life I've got now, this wheel chair. And so I got to get used to it ... I got to the point where I said to myself actually one day, 'this wheelchair is my only way of getting round. And if I haven't got that, I'm lost' (Paul, 76 years).

Equipment, or the idea a person held about equipment, could also represent a safety net, for example, when participants went on trips further away than usual and the number of hazardous variables multiplied. Tess gave an example of taking her walking frame with

her on bus tours when she went on holidays with her old tramping<sup>16</sup> club. She did not go hill walking anymore, but she really valued spending time with this group and going on these trips, even though she stayed at the hotel waiting for them to return:

Interviewer: So you're going to take the walker on the holiday with you?

Tess: Oh yes

Interviewer: Do you think you could go on the holiday without it?

Tess: Ah, no, because I don't know how far they walk from the bus to the hotels (Tess, 82 years).

Tess's walker gave her confidence that she could manage the unplanned distances inherent in trips planned by other people. Jack also talked about how just bringing his walking stick along on longer trips away from home gave him confidence and made him feel safer, even if he did not end up using it. The presence of the equipment was reassuring and it seemed that this sense of confidence was important to him completing a long journey:

Now I've even given away the walking stick, although it is there. We've just been down south. And there was a long time sitting in the car, or in the ferry, in the car, sitting around down there, then reversing the process coming back, so I took it with me. And I needed it. Because, I just needed it, as a process of being independent ... just having it there made me feel very good (Jack, 66 years).

Likewise Mary and her family made the decision to pack up all her equipment in order for her to take part in a long standing family tradition of going to the sea during the summer holidays. She had believed that she could not go due to her changed physical needs, but her family committed to including the equipment she needed when packing for the trip, which she was grateful for:

We've always gone to the coast as a family, for more than forty years. I said 'I won't go this year, because of the toileting arrangements and all of this and that'. 'No, you're one of the senior members, you have to come' so we carted that toilet thing [the toilet frame]. All the way down to the coast and back. And this thing [indicates her walking frame] ... That had to come too (Mary, 81 years).

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<sup>16</sup>Colloquial term in New Zealand to denote hiking or hill walking

For many, the realisation that equipment was truly necessary for them to do things could only come after they were back in their own valued routines. In Nigel's case, while he had agreed on the advice of his trusted therapists that he needed his walking frame for on longer trips in the community, this did not really become pertinent for him until he started doing these trips on his own again:

Oh, probably about the second time I went out. When I was first out I was over at [suburb name], and number sixty bus that I catch to go that way, the bus stop is outside, but when you got to [suburb name] I had to hop off a bus and do a bus exchange, that was a bit further away. Yeah, well when I first got out I don't think I would have made it across the road and down the road a bit if I didn't have that (indicates to his walking frame). Like, I was a bit wonky on my feet (Nigel, 56 years).

Tess had also had some varied experiences with her mobility aids when she used them for community activities. She used her walking frame interchangeably with her walking sticks, depending on the type of activity she was planning to do. On one occasion, she became distracted at the novelty of getting a taxi to go out for grocery shopping to the extent that she forgot about the walking frame and left it at the supermarket, illustrating how it takes time to embed the use of equipment into one's routine and habits:

Oh yes, I remember it now. I only lost the walker once. I was that excited about going. I hadn't been in a taxi for years and years and years, ringing a taxi for getting messages<sup>17</sup> was just the last thing I'd ever imagined and I thought that was good, great (laugh). So it wasn't great at all because I forgot the damn thing [walking frame] at the supermarket (Tess, 82 years).

For those who had been motivated to leave hospital, getting home did not always bring the relief in the way that they were expecting. Charles had had a stroke in the past and been discharged successfully to his wife's care, but his wife had since died. Being on his own made his return home different to the last time. He decided that being on his own was one of the reasons why he had to use his walking frame, or as he called it, 'the trolley':

I wanted to get home as soon as possible. And then of course my wife had died by then so this was a very different set up than the first time I had the stroke. But when I came back for this last occasion, I was faced with some real difficulties because there was no one at home to help me so I

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<sup>17</sup> Groceries

had to realise that I had to manage entirely on my own, so I had to use the little trolley thing (Charles, 90 years).

In summary, the sub-theme making sense of equipment highlights that using equipment is an ongoing process which includes discovering one's capabilities which requires experimentation and a level of acceptance to find new ways of doing things. There were elements of resignation to the value equipment offered when it started to make sense in the context of their own lives, as few people would chose to use equipment if they did not have to. One of the hardest areas to master after stroke was participating in one's community and mobilising outside the house, however, these activities were also highly valued and therefore worth the planning and effort required to use their equipment.

### **Participation makes equipment worth the effort**

This sub-theme was based on accounts gathered from participants' about how they valued the activities that took place outside their home. As this theme is categorised under the central theme of time and testing, the experience of getting out of the house safely enough to engage with community activities was only realised after they had been discharged. In some cases, this experience with equipment could be months after their original stroke and hospitalisation and these activities were generally more complex than those attempted in the earlier stages of stroke rehabilitation. Using mobility equipment to engage with valued activities happened alongside people anticipating challenges, problem solving and developing strength and confidence. In hospital, many people had felt they were required to take part in routines as directed by hospital staff and with supervision for basic activities like getting to the toilet and dressing. For many people, after they left hospital, being able to move outside of their immediate environment (for example, down the hallway in residential care, out to shops or to visit family) was very important. The value placed on leaving one's house, using equipment and possibly physical assistance, was a key driver for equipment use. It was also when leaving the house that the need for equipment to support mobility and manage fatigue became more apparent, as fatigue became more of a likely issue and unforeseen problems (such as difficult terrain) became more frequent. As mentioned earlier, it was only when Nigel came to take the bus by himself that the value of his walking frame became obvious to him:

At first you don't think you need it, because you think you are still the same before your stroke. I still do it now, on occasions, you know what I mean? I [think] 'I don't really need this', and then oops, I do need it ... Well if I didn't have that I've got nothing to sit on, unless I sit on someone's fence and then people might say thing[s], you know what I mean? Yeah, in that respect it's a life saver. And it's allowed me to go that little bit further than I normally would (Nigel, 56 years).

Nigel realising that his walking frame with a seat was a 'lifesaver' was only evident to him after he had tried it out a few times. For participants, as they recounted their experience with equipment as their rehabilitation had progressed, their feelings towards these items could change. For example, where Mike and his wife were concerned about the heavy wheelchair at the time of his discharge from hospital, Mike could walk with a quad stick<sup>18</sup> and supervision at the time of his interview, so the issues with the wheelchair had faded somewhat as his abilities had changed. For many participants, using a stick instead of a walking frame was seen as a graduation; that they had managed to recover their mobility to the extent that their equipment was more subtle and portable. This could make community activities more accessible for them. Jan further emphasised the importance of getting out onto her family's extensive property as vital to her mental health:

Because, I don't know, you just go outside, and it just makes you feel better to be doing stuff out there. I mean it would be pretty awful if you were limited to being inside, it would be, well, it just would drive you crazy (Jan, 58 years).

Jan illustrated that being able to get outside to her garden when she wanted was the difference between being emotionally well and feeling 'crazy'. There were others who felt similarly, where trips outside, however infrequent, reinforced a sense of being in the world, still having something to look forward to and being able to engage with a wider group of people. Paul lived in a hospital level care facility and his trip out of the facility for lunch once a week gave him a sense of normality which he craved. He recognised that these outings were made possible because of his wheelchair:

That's why I love going out on Friday, we can do that now we have the wheelchair, like we go out for lunch with [partner's name] and her father.

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<sup>18</sup> Specialised walking stick with 4 prongs at its base to aid with balance when people walk

And we have burgers or whatever you want. And then I look around at everybody who's eating, and they look like normal people ... a lot of them here [in residential facility] are sitting in their chair with their head on the back, snoring, mouth wide open, and I think 'God, don't tell me I look like one of those.' But I wouldn't say to the other people here (Paul, 76 years).

This value placed on getting out of hospital level care environment in particular was emphasised by another participant who lived in residential care. Tracy did not want her grandchildren visiting the facility she had lived in since her stroke, and so she saw her wheelchair as a way of meeting them outside. Being able to do this made her feel more comfortable about seeing them, which could be distressing for her as she worried about what they thought about her physical condition. She was also concerned that they may be frightened or less interested in visiting her if they only saw her in the care facility:

Well it depends how far I can go, what day it is. It doesn't really matter, as long as I get out of here (Tracy, 61 years).

Though he lived in his own flat, Nigel reinforced Paul's and Tracy's priorities of being able to get out of where they lived and to be able to see and interact with other people in different environments. Nigel viewed his mobility aid as a way of him being able to maintain social connections actively as he could go to see other people, rather than risk losing friends or feeling like a burden where they had to come and see him all the time. When he considered his walking frame in light of this priority, he saw it as something which enabled his independence:

[Gesturing to the walking frame] It is independence, you know what I mean, like I wouldn't have to rely on my friends coming to visit me all the time, I can go and visit them (Nigel, 56 years).

At the time of the interviews, generally 6 to 18 months after stroke, getting out while using equipment was the focus of participants' lives, despite the planning and physical effort required for this to happen. Tess described getting on and off a bus as her main priority as managing this enabled her to access many other prized activities and social events:

I do the garden and things like that instead and I go to an exercise class and I can go out, I was in town yesterday with some friends. I can get into a bus and out of a bus and that's all I'm worried about (Tess, 82 years).



For many participants, getting the most suitable piece of mobility equipment for outside use from the health service took time. While they were waiting, they had to rely on other people more and felt restricted which was frustrating. Therefore, when suitable equipment to enable outside mobility finally arrived, they were relieved and excited about the potential freedom to access places further than their front door:

Well, two weeks ago, nearly two weeks, I got a motorised wheelchair. The thing is, I've always had gardens, and gone to the parks, and worked outside a lot. And that was the thing I missed most. Well now, I can zip down the road, just go round the streets, go to the park, I can get up to the chemist, I can get to the library, I can get the post box, so there isn't much that I can't do. And I don't have to call my son every five minutes to come and '[son's name], I want my washing hung out' (Mary, 81 years).

As is clear from Mary's description of the difference that her power wheelchair made to her life, she came to perceive that there was little she cannot do as a result of having this freedom. She developed a greater sense of personal fulfilment by being able to complete her own household tasks, such as hanging out washing without relying on her son. The importance of being able to stay engaged with things outside of the home was significant enough to feel that some risk would be worth it in order to still get out of the house. For instance, Bert gave an example of tending to his farm animals while using his crutches:

On the safety side of it, the worst thing is getting into the yards with the cattle. I'm not quick enough to get out of the road like I used to be. You know, if one [of the cows] decides that they want to push me out of the road, well they just push me out of the road. And I can't get out quick enough (Bert, 79 years).

The activities that took place outside of the home were often the ones where equipment use was vital. If equipment could enable these activities, it was generally seen as worth the effort of dealing with other challenges such as living with greater risk and with how one looked different to other people while using equipment. There were varying degrees of activity analysis completed by participants, including how and when equipment would be used on these trips to mitigate risk and significant time was invested into planning trips. The participants considered the distances and demands involved in an activity, as well as how they would look and who would be looking at them, (for example,

at the pub or at the marae) before then making decisions about which equipment to use, if any. Risks of equipment use were constantly weighed up against the relative importance of an activity:

Because it's all very well saying, 'go round the garden' but oh, if I get stuck, as I've been telling you, on a number of occasions, one is tossing up risks frequently. One is saying, 'does it matter if I get stuck in a flower bed' [if I fall] and on the one hand my brain says 'if I die in a flower bed, bad luck' but, it's all very well if it's nice weather, but bloody cold out there at the moment. And so, I'd rather die in a comfortable chair, in that sense (Charles, 90 years).

In summary, the activities that took place outside of the home were often the ones where equipment use was vital to still be able to partake in these activities. If equipment could enable these activities, it was generally seen as worth the effort of dealing with other challenges such as reconciling how one looked different to other people while using equipment and living with greater risk.

## **5.7 Summary**

Equipment use was influenced by the four sub-themes, clustered under the two central themes. As recovery can be unpredictable, there was ongoing re-evaluation by people with stroke, affected by a variety of factors, with regards to which equipment they used and for what purpose. Shared decision making with their therapists happened in different guises and to different extents when it came to equipment selection. Their ability and interest in taking part in shared decision making often changed as their recovery progressed. Their awareness of their abilities developed after their stroke, along with realising which activities were a priority. These elements influenced the type of equipment which was acceptable to them. For example, though accessing the community and activities outside the home was more risky and effortful than staying at home, the benefits of this were clearly worth it to these participants.

Guidance from therapists was expected and appreciated, but this could be perceived as being overly paternalistic if people felt they had not been listened to during the equipment provision process. Having one's priorities and problem solving abilities respected and affirmed was important to people learning to use equipment after stroke. Therapists were only partly involved in the decision about equipment use. However, as

gatekeepers of knowledge about equipment and resources to access different types of equipment, they were important stakeholders for people with stroke. Therapists in hospital based settings supported people with stroke but this was also an artificial environment with rules and priorities which are often different to those in someone's own home. For many participants, it was only when they returned home that they learned what their bodies could do after their stroke and how that in turn affected the ways in which they used equipment.

Initial equipment assessment and provision is often the beginning of a journey for people with stroke, rather than the conclusion of intervention, so ensuring that people are reviewed regularly appears vital. It was important for therapists to take time initially and then in an ongoing way to listen to the priorities of the people they worked with, in order to establish how their clients make sense of their equipment. Recognising and supporting creativity and client-led problem solving when it comes to equipment provision is likely to encourage collaboration, with working out the best time for this collaboration (compared to therapist led assessment) being the key element. The wider funding and policy system was not considered much by participants in that they relied heavily on the expertise and advocacy of their therapists and this point will be explored in greater detail in Chapter 6.

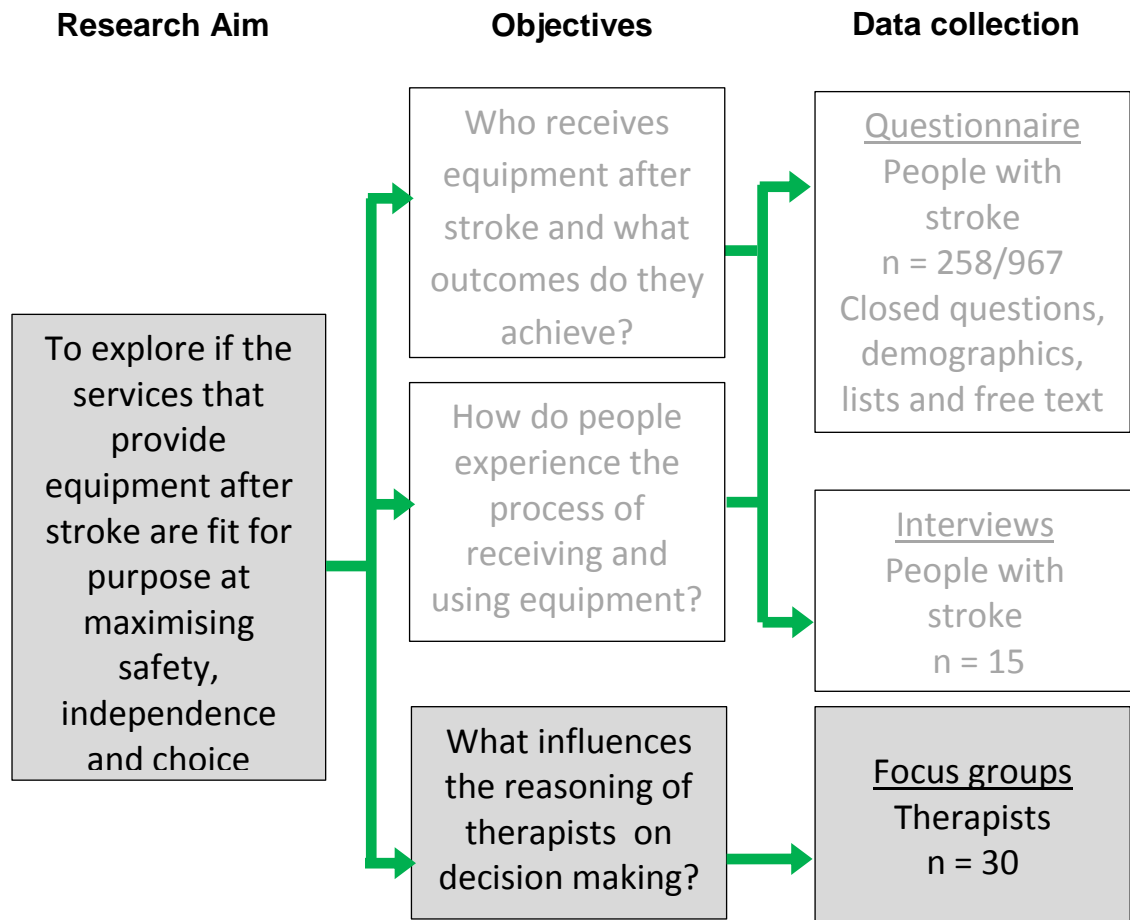
## **Chapter 6. Phase 3: Focus groups with therapists**

### **6.1 Chapter outline**

An important element in the equipment provision process is the perspective of therapists whose responsibility it is to assess for, recommend and review equipment. To gain a perspective on how and why equipment is issued after stroke, including critically evaluating the ways in which the current equipment provision system works, it was vital to elicit the perspectives of therapists. Chapter 3 details how therapists were recruited to focus groups and how the data from these groups was analysed. The therapists who took part are described in this chapter and their perceptions on their role in equipment provision after stroke are outlined to describe the key influences on their reasoning and actions.

### **6.2 Relationship of results to the overall research**

Reference was made during focus groups with therapists to key findings from earlier phases of this research. The relationship of these data to earlier stages of this thesis is outlined in Figure 9.



*Figure 9 Relationship of data collection and objectives: Phase 3*

### 6.3 Description of therapists

Thirty therapists from two DHB in the lower North Island of New Zealand participated in the six focus group meetings. The groups consisted of 17 physiotherapists and 13 occupational therapists and almost all of the therapists were female (29/30). All allied health professional therapists worked for a publicly funded service, in inpatient rehabilitation or community based rehabilitation. The average time since qualification was 11.3 years and the average age of the participants was 34.6 years. Twenty-three therapists were working with people with stroke at the time of the focus groups, while seven had previous experience with this group. Twenty-five therapists had qualified in New Zealand and the rest had qualified in either a European country (4/30) or Australia (1/30). The mean group time was 35 minutes, ranging from 30 to 55 minutes. Further details about these participants are outlined in Table 6-1.

**Table 6-1 Therapist demographics**

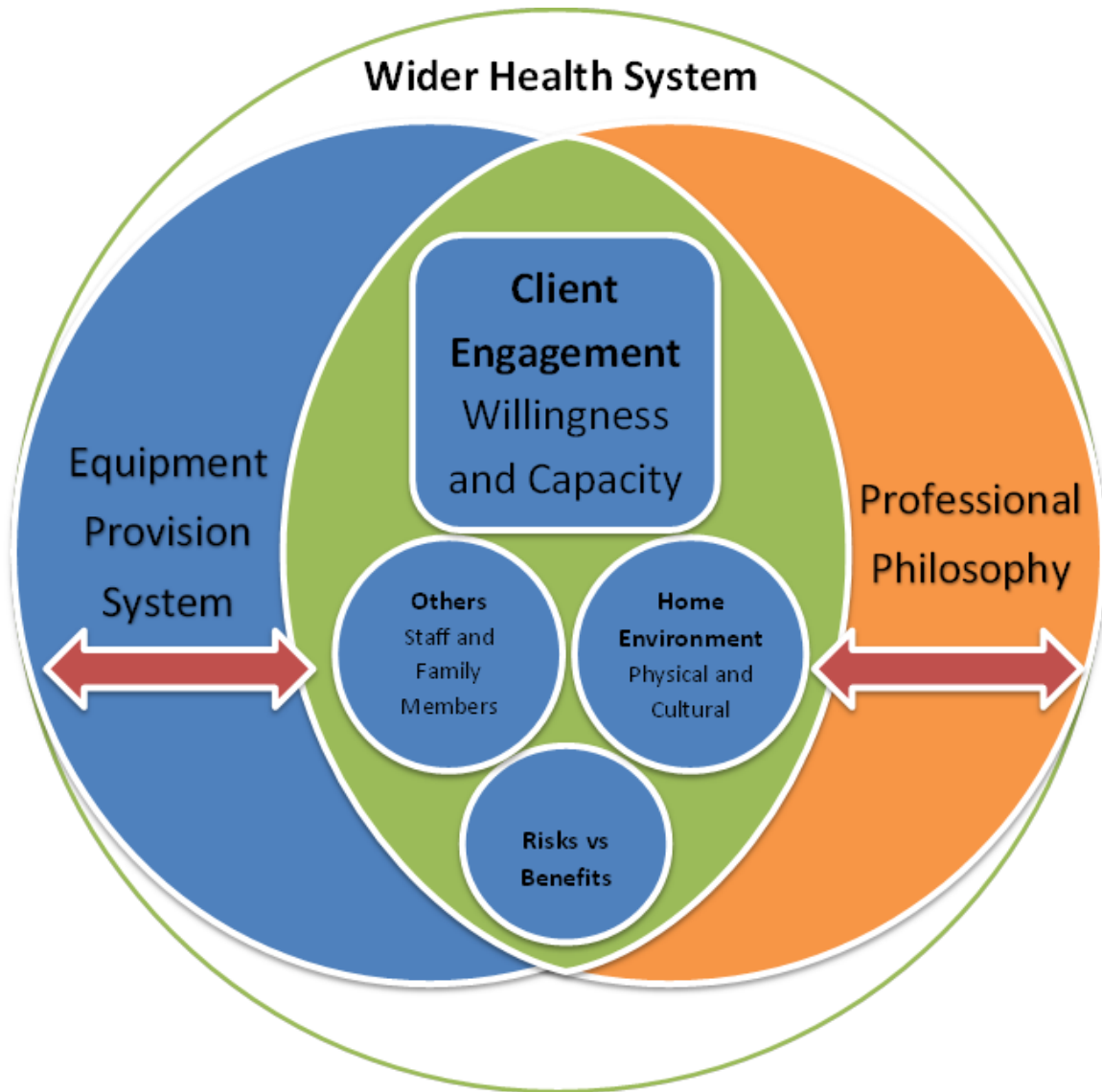
Demographics	%	n
<b>Gender</b>		
Female	96.7%	(29)
Male	3.3%	(1)
<b>Ethnicity</b>		
New Zealand European	66.7%	(20)
European Other	16.7%	(5)
New Zealand Māori	10%	(3)
Indian	3.3%	(1)
American	3.3%	(1)
<b>Years of experience</b>		
<1	26.7%	(8)
1-5	33.3%	(10)
6-10	23.3%	(7)
11-15	13.3%	(4)
>20	3.3%	(1)
<b>Profession</b>		
Occupational therapist	43.3%	(13)
Physiotherapist	56.7%	(17)
<b>Hours of employment</b>		
Full-time	76.7%	(23)
Part – time (<30hrs)	23.3%	(7)
<b>Highest professional qualification</b>		
Undergraduate degree or diploma	80%	(24)
Post-graduate	20%	(6)

#### **6.4 Model of clinical reasoning for equipment prescription**

A model was developed to illustrate the reasoning process of therapists when they prescribe equipment after stroke (see Figure 10). This model describes how this process is layered and affected by factors relevant to the client alongside the systems the therapists work within.

‘Client engagement’, including their willingness and capacity to engage with equipment and the provision process, was reported to be the therapists’ primary consideration. Client engagement was seen as being influenced by three related factors: the clients’ ‘physical and cultural environment’, ‘other people involved in their life’ (family member and other healthcare staff) as well as by the ‘risk versus benefit’ of equipment, which therapists weighed up the with them and sometimes for them.

Additionally, there were non-client related factors which influenced this process. Equipment provision occurred within a ‘wider health system’ and was therefore affected by tensions between different components of the healthcare system with competing resource management issues and conflicting views on rehabilitation and patient-centred care. The ‘equipment provision system’ and their own ‘professional philosophy’ could align well as the therapists worked out potential equipment solutions with their clients, or they could pull in opposing directions (illustrated by the arrows) with different ideas about what was fair in terms of the needs of a person with stroke and the restrictions and capabilities of the healthcare system.



*Figure 10 Clinical reasoning for equipment provision*



**Client engagement: Willingness and capacity**

The concept of client engagement related to the therapists' perceptions about the willingness and capacity of a person with stroke to engage with adaptive equipment as well as with decision making within the equipment provision process. The first and most important action considered by therapists was to engage their clients about their own personal goals for equipment. Influencing factors in this process were the potential symbolism of equipment for the person with stroke as well as their personal ideas about health, recovery and ageing. Most commonly equipment use was associated with being old and disabled and pride was often recognised by therapists as a barrier to uptake of equipment after stroke. The financial freedom to purchase privately and cognitive capacity to do so were also considered. Sometimes these issues were intentionally explored by therapists as part of the equipment prescription process. For example, therapists used standardised cognitive tests with their clients with stroke to support their reasoning about someone's cognitive capacity to engage. At other times, the therapists' perceptions were formed more implicitly, by subjectively observing how much their clients used equipment and how much repetition was required for safe use.

From the perspective of an experienced physiotherapist, deciding what to recommend for a person after stroke was determined to a large extent by an individual's expectations of themselves and their recognition of an equipment-related need:

I think it depends on the client's expectations. So if the client is happy walking with a walking frame and they've started to participate in life and they've started to do things that they want to be doing, and the frame is part of that, then that's fine. Or the equipment they need, is fine, but if the client is not happy with that, then that means that from a community point of view we've still got work to do (PT, community, focus group (FG) 4).

The levels of dissatisfaction a person with stroke had with equipment use could in turn indicate that more clinical time needed to be allocated to that person to work with them so they could gain the ability to take part in activities without the equipment. One experienced physiotherapist discussed how there were subtle indicators which she would look for to help her decide what equipment someone may need, with these indicators being based on the person's engagement with equipment and his or her motivation to pursue certain activities:

Well, just their general strength and positioning, and functioning, and whether they're motivated to practice their exercises, and whether they're keen to get outside, and all those sorts of things, you soon pick up if they're really just quite happy just to sit in the corner chair, and not take in their environment. Although in saying that, I think a lot [of] progress [is made] once they're home as well, more than you see round a hospital bed (PT, inpatient, FG 1).

Assessing for client's motivation levels and their interest in more strenuous activities outside the home seemed to happen implicitly. Furthermore, this subjective assessment happened prior to discussing equipment options or what the available funding could provide. An experienced occupational therapist structured her assessment for equipment specifically around what she thought a person with stroke needed and wanted prior to discussing the different ways in which the equipment could be provided for them:

And I look at what would the person like, what would be the ideal, does that meet what they are wanting, is that what I'm assessing for. And then we get into the discussion about funding, okay ... so take that out of the equation until I've done my OT bit first and then open up those conversations (OT, community, FG 2).

Where therapists perceived that clients had cognitive challenges, they formulated strategies to compensate for these cognitive deficits during the equipment provision process. These strategies developed in response to common challenges and were of a trial and error nature rather than following a systematic process. There was a hierarchy of techniques therapists tried in relation to equipment use aimed at increasing independence, including educating family members and other staff as well as the client about why they thought that an equipment item would be beneficial. If equipment could not be used to increase independence for their clients, often the therapist recommended that supervision or assistance was required. This recommendation had a significant consequence for a person's support needs both in hospital and when home, hence why this was often the last option considered. The new graduate physiotherapists who were based on hospital wards spoke about this extensively:

PT1: I find working with people, because I work in older adults at the moment, people that have more cognitive issues, aren't as cognitively intact, [they] often struggle with something new like that, a new piece of equipment. They can't often follow instructions well and it doesn't come naturally to them because they've never really used it [equipment] before

so they might just do things like pick up walking frames and carry them or just push them out of the way and they see them more as an obstacle than as something that can help them to move about.

Interviewer: What would you do in that situation?

PT1: (Pause). Quite often, you know, I would have gone through to keep practicing with them, so make sure you've always got someone with them and always keep practicing with the walking frame, but at times, it just doesn't work. So you just, if they are walking you just make sure that they are always supervised.

PT2: We found that some clients just seem to forget a lot and we put big signs on their walking frames and that's kind of like 'this is your walking frame, you need to have this when you get up'. That seemed to work for some clients, but not for others.

PT1: And can be more unsafe at times than safe, if they don't know how to use it and it's just going to get in the way when they're trying to walk around (PT, all inpatient, FG 6).

Where someone with stroke had a cognitive impairment, the therapists would reduce their expectations about the person's ability to engage in discussion about equipment provision. They were mindful that changes in routine, such as the introduction of new equipment, could have negative consequences like equipment introducing a falls risk. So a compromise needed to be reached where the therapists placed greater emphasis on evaluation and checking than for people with stroke without cognitive impairment:

Something that I find interesting as well is people who have dementia or an aspect of cognitive impairment, if you change their walking aid, it's sometimes more unsafe for them because they're so used to that routine of using the walking stick, and you give them a walking frame and they just, it becomes a lot more unsafe for them. So it's judging their ability to learn to use it appropriately (PT, community, FG 1).

The therapists had experienced varying reactions from their clients about the aesthetical impact of a piece of equipment. Learning to recognise this concern about how something looked and to then tailor and accommodate personal preferences could be counter-intuitive. For example, while some people with stroke found larger equipment more cumbersome and attention grabbing, others were more accepting of medicalised

equipment over everyday items. New graduate physiotherapists had observed that people's acceptance of equipment were influenced by a perception about how the equipment made them look:

PT1: I find with some clients though you can get around it, if they don't want a walking stick, put them on a frame or a crutch, I think that's a lot more acceptable ... it looks more like they've got an injury than they are just, you know, shuffling.

PT2: And I've noticed that people, the walking sticks, you know, the Nordic ones, so they'll use one of them instead of an 'old person's' walking stick (laugh) (PT, inpatient, FG 4).

While most therapists did not consider aesthetics in their reasoning about what equipment was issued, they did acknowledge that this could have a bearing on whether clients would use the item. Some therapists did try to find more visually pleasing items as they thought that people in hospital had been through enough without having unnecessarily ugly equipment to contend with. One experienced physiotherapist imagined what it would be like to use a walking frame. She described it as an object which conjured up images like restriction and entrapment:

They're horrible [walking frames], if you think like, you're sitting down and you're given this frame, it looks like metal bars and grey and prisoner-like and you always have to be near it, it always has to be in arm's length, and you can't get away from this blinking grey metal ... yeah, do you know, it's not part of you, you're you and then there is this thing (PT, inpatient, FG 4).

Others, who were new graduate occupational therapists, also expressed that they had noticed client reactions to equipment and based on these observations, they had changed how they themselves viewed equipment. Their clients could view equipment as something that held them back or made life more difficult rather than the intended consequence of enabling independence:

OT1: They [people with stroke] don't see it as an enabler, do they? They see it more as a ball and chain.

OT2: I have lots of people say 'oh I don't want to become dependent on a piece of equipment' so they would prefer to struggle through something rather than take a piece of equipment and think 'this is how it is going to

be, then' (OT, inpatient, FG 3).

This observation illustrates how the new graduate occupational therapists started to notice a concern from the people they worked with about becoming dependent on equipment. Also, these occupational therapists noted that people with stroke predicted a future for themselves where using the equipment could make them nervous or sad. That the person with stroke chooses to struggle through an activity with greater effort rather than accept equipment can make others nervous for their safety, but this can also be admirable to a therapist. Similarly, the symbolism of moving from one piece of equipment to another was described by therapists as something to celebrate, a graduation of sorts, particularly in relation to stroke rehabilitation:

That big step from the frame to the [walking] stick, is a big one. And people really see it as a massive change going from having a disability to having normal walking gait and a stick is very acceptable, people age and have sticks (OT, community, FG 5).

The decision on when to try an alternative piece of equipment appeared to be driven primarily by the therapists' observations of how safe and strong a person was after their stroke. The degree to which people with stroke could take part in collaborative decision making about the selection and use of equipment was usually implicitly evaluated by therapists and their actions, including the depth of explanation about equipment recommendations, was tailored accordingly. Where the therapists decided that their clients would not be interested in, or able to, discuss options about equipment, they took a more directive approach with little consultation. Having the equipment recommended by a therapist, with possible reassurance and encouragement about safe use, was something that therapists thought made the difference between their clients using the item or not:

They'll [people with stroke] be better in their own home than they will in here [hospital] so if they are doing it [walking] they need to know they can do it because a professional person has told them 'yeah you can walk, go' (OT, inpatient, FG 3).

So this occupational therapist was aware that by predicting that their client will be safer in their own home and endorsing the equipment as essential in this process, therapists could improve confidence about their client's current and future abilities. For some

therapists, there was a strategy of showing rather than telling people about equipment and why it was useful. Therapists described how they had observed that greater independence could be an incentive which would sometimes only become clear to a person with stroke after the therapist had persuaded them to try the equipment, as illustrated by this new graduate physiotherapist:

I had a 40 year old stroke client and he would prefer to hold onto two of his sons or a friend to walk to the loo rather than using a walking frame. Just cause he thought 'no, that makes me look like I'm old'. But once we tried walking with the frame he was like 'oh I can get there by myself' ... I usually say, 'well from what you've told me you're feeling a bit unsteady on your feet, would you be willing to trial this? Which might help? And it's not necessarily a long term thing but it might help you to get back up on your feet' (PT, inpatient, FG 4).

In the above examples, there was evidence of negotiation between the person with stroke and the therapist. The therapists were motivated in two ways: that the person with stroke would understand that equipment could make them safer or more independent and by a professional obligation to ensure maximum safety for that person and those helping them. In such a scenario, the negotiation about how and when to use the equipment, and for how long, could be viewed as being gently manipulative. The therapist in the example above reported telling a client one thing (that the equipment might only be needed short term) in order to achieve something else (to get the client to trial a piece of equipment for a period of time with the hope that they would then discover how useful it is). Other examples of achieving client 'buy in' to use equipment included therapists identifying to their clients that a change in equipment as a tangible sign of recovery and progress:

I try and make it a really positive thing, like 'you're progressing'. You try and be quite goal orientated, so their goal is to walk with no aids in the long term, I sort of sell it to them, the walking sticks, if they're on a frame, the half-way point to sort of no aids (PT, community, FG 1).

This is subtly different to earlier observations from therapists about clients identifying a change in equipment as progress: here the physiotherapist is predicting that different equipment will indicate recovery as a means to encourage clients to try different equipment which they may be resistant to initially, but the physiotherapist believes will be to their benefit. Working out what is most beneficial for someone with stroke regarding

their recovery, alongside considering their safety needs, appears to be something that grew as one therapist gained experience and became more comfortable with watching their clients take risks with their equipment and their mobility:

Interviewer: So figuring out what is most safe for someone to use sounds like an actually quite complex process?

PT: I think its lots of things you just sort of ... you just do. I don't know ... it's experience. It's just years of experience. You're not as risk-averse, I guess (PT, community, FG 1).

The concluding remark from this experienced physiotherapist points to an acknowledgement that with experience, one becomes more comfortable with your clients living with greater risk and this had an impact on how therapists engaged with clients about equipment options. This is one example from these groups of how reasoning about equipment changes as one's professional career progresses and you develop your own (often personal) sense of professional accountability and risk management priorities. In addition, for those working in community settings, there was the option of checking in the future as to how equipment was working out for people, whereas there was little ability to review equipment in the inpatient setting.

### **Role of others: Healthcare staff and family**

People other than the client with stroke and the therapist had ideas about the usefulness and role of equipment in stroke recovery. There can be different agendas between a person with stroke, their family and therapist, as summarised by this experienced physiotherapist:

I feel like we are enabling mobility and the family think that the agenda is preventing falls (PT, inpatient, FG 4).

This is an interesting reflection on the multiple stakeholders involved in endorsing the use of a mobility aid, with the therapist being just one person with a view on how this should happen. Also, while several people involved with a person using equipment might agree on an equipment trial, they may have different expectations about what can be achieved with that equipment. The therapist can become the primary moderator in such a situation and they are often expected to understand and communicate with all others

involved:

I think that sometimes the family are trying to fix things that they can't be there in person to oversee and they see equipment as a strategy for that. Like if you give them lots of grab rails and you give them a perching stool for the kitchen and they've got the right walking aid and you've raised their chair, then it will be more okay and less of a problem that [the family member] needs to be at work or lives in a different city. [The family members] need you [the therapist] to fix these things so that 'my relative will be safer, so that I can cope with the fact that they are at home and at risk and I'm not nearby'. Now that certainly seems to be quite true at that inpatient stage where people don't really know how this new situation is going to work when they actually go home (PT, inpatient, FG 4).

This example illustrates how equipment provision can happen against a backdrop of complex family adaptation to a relative having a stroke. Family members tended to be the ones who were expected to manage the process of equipment checking and follow up when the person with stroke had a cognitive impairment. This meant that education about funding options and instructions on how to safely and effectively use equipment often needed to be directed at family members. This experienced occupational therapist applied the same process of providing information about equipment related to the interest and expectation of the family member, as they would if it was directly to the person with stroke:

I also think about the extent to which I explain things. I obviously go through the basics like 'this is Enable, this is my role, this is what Enable expect you to do, here's the loan form, here's the phone number' all those sorts of things. But if someone and their family, cause often if someone's got a cognitive impairment then it's not going to be just them it's going to be their family and whānau and whoever else, then if someone really wants to know every single thing about the frame and about the equipment process, then I'll go into that detail. I do go out of my way to write it down as well (OT, community, FG 2).

It is interesting to note that this occupational therapist tailored the extent to which she explained things depending on whether someone had a cognitive difficulty or there were family members involved, indicating that the depth and extent of information provision varies from person to person regardless of the equipment being provided. The needs of others sharing a house with someone who had a stroke was also taken into account when it came to equipment and areas of daily life which were shared, as described



by this new graduate occupational therapist:

Especially those raised toilet seats and if you've got kids using the toilet and it's like 'uh, we're going to have to take it off'. Yeah communal use toilets are just a bit frustrating (OT, inpatient, FG 3).

The therapists who worked on inpatient units gave examples of also needing to consider equipment provision in relation to other staff members' needs and requests (for example, to enable safe manual handling). This meant that the attitude of other health professionals in relation to equipment provision sometimes needed to be factored into decision making:

It is relevant for us [inpatient physiotherapists] we have staff members who have a different level of confidence in seeing people struggle to move around. So you have a client and the walking aid and it is obvious that they are unsteady and it is one thing too many for them to concentrate on or they trip over it. The walking frame is just no help and you take it away and the first comment you get back from a couple of members of staff is 'they are quite unsteady aren't they'? So there's a sense [from other staff] that if people are unsteady they should have equipment, as opposed to they should practice and get better ... you [the therapist] should fix that problem and make it go away by giving them a piece of adaptive equipment and letting them get used to that (PT, inpatient, FG 1).

Other experienced occupational therapists reported the need to assert themselves and their reasoning when a decision was made to not issue equipment. This happened when communicating with other healthcare staff who may be more risk averse or have a different opinion about what equipment could and should do. This experienced occupational therapist discussed that as her comfort levels with risk increased with experience, she reduced her tendency to issue equipment to people after stroke, even in the acute setting which all therapists acknowledged as different to working with people in their own home:

I think I feel comfortable with taking risks, because I've worked in the community and when you're in rehab[ilitation] and kind of projecting where things are at and actually allowing people to talk me through what they may or may not have been doing and watching them work through other ways of managing issues ... as opposed to just giving them equipment because others are scared that they may fall. So I'm quite comfortable with risk ... Absolutely and that is the hardest part I think, to actually be confident in your reasoning with people as to why you haven't

just put them [clients] on a shower stool. Heaven forbid that they are a bit wobbly (OT, inpatient, FG 5).

Other examples about the impact of equipment on others were given where a person with stroke would not find a piece of equipment visually offensive but a partner might, for example, when raising a sofa on blocks or having a board in the bath. Negotiating how equipment can be used in shared spaces in a home or hospital setting illustrated how the therapists needed to consider the concerns of not just the person with stroke, but their family and possibly other healthcare staff also.

### **Balancing risk and benefit**

The risk negotiation process involved therapists thinking about what advantages a piece of equipment offered a client compared to another item or no equipment. This balancing process by the therapists could be inherent throughout rehabilitation, but it was most notable when the therapist was supporting the person with stroke to challenge themselves while still avoiding injury or fatigue. The following risks represent the range of issues brought up by therapists, with varying degrees of confidence in whether there was research to support these ideas.

The identified risks of not issuing equipment included that someone would become immobile and be at risk of injury, de-conditioning and loss of confidence with everyday tasks. However, the risks of issuing equipment potentially included some of the same outcomes. For example, therapists expressed concerns about the risk of: people sustaining injury related to the equipment itself, the risk of someone becoming psychologically dependent on a piece of equipment (where the therapist felt they could be starting to move without it) and the risk of physical de-conditioning, where a person's musculature and physiology may change adversely due to over-reliance on equipment. The main benefits of equipment provision were seen as enabling someone to move with less or no assistance from others, to regain confidence in their own abilities and to do the activities they wanted to do again. Weighing up the risks and benefits often took place without a lot of discussion with clients.

Many therapists discussed, directly or indirectly in the focus groups, feelings of guilt about equipment prescription. This resulted from the ongoing tension between

compensating for lost abilities (often to keep a person with stroke or their family safe and to help them to move themselves) and wondering what physical rehabilitation may have been possible if that compensation had not happened:

For me there is a bit of guilt involved too. The word compensation has some negative connotations to it ... So you can think, 'did you give that person a quad stick too soon' and limit their further improvement in a way. So with an aid you can get them up walking further faster and sooner but could you have gotten closer to your previous mobility if you hadn't done that? (PT, inpatient, FG 6).

Other physiotherapists also wrestled with a sense of unease about issuing equipment, where this act may disadvantage a person's overall recovery. They expressed concern that they were denying a person with stroke the opportunity to move more 'normally' without equipment and also felt responsible for encumbering their clients' lives with equipment items:

I also worry about the detrimental effects of having walking frames or a walking aid or a mobility aid, in that you're taking away someone's opportunity to move in ways that are more natural and you're going to lose out so much by having something to help you walk. I think it is a huge thing because if you think about how much you take out by putting your two hands on a walking frame and pushing and then if you add onto that someone has a raised toilet seat and raised couches and then a bed lever, they are never going to use a whole group of muscles ever. And if these things have been permanently loaned out, you're basically inhibiting movement which wouldn't be great (PT, inpatient, FG 4).

The physiotherapist speaking here also discussed the practice of building into their intervention plan the opportunity for people to spend time not using equipment. This could take the form of advising their client when and how they could (or should) learn to do activities without equipment. At other times, therapists queried the timing of equipment provision, where issuing equipment too soon would be contrary to their idea of best practice in rehabilitation:

PT1: Acutely I very, very rarely use frames for stroke clients. I think it [walking frame] kind of sets them up to try and do things differently.

PT2: I don't like using aids until I have to. Because it's not normal, walking with a frame (PT all inpatient, FG 4).

Later in this same focus group with experienced physiotherapists, there was discussion about how equipment trials should come ideally after a more rehabilitative approach had been tried and had not worked, suggesting that needing equipment was a slightly second rate outcome compared to one where a person did not need equipment:

PT1: So you try the rehab[ilitation] approach first and then if that wasn't going to work, then I'd, or if it wasn't feasible say, then you'd try equipment. But you'd be thinking about another goal and the equipment might help you reach that goal.

PT2: But it [issuing equipment] is not your treatment.

PT1: It wouldn't be the first thing that you'd go to (PT, all community, FG 1).

There seemed to be an accepted belief that equipment could ultimately disadvantage a person's physical recovery more than having no equipment. These physiotherapists had impressions of what deterioration may happen in muscle function as a result of using equipment to walk. However, they acknowledged that there seemed to be a lack of evidence to guide them on this issue:

PT1: You know, walking frames, how much less am I using my back extensors, my posteriors, using a walking frame and over a 6 week period, what does that change, you know there's not enough information for me to know 'gosh the back extensors reduce by 20% with a 6 weeks of walking aid', you know I don't have that information, I can only use my experience to think 'ah, it just doesn't sound good to me'.

PT2: But you think postural, you can see postural changes with people kind of leaning over their frames (PT, all inpatient, FG 4).

Despite beliefs held by physiotherapists about the risks of weakness to specific muscle groups due to altered mobility when using an equipment item, most therapists agreed that there were greater risks which tipped the balance in favour of them issuing equipment. These risks were that someone would injure themselves or lose confidence and stop engaging in valued activities if no equipment was prescribed. As one experienced physiotherapist described:

Because the flip side is they'll lose confidence, if you encourage them to walk with no aids, they end up just sitting. Because 'oh, what if I just, if I

fall on the way to the letter box?’ So ‘oh, okay, it’s easier just to stay here and get someone else to bring the mail in,’ and they’ll do less and less and less (PT, community, FG 4).

When weighing up risks and benefits of equipment provision, there appeared to be some general principles about physiological strength and movement which were valued and applied to differing extents by therapists and by physiotherapists in particular. This could be as a result of their physically based training or the model of practice they aligned themselves to, which is discussed in more detail in professional philosophy.

### **Environment: Physical and cultural**

There was consensus among all therapists that they thought people were able to engage with and use equipment differently when they were in their own home compared to being in a hospital. This appeared to therapists to be due to people with stroke being more familiar with their physical setting and more able to identify for themselves the activities they wanted to achieve but were struggling with. Community based practice was felt to enable a broader assessment by therapists:

PT 1: Now it’s easier for us because we work in the community. Because if you’re in the hospital, you are so limited, you’ve only got such a small frame of reference with just the person, but if we’re in their homes it’s so much easier, you can get a really good idea.

PT 2: Yep, you’re seeing the bigger picture.

PT 3: They’re more in control, that’s a key thing (PT, all community, FG 1).

The physiotherapist who concluded that clients were more in control in their own home has touched on how therapists may respect a person’s decision making differently when they are back in their own personal space and routine again. The therapists acknowledged that their clients are seen as more like experts on their capabilities when they are in their own home, whereas in hospital a paternalistic model of care seemed to prevail. The ability of people with stroke to problem-solve and exceed the expectations of the therapists was also seen as greater in their home than when they were in hospital:

They know their environment. Whether it’s a set of spiral stairs that they can manage, and you go ‘how does that happen, how can they do it?’ And

we just think, ‘why isn’t there a barrier there?’ But they know it, they can do it, it’s their home for the last 30 or 40 years (PT, community, FG 1).

This belief among therapists that a person with stroke was more in control in their own home was consistent among focus group attendees. This experienced occupational therapist described this further where she noticed that her clients were more sure of themselves and assertive about the ways which they wanted to move themselves than they would be in a hospital environment where they would need to follow pre-set rules:

So are we saying that in somebody’s home environment they make the rules and outside of that environment people have to follow the rules of wherever they are because they are imposed on them and I think that is how we work in the community. We don’t feel we can impose, that when somebody says ‘no I want to furniture walk<sup>19</sup>, I don’t want to use that frame’ or whatever, we’re keen to go with that (OT, community, FG 2).

Often the first concern for most therapists was what equipment would enable people with stroke to be safe when moving. However, asking about the best way to achieve this sense of safety elicited a variety of responses. One experienced physiotherapist reported that she had grown more relaxed over time regarding what constituted safe use of equipment. This was associated with the realisation that there was often no prescribed way to use equipment in any one person’s environment:

Probably over time I’ve got a little bit more relaxed in terms of doing the transfer exactly correctly, or walking with the aid exactly right, which is probably what I did when I was a new grad. But, I mean obviously if someone is safer using a walking frame and as soon as they get into their house they park it in the corner, and then they grab the furniture, with some people, it looks all right. And you know that that’s what they’re going to do ... Steps are a classic example as well, cause there’s no right way or wrong way to teach them how to use a walking frame, or any aid, on a step, they just have to learn to practice the way that works for them. And I’ve seen them walk backwards. And I’ve been fine with it, because you’ve watched them do it safely. And they say ‘well how do I use it on steps?’ I said ‘we just have to give it a go’ see, it’s like folding up a stroller or pram, everyone does it differently. They’ve just got to work out a way that works for them, and hopefully it is safe (PT, community, FG 1).

The reference to ‘hopefully it is safe’ illustrates how there was uncertainty about

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<sup>19</sup> Colloquial term to describe when people lean on furniture to give them support them while walking, either instead of, or in addition to, equipment.

what actually constituted the safest way to use equipment, or even walking in general. When there were concerns about how safely someone was mobilising while on a hospital ward, therapists acknowledged that they had a greater sense of responsibility to intervene and advise them to do things differently than they would if they were seeing someone outside of the hospital setting:

Because often if you're seeing it [someone using equipment unsafely] on the ward you feel obliged to jump in and correct them. I know that, just from being at physio school, you are sort of trained to watch people walk. And if you see someone in the community using something strange, you want to kind of approach them and they might have been doing that for the last 30 years or so and it's just you kind of feel bad to approach something like that but on the ward definitely you have to look at the safety and try and help them out (PT, inpatient, FG 6).

Despite the imperative being greater to advise about equipment use and safety in hospital, other physiotherapists agreed that the ability to understand how someone will use equipment once they leave the hospital ward is very limited. Working within the hospital environment with clients who needed to manage basic tasks such as self-care and mobility meant that for the therapists who worked in this setting, their view on equipment prescription was understandably narrower as a result which they acknowledged:

And I think that's what I don't see in the acute side of things, because I don't necessarily have the time, or I don't see that person's daily life - how they function within their own environment, so to me, a frame is a frame is a frame. I'm sometimes a little bit more focussed on 'is this person able to walk safely up to the toilet, what do they look like on their frame?', rather than thinking the long term sort of how will this help people get back into their hobbies, and their daily life, because I'm probably more acutely focussed on what are they doing right now (PT, inpatient, FG 1).

In addition to whether their clients were in the hospital or their own home when using equipment, therapists had observed that the cultural background of someone with stroke could affect the way in which they used the equipment in either physical setting. Experienced occupational therapists had noted that people from some cultural backgrounds had an acceptance of family members being physically involved to support them when they were unwell or disabled. In such situations, either the person with stroke or their family may prefer to substitute recommended equipment with assistance from a family

member:

I've had situations where for the family it's really important to help their family member even though a piece of equipment might enable that person to be more independent, culturally, the family will help them ... the Indian cultures. So say if I was looking at someone feeding themselves and looking at a grip, you know that they'd be able to hold the utensil, that is still not done because there are daughters who will look after Mamma and she will sit there and you will feed her so and then in some Pacific cultures, it's been the same thing as well, it's been very important that they go in and shower someone (OT, inpatient, FG 5).

Other therapists noted that family members would rather assist their relative with certain tasks rather than break cultural taboos. For example, while placing a commode beside the bed could make independent toileting easier, some families would rather keep personal care activities away from the sleeping space. Again, in these instances, therapists reported that family members appeared to prioritise their cultural preferences over the potential independence offered by using a piece of equipment:

I had a Māori family I was working with and it was their elderly Mum and I offered the use of a commode to use in her bedroom and they were very reluctant. I mean I said 'that's absolutely up to you I'm just offering, you know if it's going to be easier for you to manage her at home, then you're more than welcome to use this [commode]' and they didn't like the look of it, they didn't like the idea of it or just that, culturally, you know anything to do with toileting and personal cares and things should be done in an area which is suited for that, not in a living area, which is fine and fair enough. And they had enough support to manage her without that, so that was fine (OT, inpatient, FG 3).

A new graduate Māori physiotherapist noted that some of her Māori clients had certain equipment items in their family which had cultural meaning. These may or may not be suitable for the person in question, in the opinion of the therapist, but discussion about the best way to keep using these valued items, or *taonga*<sup>20</sup>, appeared important to this therapist and to the people she had worked with:

Amongst some of the Māori clients I've worked with, you can get like a walking stick passed down to you from grand-parents or something like that, so they prefer to use that than something that you [physiotherapy service] gives them. And often something that you'd give them that might

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<sup>20</sup> A treasure, anything prized - applied to anything considered to be of value including socially or culturally valuable objects, resources, phenomenon, ideas and techniques.



be a bit more appropriate, but they'd prefer to use their own one because it's been handed down and it's a family heirloom or something like that. But then when you kind of try to say 'you need a walking frame' or something like that, they're all 'no, no I've already got something, it should be fine (PT, inpatient, FG 6).

For other therapists, when asked about the cultural differences in relation to equipment use among their clients, they held a view that how masculinity is expressed in New Zealand impacted on whether or not someone would use a piece of equipment. The perception that some men who based their sense of worth on being physically independent made them consider this group differently when they were assessing them for possible equipment provision:

I think it's more the Kiwi<sup>21</sup> blokes<sup>22</sup> who don't want it as much, because they are all, 'I want to be independent and staunch and I don't need it' especially the older males (OT, community, FG 5).

The views held by different therapists on whether one's cultural background influenced their interest and uptake of equipment after stroke were developed based on personal and professional experience. They could not be proven per se but these beliefs did influence how they spoke about equipment and equipment options to different groups of people in different ways.

### **Professional philosophy**

Identifying with a professional philosophy was important for most therapists and this could be related to discipline specific ideology or more general concepts like what it meant to have a rehabilitative approach. How a therapist's professional philosophy impacted on how they prescribed equipment often became evident when they talked about having their professional identity compromised by external health and disability service protocols. There appeared to have been conflict between different professional models of practice when they issued equipment:

Interviewer: So do you think rehabilitation and equipment provision are quite separate to each other?

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<sup>21</sup> Colloquial term for New Zealander

<sup>22</sup> Colloquial term for a man

OT1: Absolutely, that's about [the] model of practice, you assess the person.

OT2: It's one tool in the toolbox. I probably have an underlying philosophy that equipment isn't the be-all and end all. But I can understand why somebody in a new practice, as a new grad, would hook onto that. Because that's how they see and define occupational therapy, around prescription of equipment, as a means towards independence. I don't see OT like that but then I have a lot more tools in my belt and I can do a lot of other things now, so I don't need to rely on equipment so much (OT, all community, FG 2).

Other experienced therapists working in inpatient settings reflected that when they were new graduate therapists, equipment provision was like a 'fail-safe' solution. Interestingly, quite in contrast to this view, new graduate therapists themselves described resenting that others perceived them as the equipment providers. They found that this was something which they felt was forced upon them and that they had to argue against this imposed expectation. They had also not expected this to be such a large part of their role based on their undergraduate education. For these therapists who were more recently qualified, there was often a sense of surprise or hesitant acceptance about the amount of time spent on equipment assessment and prescription. These new graduates did not perceive that they necessarily embraced their role as equipment providers and they described having little training about different equipment or being an assessor.

There was a presumption from other healthcare staff that for a therapist to have done their job properly, they needed to have issued equipment. However, to therapists, doing one's job well in terms of one's own philosophy of practice may or may not involve equipment provision:

I might often say to them, some of the people that I give equipment to, I actually don't do a lot of equipment, if you look at my stat[istic]s, maybe I'm not doing my job properly, but I think I have one of the lowest amounts of equipment issuing (OT, community, FG 5).

In the above quote, the occupational therapist implied that her lower frequency of issuing equipment may be viewed negatively by others because productivity was judged by the completion of particular tasks, such as equipment prescription. Despite these beliefs, she reported making a conscious decision to be cautious about how much and how

often she issued equipment.

There seemed to be a divide among participants about how the philosophy of hospital based therapists were challenged differently to those based in the community. In addition, working in a clinical team that has the word 'rehabilitation' in the title meant that the philosophical underpinnings of such a team were perceived as being, for some therapists, more client-centred than in a hospital setting.:

For us working in a rehab[ilitation] team, our philosophy, because it's so client-centred. That is where you always start and equipment may or may not be part of the solution (OT, community, FG2).

This community occupational therapist was confident that her philosophy of client-centred practice was paramount regardless of external pressures on her assessment and intervention with clients. In contrast, hospital based physiotherapists were more tentative about the client's needs and goals being at the centre of the assessment process. Rather, for them, goals were viewed more as something that the therapist could use to persuade the person with stroke to accept some equipment that they wanted to recommend:

Well I guess goals will often come into it as well, where if they are kind of saying 'I can't get to the mail box because I've got to lean on the fence' or 'I need to hold something' so often convincing them that 'maybe a walking aid', maybe will help you a little bit more with setting goals and in helping them achieve those (PT, inpatient, FG6).

Here it is suggested that varying amounts of effort were required from a therapist to contextualise equipment for a client. There was a difference of opinion between the focus groups as to just how much special skills and professional attributes were really required for successful equipment provision. In one group with experienced physiotherapists, while they accepted the expectation that equipment provision was part of their job, they felt that higher professional education was not required to accomplish this:

It's expected [as a therapist], but I don't think it's something that you necessarily have to learn to study at university (PT, community, FG1).

Experienced therapists also noted that when other professional groups, such as nursing staff, were given training and accreditation to issue some equipment items, they often commented on how much more difficult it was than they had imagined. This move

to increase the pool of professionals eligible to assess for and provide equipment was reported as happening increasingly to reduce waiting times for basic items. In general, therapists found that only the most basic issues and equipment items were dealt with by other professional groups, with occupational therapists and physiotherapists still primarily sharing responsibility for equipment provision between them:

I think sometimes we rubbish ourselves for the fact that we issue equipment and I think that we should respect that in ourselves because since service accreditation, so many people that were involved didn't take it up as a long term thing and said 'actually, I don't want to do this, this is actually not as easy as it looks'. A lot of people made that comment. The physios have been okay, I think between OT and physio that has worked quite well, but other professions haven't taken it up in the area that I work in. And we do undervalue how much thought we do put into issuing a piece of equipment and just go 'oh cause it's equipment it's an easy solution' but the thought has gone into why we are having that equipment (OT, community, FG2).

Therapists felt the need to defend or articulate their professional philosophy when challenged to issue equipment by other staff with a different agenda to them. Occupational therapists working in a hospital environment appeared to resent the roles they felt pushed into as equipment providers, that by focusing solely on equipment provision diminished the potential for the other interventions they could offer:

I kind of don't like it [equipment prescription]. Kind of because I think that's the perception of an acute OT's role on the ward and a lot of people just think that we've studied to just issue people equipment. And that's really frustrating. I'll decide that I'm going to give them that [equipment] rather than somebody coming up and being, like, you know, 'they are going to need a shower stool and this and this' and it's real just process ... whereas everyone's different and so is every piece of adaptive equipment, you actually have to think about that person instead of just giving it to them because they've had a certain operation (OT, inpatient, FG 3).

This new graduate occupational therapist illustrates how resisting the pressure to issue equipment in a standardised, one size fits all way, was challenging to others within the hospital system. They also raise the issue of professional autonomy, where a healthcare professional feels they should have the authority to decide what they will recommend and when, rather than having this directed by other staff or external policy. This issue was particularly prevalent in relation to funding guidelines influencing

equipment recommendations and this is explored further in the theme ‘equipment provision service’ and ‘wider health system’.

An occupational therapist, with a lot of experience in different clinical areas, talked about how equipment provision has fitted with her professional practice over the years. She described again that when taking a rehabilitation approach, there should be less emphasis on equipment use and provision than with other approaches. She also discussed that she saw a hierarchy of roles where she first considered herself to be an occupational therapist and then as an assessor for funding of equipment:

When I worked in orthopaedics it [equipment] was massively on my radar. Now I work in rehab[ilitation], it is no longer on my radar, because it is a different model of care in each of those places, it’s a completely different approach ... I think that personally I’ve always felt very strongly that I’m OT first, so I like to go into whichever situation and I’m looking at the client and I’m deciding on need and funding comes second in my mind (OT, community, FG1).

This therapist suggested that equipment provision should be a last resort when working with people with stroke, a sentiment echoed by other therapists for different reasons in the theme balancing risk versus benefit. This feeds into an idea expressed by therapists that to issue equipment without exploring other ways of achieving a goal is somehow lazy or less holistic than other models of practice. However, therapists were divided as to how feasible it was to hand the task of assessing for equipment to other professional groups, illustrating an ambivalent ownership of the equipment prescription role within their professional practice.

### **Equipment provision service**

There were two drivers for rationalising equipment funding decisions: criteria set by the health funder for equipment purchases and clinical rationale for achieving an ideal health outcome for a client based on professional judgement. There are instances where these agendas aligned well, however, at other times they were at odds with each other. For example, a therapist and a client may ideally prioritise community mobility as a goal of treatment and therefore the purpose of equipment provision. However, the criteria set by the health funding authority could restrict this goal as it was not designed to fund equipment for these activities. In such situations, the therapist had to resolve this tension

in some way, either by adhering more strongly to one rationale or another or, more frequently, making compromises between the client's goals and the funders' criteria. This situation could leave therapists ethically challenged.

Having the understanding of, and therefore some power to influence, the healthcare system which provides equipment was one of the key expectations of therapists in their role. The extent to which it is true that therapists do understand the system they work within and have the ability to challenge this system varies greatly. Many therapists gave examples of system changes which did not appear to make sense to clients and which the therapists did not necessarily agree with themselves but which they felt they needed to explain and, in some cases, defend:

I think wheelchairs is a big one, like some people might want a wheelchair for community access and they don't understand that just because that person has a wheelchair that their needs are different and that they don't meet the eligibility criteria. Or if somebody does need a wheelchair that they have to be discharged in one of our short term loan wheelchair that are terrible, then that puts a lot of stress because the family and the client don't understand why they've gone from a nice hired wheelchair [on the ward] into a really old, terrible, unsuitable wheelchair for a few weeks (OT, community, FG 5).

In some situations the primary reason that a therapist might wish to issue a piece of equipment was not a sufficient justification according to the funder's policies. As a result, disagreements with the funding administrators could arise and these often related to issues with the intent or the wording of certain criteria. This was particularly the case for mobility equipment where people with stroke and the therapist envisioned the equipment being suitable to use for community mobility.

There were differing opinions between the therapists about the appropriateness of current criteria whereby funding is only provided for mobility equipment to enable mobilising within the immediate home environment. Most therapists recounted specific experiences where they had found it challenging to adhere to this criterion, describing how they tried to work around this criterion in creative ways. The following excerpt highlights this dis-connect between policy directives and the way therapists view and treat policy in relation to their practice, including moral or professionally based reasons:

OT1: I think that having mobility, or having access to get out of the

house, is hugely important. So I think that it is appalling but it's one of those things, like, you know it's criteria that we have to abide by.

OT2: From an OT perspective, it doesn't fit that well but from a funding perspective you can totally see why they do it. Cause it goes against every grain in our profession really.

OT3: I think it can work when you see people who, like they can walk, their mobility is going to continue to improve, if they had a wheelchair that would actually limit their amount of physical participation and physical activity rather than if they, you know, keep walking for the next few months and progress and get back to the function that they were at before. Like when I think, so sometimes we can say 'you're definitely not eligible' because we know that actually if we gave you one that would actually be a hindrance rather than a help (OT, all community, FG 5).

The final example from these occupational therapists, where eligibility could be decided by the therapist based on what the therapist feels is best for the client, is an interesting idea. The first occupational therapist was appalled by the funding criteria not supporting people to meet what she perceived as a fundamental right. The third occupational therapist, on the other hand, outlined how she used the funding criteria as a reason to with-hold community mobility equipment when she feels some people would be disadvantaged by having items like wheelchairs. For this occupational therapist, the funding criteria were used as justification to not provide a wheelchair when in fact her clinical rationale was based more on what she felt was in the best interest of the person with stroke. Other therapists concurred that mobility outside of the home environment enabled enough benefits to encourage them to advocate for their clients receiving funding for equipment for this, even though at times this meant their recommendations were more difficult to fit with existing funding criteria. The therapists' impression of their role was possibly wider than the role they felt was expected of them by the health service, for example, when considering issues like loneliness as well as physical fitness:

PT1: I think also if you can have someone who can get out and walk, walk round the block, the benefits of cardio vascular exercise is huge.

PT2: And I'm sure it helps prevent clients getting further deconditioned, it helps potentially reduce the risk of further stroke, and secondary complications.

PT3: And loneliness, all that sort of thing. Cause they will just sit and do nothing, and so whatever work has been done as an in-patient, is undone, whether it's a fractured hip, or stroke, or any illness for the elderly (PT, all community, FG 1).

Elsewhere, physiotherapists reported that their impression of equipment for outside use was that it meant participation in a variety of settings was more possible. This led to more complex activity planning for both the therapist and the person with stroke but both parties were rewarded if the community activity worked out satisfactorily:

And with things like the stroller, you are kind of opening up a world of opportunity by taking your chair along with you, that you don't have to be able to predict how far you can move before you need to rest, because the chair is always right beside you for when you do need to rest, so that those people can perhaps plan different activities than they could plan if they needed to be able to identify where they were going to sit down before they set off (PT, community, FG 4).

Furthermore, therapists expressed that seeing the people they worked with able to do things outside of their house was satisfying for them to witness because their clients were often happy about engaging with their community. This sense of satisfaction was partly why they justified finding ways to manipulate the criteria to fit their clients' goals to mobilise outside the home. For example:

PT1: Just thinking about that kind of increasing people's confidence and independence and stuff, if they do need a walking aid indoors, I will get them a stroller, because then they can use it outside as well, even though I know technically we're only meant to get them for people who need to have them inside. But if it means that they can walk to their letterbox and collect their mail.

PT2: In their home environment, it's pretty much - it is an 'outdoor to their letterbox'<sup>23</sup>, but I like nothing better than seeing someone head to the library, you know, you see them out walking, or going to the dairy<sup>24</sup>, or keep that independence (PT, community, FG 1).

The physiotherapists had picked up on tensions that can exist between what a client wants and health funders' requirements for funding. These therapists had moulded their

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<sup>23</sup> Reference to an older, slightly different, version of current funding criterion for mobility equipment, where funding was available for equipment to enable people to get as far as their letterbox

<sup>24</sup> Colloquial term used in New Zealand for a small local shop selling grocery items.



practice to find ways to get the things they thought people needed. To make sense of this process for themselves, they rationalised that the immediate cost for a clients' equipment would ultimately act as a cost-saving for the healthcare system, thereby subverting the current policy in favour of their own professional reasoning:

Well if you can justify the need for it [walking aid] inside, any smidgen of a reason, then by getting something that is predominantly going to be used to enable outdoor mobility, it's going to mean that the indoor mobility is much better, is much more improved because they are going to have more time strengthening, and more time being out there on their feet, will be participating more. So that frame that cost maybe 200 or 400 dollars, is going to save the DHB a lot, or the Ministry of Health a lot, by not having them [clients] require a lot of services because they are stronger. So you have got to find a smidgen of a reason for the indoor mobility side [to be able to justify equipment to help with outdoor mobility which is not technically funded by Ministry of Health] (PT, community, FG 4).

So some therapists would look for reasons to justify funding that would not technically be considered with the current Ministry of Health criteria. They expressed their desire to exert professional autonomy about recommending equipment, having completed an assessment and developed an understanding of a person's needs and a rapport with them. Talking about themselves as being therapists regardless of the funding situation was sometimes imbued with pride in their professional background, which could lead them to be resilient in their arguing when they felt that the funding structure was not aligned with their professional values or was trying to control their reasoning:

PT1: But from a clinical point of view I wouldn't take that [criteria] into account, I'd just think 'what does this person need'?

PT2: Well, that's because we are clinicians (PT, community, FG 4).

Resolving the tension between dual roles of being assessor and a therapist was not easy. For some, there was a clear separation between the duties of the two roles, for others there existed an antagonism which they struggled with. This tension further reinforced the idea that therapists were playing by two different sets of rules when making recommendations and looking for ways to align them:

It's a conflict for us as clinicians, because if you asked me Enable has their rules and we have to work within that so yeah, there is an expectation

on Enable's side that I do have to consider money in a big way and that I am operating as their gatekeeper, that's their perception. My perception is that actually I trained as an OT and my thing is to do what the client requires so I would put that as my higher priority, but I'm certainly aware that the other is a limitation. And being an assessor I have an obligation to act upon that, but I wouldn't say that one actually over ruled the other. I still fight that one constantly in my head (OT, community, FG 2).

Despite there often being a prioritisation of clinical reasoning before funding considerations, there was also an acknowledgement of the need to be accountable financially for their decisions and recommendations. Therapists were disheartened when they witnessed equipment which was not being used and they could link their beliefs about the consequences of unused equipment to other people they knew or issues in the healthcare system. This could extend to feeling responsible for money being potentially then not spent on other services:

PT1: I think it's horrible to see waste when you know that someone else could be using this [equipment]. That waste is going to potentially have meant that the health system would have had more people on board, or more equipment or something (PT, inpatient, FG 4).

How much a therapist considered the financial implications of their equipment recommendation increased relative to the cost of the piece of equipment or how easily a piece of equipment could be re-issued to another person. Where equipment options started to require greater tailoring to an individual and greater cost this created more questions for therapists about whether it was really necessary, thereby making them wonder again about the needs of the person they had assessed. So, while they did manipulate the system to meet the needs of the people with stroke at times, they were not blind to the fact that they were influencing public expenditure:

Personally I have to be able to justify the bigger cost items in a much bigger way for myself, as a clinician, than a shower stool and an easi-reacher<sup>25</sup>, I can quite happily offer to anybody at any time, if I feel that it is justified. I don't even sweat it anymore, not at all (OT, community, FG4).

How far therapists could or would go to either argue a case or even manipulate their

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<sup>25</sup> Pick up stick which enables someone to pick up light items without bending over – a low cost item of equipment

report writing for someone who did not strictly meet criteria varied across groups. Many therapists described tensions when creating arguments, selecting their terminology use carefully and sharing reports with each other to help strengthen arguments for funding. When funding was declined, therapists could feel a sense of responsibility for having let their clients down. While they were still within their first three years of clinical practice, these new graduate physiotherapists had experienced and reflected on personal reactions to not being able to supply equipment due to financial issues as well as having a moral responsibility to manage funding as best they could:

PT1: I guess there is always going to be a limit to what you can do with funding and things. Sometimes when you build a rapport with these clients you want to be able to do so much for them and when you are limited by money, I don't know, it's a little bit gutting for you and for the client.

PT2: But where does it stop then, do you get stair lifts then for every client that comes in and at what point does that mean that you can't go out with zimmer<sup>26</sup> frames because we've run out of money? (PT, all inpatient, FG 6).

Many therapists were aware that incorrect assessments could waste resources and they took their responsibility regarding resource management seriously. They received feedback from administrators about the cost of the items they trialed and this increased their awareness of the financial implications about recommendation for equipment. While this awareness could be helpful for them, it also increased pressure to get their assessment right first time, which could be difficult when neither they nor the person with stroke had seen the equipment used yet:

So you have to make a decision about whether or not it's [equipment] going to work before you've ever had it in front of the client. And you kind of feel that you are potentially wasting resources with that, especially when you have that 'it's going to have to be hired' in conversation and it turns up and it turns out that it isn't much use and it goes straight back again (PT, community, FG 4).

While there were tensions and stressors associated with the funding system for some of their clients, most therapists acknowledged the need for such a system and that for

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<sup>26</sup> A brand name for a relatively basic walking frame

people who had relatively straightforward needs, the system worked well. For those who had more severe strokes or other co-morbidities, there was a perception that navigating a way through the equipment funding process was more difficult for them, potentially putting them at a disadvantage as they would need to wait longer and undergo more equipment trials:

I think for the less impaired you can often sort something out reasonably okay, if they're less impaired and they can make do with a standard walking frame that's easier to get funded. It's the ones that are a little bit more tricky, or have slightly more impairment, where you need more specialised equipment, you can come up with some more road blocks in the way (PT, community, FG 4).

The experienced therapists acknowledged that they were inclined to write more persuasively in their reports for some clients rather than others. The decision to do this was sometimes based on whether they felt that someone with a stroke could privately fund the equipment and whether they had a lot of other stressors going on and that not receiving the equipment would add to these stressors. These reasons were not always directly related to funding criteria but they weighed on the minds of therapists as legitimate reasons why someone needed or deserved equipment. In these instances, therapists appeared to be keen for some discretionary abilities:

OT1: When I did community OT years ago and yeah sometimes I would do a little bit of creativity with my reports and it sounds really bad, it's not very ethical, oh it could be ethical, I don't know, I'd be looking at other factors like their finances, the sort of environment they are in, the stress in the family and kind of weighing that up. I kind of have my own little weighing criteria so to speak. And that's what I would do.

OT2: And every now and then you'd fudge it. Well you do, don't you. Because you're thinking there's no way that they can afford it, the family is so stressed.

OT3: Because sometimes you will advocate harder or creatively write a report or get on the phone to somebody if you think it's a really big barrier (OT, inpatient, FG 5).

The idea that one can creatively write a report if you feel adequately justified was reinforced by physiotherapists also. There was some contradictory comments about what came first in recommendation decisions: criteria led (ordering what one can get easily and

without argument) or what the person needs (which may or may not fit neatly with funding criteria). Either way, this reasoning was still about need primarily, as defined and decided by the therapist:

I think you tend to order what you can, what's available ... I would think, 'what do I think the person needs'? And then make the criteria fit. I wouldn't think about the criteria at all really. Because I think that the criteria are very limited (PT5, community, FG 4).

This physiotherapist highlights an essential skill which therapists often need to develop, to work out the maximum one can get for one's client by writing funding applications in a way which would maximise the chances of success. This speaks to some flexibility or interpretation of funding criteria. One of the drivers to advocate more passionately for funding for one's clients occurred when therapists worked in lower socioeconomic areas and saw inequitable living conditions among their clients. In relation to assessing a client's ability to pay for equipment, therapists who worked in poorer areas experienced conflict about discussing self-funding equipment:

I'd love them [funders] to allow us to get for people that can't afford it, things like crutches and quad sticks and [walking] sticks, because it's saving the government a lot of money if we get these really low cost items, that these people aren't going to buy, if we can sort them out and then they are much more active and they are participating more (PT, community, FG 4).

This dismay was less relevant to group members who worked in more affluent areas, where paying for even quite expensive items was something their clients would often choose, rather than engage with tedious funding applications and waiting times. Therapists had differing levels of comfort with how much they should be responsible for money spent on equipment. For some, explaining the funding limitations was a part of their role which they found hampered their therapeutic relationship with clients who perceived them as personally responsible:

PT1: There's people who ideally would have the equipment but then they don't meet that criteria and we're the ones that have got to tell the client that, like Enable don't call the person up to say 'sorry you can't have that'. Then we lose a little bit of that therapeutic relationship with them.

PT2: Because it is almost like it is our fault.

PT1: Yeah, exactly. We're seen as the blockers as opposed to the enablers, but we just can't get that for them. Which has been tricky in recent times (PT, community, FG 4).

Overall while therapists appreciated the need for a funding system to manage resources effectively, they felt that their professional opinion and expertise were not valued as highly as they ought to be. They were mindful of the equipment provision system, with its financial limitations and processes, while also being aware of the wider healthcare system and this too had an impact on how they reasoned and recommended for different items of equipment for people after stroke.

### **Wider health system**

There was an uneasy tension at times between the equipment provision criteria and process in relation to one's professional practice. In addition, there was a frustration among therapists about how the wider healthcare system's limitations affected their ability to practice in a client-centred manner when it came to equipment provision:

If we can, I personally try and get them so that they are off their aid if it's what they are wanting. I have to be led by the client, but then we're also led by the health system's dollar as well and the expectation that we don't stay with a client forever just so that they can get off an aid (PT, community, FG 4).

There was a tension between the therapist's desire to spend time and energy on seeing through a client's goals to mobilise without equipment, but they were aware that their time was also a cost to a health system. Even if their goal included reducing dependence on a piece of equipment, there were limitations on the amount of time a therapist could legitimately work towards this goal. This limitation and consequent curtailment of client goals was associated with health service funding for this particular physiotherapist, something for which she felt responsible. Respecting clients' wishes regarding whether or not to use equipment could come at the expense of moving them through a healthcare system that requires healthcare staff to 'free up' beds and waiting lists for services in minimal time. For example, this physiotherapist described how she would despair when people declined a walking frame for personal reasons. She then felt responsible that they were not progressing quickly enough and therefore staying in a hospital bed which another person may have otherwise have had:

There's definitely those people who say 'oh I don't want a frame' but in the sub-acute rehab phase where there is that element of 'how am I ever going to get back to moving again?' (PT, inpatient, FG6).

Being seen as offering more services than equipment provision changed how therapists viewed their own practice and their use of equipment within their practice. For the new graduate occupational therapists, who primarily worked in an acute setting with little time for home visits or long discussions and trial with equipment, when their clients declined using equipment, it was often a source of stress for them as it made their ability to 'sign them off' as safe for discharge more difficult.

Equipment was a concrete visible item, a tangible outcome of having attended physiotherapy or occupational therapy. Equipment items are symbolic of what the general public associates with rehabilitation and for some therapists their professional identity was associated with prescribed equipment. For many therapists, equipment acted like a calling card or representation of their profession, particularly in the eyes of their colleagues and the wider health care system:

Well, it's a physical prescription, isn't it (PT, inpatient, FG 4).

Therapists working in both community and inpatient settings agreed that hospitals appeared to be impairment and safety focussed, prioritising discharge as an ultimate goal and reducing length of stay. This in turn focussed decision making and recommendations of therapists when prescribing equipment:

OT1: Yeah, safety would be high. And the biomedical model, people operate from that. That would be pretty high. Impairment, bang, we need to just do this, you know, versus looking at function.

OT2: And the values of all the staff, up there, [on rehabilitation ward] like not all staff value independence up there as well, so it's 'give them a piece of equipment, get them home' rather than about their actual ability. It's a huge battle for us.

OT3: Yeah, it's the culture of the place as well.

OT1: When I've had a physio who has not worked closely within the team, who doesn't have that background [rehabilitation], I've been amazed, where it's been 'who cares if they go home with a walking frame,

too bad that they were walking independently, driving a car before, we just need to get them home, who cares' and it's like 'wow', their view of rehabilitation and my view of rehabilitation are two different views. And they are looking at the cost of a bed and the person sleeping on the ward sending them home versus quality of life and performance (OT, all inpatient, FG 5).

There were arguments between therapists and other healthcare staff about how to prioritise people they identified as needing more time or more expensive equipment. At times, therapists felt that they were doing the bare minimum and this was happening as a result of pressures to curtail cost while still providing some service. For this group of experienced occupational therapists, there was a perception that the speed of discharge and expectation of throughput in a health service increased pressure to issue equipment sooner rather than later, which echoes issues raised in the 'risks versus benefits' theme:

I think that I find that it's often, we're using compensation rather than remediation, you know. It's cheaper to just put a piece of equipment in place rather than to rehabilitate someone so that they can really do it without assistance (OT, community, FG 5).

The availability of other staff (who may also have waiting lists for their service) or more complicated and long term funding processes like housing modifications and packages of care were other factors considered when weighing up whether or not equipment should be issued:

Or whether or not there are other options, like housing mod[ification]s. Or how long the physio is going to be to come and do some rehab[ilitation] so that they can step up into the shower or whether there's a possibility of doing some joint work, there's heaps of variables, I think (OT, community, FG 2).

This group of experienced occupational therapists went on to describe the priorities of their workplace as depressing and that the pressure to provide equipment quickly was one example of where they struggled against the ideology of their workplace. The idea that fast equipment provision was part of a compensatory model of practice was reiterated in relation to the culture of the wider healthcare system:

OT1: There is a really big focus on discharge planning and people being out from hospital and the push on beds and just case load pressure as well.



OT2: Well I think that our priority is discharge. The top of our list is discharge. Rehabilitation comes fifth on the list which I think is appalling.

Interviewer: What's this list?

OT2: Oh, it's the priority list for OTs on [rehabilitation] ward.

Interviewer: Right, so that is a rehabilitation ward ... that's really interesting.

OT2: Isn't it? It's quite soul destroying when you think you're taking on a rehab[ilitation] role where you are going to rehabilitate somebody, not compensate (OTs, all inpatient, FG 5).

Equipment was symbolic to therapists throughout the themes described in this chapter and there was often ambivalence about the place of equipment, and funding structures associated with equipment, to their practice as autonomous health professionals. Equipment provision linked to tensions and conflicts within rehabilitation models after stroke and challenges to providing shared decision making with clients when resource allocation was involved. There were a variety of opinions across the groups and these differences will be summarised in the next section.

## **6.5 General differences between groups**

Broadly speaking, there were greater differences in the concerns and considerations expressed between the new graduates versus more experienced therapist groups than expressed between the physiotherapy and occupational therapy groups. New graduates were less likely to mention concerns regarding tensions between compensation and rehabilitation and were more likely to feel that the provision of equipment was 'expected' in their area of work. Compensation, loosely speaking, occurs when therapists provide supportive items and strategies to an individual with stroke to enable them to do a task (for example, a stool to sit to shower instead of standing). Many therapists associated rehabilitation with the idea that a person with stroke should be encouraged to do a task exactly as they had before their stroke, without any change to his or her neuromuscular system (so in the given example, that they would re-train their physical ability to stand to shower). The discussion about which was the best outcome, and for whom (people with stroke, their family, the health service professionals or the health funder) was a thread

running through these results and is explored further in Chapter 7.

New graduate therapists seemed to have grappled with the consequences of a client declining equipment, whereas this did not arise as something that was difficult to manage for the more experienced therapists. Unsurprisingly perhaps, experienced therapists appeared to have considered the wider system and their role within it more critically. For instance, there were occasions where open questioning on this topic did not result in any response in the group meetings with new graduates. This may have been due to these groups having less confidence about discussing the topic or simply due to them having thought less about this topic. As a result, questioning was necessarily a little more directive with new graduate therapists.

Experienced therapists generally had a greater understanding of the equipment provision system and perhaps as a consequence of being able to compare with alternatives, they were respectful of the need for a system to exist in order for them to do their jobs properly. Many expressed that they did not think that the current provision system was perfect, but they often struggled to identify efficient or fairer ways services could be delivered.

The physiotherapists discussed the issue of compensation versus retraining to reduce impairments more than the occupational therapists, though most experienced occupational therapists had a similar line of thought, using different terminology, about the importance of clients reducing reliance on equipment. All experienced therapists acknowledged that how they thought about equipment and their role as providers, advocates, and gatekeepers had evolved since first qualifying. These experienced therapists generally had reconciled the existence of, and tension between, the role of being both a gatekeeper and an advocate for service users, though this could be inconsistent at times within groups and even within individuals.

The experienced therapists were also inclined to incorporate equipment provision more explicitly within their clinical reasoning, in most cases seeing it as the end result of assessment, goal planning, and trials of a range of interventions. They were also mindful of setting equipment up with clear expectations with the client about its possible withdrawal: a step not discussed by less experienced therapists who were typically based

in a more acute setting with a different demand on their clinical time. One possible explanation for this is that those in acute settings do not have adequate time to include this kind of discussion about the possible future relationship someone with stroke could have with their equipment.

Physiotherapists in the new graduate group discussed outcome measures to help them decide whether or not to issue equipment, they were the only group to bring this up as part of their decision making process for equipment provision. This may indicate a relatively recent change in undergraduate education, where outcome measurement is increasingly emphasised as an integral part of practice. Often therapists gave examples of equipment provision from their own families, highlighting that this issue had been relevant to many in both their professional and personal lives. For example:

My grandparents are two completely different, like opposites. My granddad is like 'no I don't want a walking aid', or anything like that. He's like 'oh when I have my next fall, I'll get a walking frame then' kind of thing. Whereas my nana uses a walking stick and she's got about five different coloured walking sticks that she matches to outfits and things like that (laugh). It's more of an accessory than anything, whereas for my granddad it is more of a sign of being old (PT, inpatient, FG 6).

Approaching equipment provision using these personal reflections could enable therapists to take on more of a consumer perspective, by examining what the experience had been like for their family member and for the rest of the family who was involved.

## **6.6 Summary**

The priorities of the equipment provision system and philosophical or professional perspective of the therapist who issued equipment could be at odds with each other. This was a tension most therapists had recognised and learned to come to terms with. In these cases, their model of practice, most typically cited as person-centred, could be in conflict with the equipment provision system or the wider health system. Equipment provision could cause a therapist to take on multiple roles, sometimes simultaneously and this could be confusing for them and their clients. Being an equipment provider could mean that one was an assessor, gatekeeper, consultant or advocate for people with stroke and each therapist had a choice about which role they took on and when.

While the equipment provision process was seen as necessary and the presence of

funding criteria as understandable there was concern that these criteria did not truly reflect the needs and priorities of the people the therapists worked with. The processes within the equipment provision system could be interpreted as undermining therapists professional autonomy when it came to making equipment recommendations. The complexities of being an equipment provider and a therapist were evident when trying to work out the order of steps to justifying equipment: whether one makes a clinical decision on what equipment is ideal or first checks funding availability. Where a therapist makes a person-centred recommendation about equipment in the first instance, they often needed to adjust this or negotiate in some fashion with either the person with stroke or the equipment provision service to address funding and availability constraints. These interactions could be morally challenging for therapists.

Therapists acknowledged difficulties in predicting who would require equipment long term, which is a challenge for the healthcare system in general. This difficulty with predicting equipment need over time was a thread present in all three phases of this research. There were further philosophical and ethical tensions about whether to consider equipment as rehabilitative or compensatory, which linked to a wider debate about what the distinction is between these two concepts and which is more favourable and to whom.

This chapter outlined the experience of therapists in relation to their role in the prescription of equipment to people after stroke. Seven inter-related themes emerged illustrating the factors influencing reasoning when issuing equipment for people after stroke. Tensions exist between different aspects of these factors and many therapists undergo a process of weighing these drivers up in different ways for different clients and different pieces of equipment. The tension between philosophical practice and person-centred care and the equipment provision and healthcare system is discussed further in Chapter 7.

## **Chapter 7. Discussion and conclusion**

### **7.1 Contribution of this thesis**

The aim of this thesis was to explore whether the policies and procedures for provision of adaptive equipment to people with stroke are fit for purpose in terms of maximising safety, independence and choice. The results of this thesis provide unique insights into a number of areas which are summarised in this chapter. I also draw together the findings from each chapter (as much as is reasonably possible) and I reflect on how these findings address the aims of this thesis. Thereafter I focus on three primary issues for discussion: 1) that participation is prioritised over safety in terms of funding for equipment, 2) that shared decision making offers an avenue to patient centred practice for equipment provision and, 3) that therapists prescribing equipment can experience moral distress about this process.

Chapter 4 reported on who received equipment after stroke and what equipment was most prioritised by people recovering from stroke. This chapter also described the outcomes which were reported by people with stroke as a result of their equipment use and their satisfaction with the equipment provision system. Estimates of the cost of publicly funded equipment in New Zealand in 2012 were also provided. Prior to this thesis, the cost of equipment to people with stroke was unknown, as were the outcomes of equipment provision from the perspective of the equipment user. While there are a number of limitations associated with the cost estimated in this thesis, it appears that the annual cost of new equipment for people with stroke is around NZD \$1.2 million, approximately 0.2% of total stroke related health expenditure. In other words, the equipment itself for people after stroke does not appear to consume a lot of financial resources, compared to total public healthcare costs for this group, yet it can have a significant impact on their quality of life and ability to participate. It is therefore very important to consider how the equipment provision services structure their administration, to reduce bureaucracy while ensuring efficiency, around what is essentially a low cost intervention with relatively high potential cost benefit.

Chapter 5 focussed on qualitative data to provide deeper understandings of the meaning of adaptive equipment for people with stroke, and of the interactions these people

had with the health service when procuring these items. Important differences in decision making about equipment depending on one's environment and the value placed on equipment was illustrated in this chapter with the development of two central themes (inpatient impressions and time and testing) and four related sub-themes (trust in health professionals, shifting worlds: from hospital to home, making sense of equipment, and participation makes equipment worth the effort). The change over time in how people with stroke view their equipment and their ability to engage in decision making about equipment with their therapists adds to understanding about use of equipment and guides therapists about optimal support at different times for shared decision making.

In Chapter 6, the perspectives of therapists were explored regarding their role and the influences of equipment funding on their decisions was explored. The model of reasoning which was developed from analysis of qualitative data in this chapter illustrated that there were seven factors which influenced how and why therapists recommend equipment after stroke. While other models of practice endorsing best practice in equipment assessment exist (Cook & Polgar, 2015b; Scherer & Craddock, 2002), the model presented in this thesis is the first to explicitly explore and integrate systemic issues, with their resultant ethical challenges, into reasoning for therapists when prescribing equipment. Though endorsed as important in shared decision making, cultural factors have been notably missing in theory development (Charles et al., 2006) and this thesis contributes to greater understanding for this field.

As outlined in Chapter 1, the priorities for public healthcare funding in New Zealand, according to the Ministry of Health (2013a), were providing value for money, being person-centred, ensuring equity, timeliness and effectiveness as well as sustainability. This discussion chapter is focussed on issues which arose from this research related to the current equipment system failing to maximise participation for people after stroke, the challenges inherent in shared decision making in this area and the moral distress faced by therapists when they are deciding whether or not to recommend equipment for someone after stroke. There are two main areas where moral distress occurred for therapists: 1) balancing tensions between beliefs about compensatory approaches for impairments to support return to activities versus the negative impact the compensatory approaches might have on physical recovery of motor function after stroke

and 2) the issues which arose when therapists had to balance their role as a resource holder versus being an advocate for the people with stroke they worked with.

While the idea that people who use equipment can have an ambivalent relationship is one that has been gaining credibility in recent years (I. Pettersson, Appelrosi, et al., 2007; Skymne, Dahlin-Ivanoff, Claesson, & Eklund, 2012) the findings from this thesis illuminate how people's relationship with their equipment and their perception of the equipment prescription services evolves over time.

## **7.2 Relationship of data across stages of data collection**

As data was collected one stage at a time, information on how data related to other phases was outlined in Chapter 3, however, data has been presented separately across chapters. While the responses and responsibilities of people with stroke compared to therapists is fundamentally different, there are some conceptual areas where there was overlap. Equipment was symbolic to both groups, though often symbolic for different reasons: for example, people with stroke could view their wheelchair as something that stigmatised them whereas their therapist could view it as a successful rehabilitation outcome that they were able to move by themselves again. Essentially though, the equipment has quite different meanings for each group.

People with stroke value having their individual needs considered and this was reported to be to the forefront of therapists' minds when they were deciding about their equipment recommendations. People with stroke wanted to be treated as autonomous beings, increasingly so as their recovery progressed, and therapists' appeared to be keen to incorporate this desire into their reasoning. In other words, both therapists and people with stroke agreed that client's concerns regarding what they wanted to get from their use of equipment needed to be central to the decision-making process. Both people with stroke and therapists expressed that, ultimately, seeing people be able to leave their house and participate in their community again was a highly valued goal. This overlap between the reported experiences of people with stroke and therapists providing equipment provides an example of where patient centred care currently occurs in practice.

The views of people with stroke and their therapists diverged when it came to their understanding of equipment over time. People with stroke experienced equipment over a

period of months to year, during which time their bodies, needs and abilities changed. The timespan for considering equipment was much shorter for therapists however, and was limited to the time required to determining immediate needs and issuing equipment. The reports of people with stroke also differed substantially from those of the people who prescribed equipment regarding views on the role funding played in their perception of equipment. Discussion about funding considerations was notably absent from the experiences described by people with stroke whereas funding and related criteria for equipment provision was key in decision making about equipment provision for therapists and moral conflict about the role funding and related policy plays in equipment provision is discussed later in this chapter. These differences between people with stroke and therapists regarding the timeframe for viewing equipment and the pertinence of funding issues had a major impact on the ways that these groups of people thought about and spoke about equipment after stroke. Ultimately, these differences limited the degree to which the different data sets in this thesis could be meaningful synthesised

### **7.3 Prioritisation of safety over participation in funding policy**

This thesis questions what is, and also what should be, the core focus of equipment provision services in New Zealand. In this context, the ‘equipment provision service’ includes both the therapists who carry out assessments and make recommendations and the funding and policy sectors which are responsible for strategic management of this area. If the primary aim of this service is to ensure the safety of people with disabilities then the results of this thesis endorses that this is indeed happening to the satisfaction, by and large, of the people who receive and use equipment. However, if the primary goal of these services is to enable participation and to maximise meaningful occupation, then the current equipment provision service is not currently fit for purpose. The role of participation appears, from this research to be the ‘poor cousin’ when compared to how safety within the home is prioritised in terms of funding allocation.

Notably, both the ICF and the UNCRPD prioritise participation as an outcome for adaptive equipment (Bickenbach, 2009; WHO, 2001). To comply with the UNCRPD’s recommendations (United Nations, 2007) , the New Zealand Disability Action Plan has cited promotion of access to the community for disabled people as one of four important targets (Office of Disability Issues, 2014). However, the research findings presented in



this thesis demonstrate that people who used equipment had varying experiences of incorporating their equipment into their world to enable participation and therapists had experienced moral distress when advocating for equipment in order to enhance participation (particularly outside the home).

That people with stroke in this study highly valued mobility equipment is in line with other research, where mobility deficits are often identified as those causing the greatest difficulties (Schulz et al., 2012). Accessing the community for social participation is often one of the most challenging and valued aspects of life after stroke (Mayo et al., 2002) and people who use wheeled mobility make fewer trips outside of their house and engage in fewer social activities than non-wheelchair users (Harris, 2007). Substantial attention has been paid to the need for community services to rise to the challenge of supporting people to live in their own homes again after stroke (Mortenson et al., 2015; National Institute for Health and Care Excellence, 2013; Reed et al., 2012; Siemonsma et al., 2014; Stretton, Mudge, McPherson, & Kayes, 2014). This thesis correlates with other research about life after stroke in that the provision of equipment to enable social interaction outside the home was considered highly important but generally lacking (Tyson & Turner, 2000). Arguably, by restricting funding for equipment aimed at supporting mobility outside the home, the Ministry of Health is in conflict with its own policy goals around improving engagement in the community and encouraging physical activity for people with disabilities (Ministry of Health, 2013a).

By not investing in equipment to support community mobility, there could be longer term consequences for the health service. Kunkel et al. (2015) reported on a 3 year longitudinal study on activity levels after stroke (using an activity monitor attached to the unaffected leg), stating that poor activity levels correlated with depression, visual neglect and compromised balance. While the direction of causation could not be established with this research, the results from Kunkel et al. (2015) do suggest that extending the distance and terrain a person with stroke is able to mobilise over could have a positive effect on other areas of their physical function and general wellbeing. Increasingly research endorses the view that physical activity is a protective factor for older adults from health conditions such as another stroke and secondary diabetes (Hu et al., 2000; Warburton, Nicol, & Bredin, 2006), so by not encouraging more sustained physical activity outside the

house, the health service is running the risk of ultimately creating greater healthcare costs in the future.

There is increasing evidence as to the psychological distress and social isolation experienced by people after stroke (J. White et al., 2014), both of which may be ameliorated by greater community participation (Woodman et al., 2014). Furthermore, a reduction in social isolation has been recognised as important in New Zealand, as social isolation and loneliness are associated with health issues such as increased blood pressure, depression and increased mortality (Statistics New Zealand, 2013a). In turn, depression has been noted as a significant predictor of mobility decline in people in their second year of stroke (van Wijk et al., 2006), so an interactive effect between depression and mobility can be observed. I would argue that the lack of provision in the current system for equipment to enable access to the community results in an increased risk of social isolation and worsening emotional status for people after stroke, which will affect their future mobility. In this regard, the current equipment funding and provision service could be seen as not fulfilling its remit to protect the health and well-being of these individuals. As the estimate for new equipment reported in this thesis was just .2% of stroke related costs, equipment provision is essentially a low cost solution for supporting people. The longer term cost consequences such as remaining more physically active, engaged in one's community and connect socially would appear to warrant an increase in funding for equipment for people with stroke

In addition to funding issues, there is also the matter of having sufficient allied health personnel and time (Ministry of Health, 2011) to assess for and deliver evidence based community mobility interventions to enable participation. Adequate time for working on community mobility can be jeopardised by a systemic prioritisation on safety, meaning that allocated time to work on participation is not protected. Questions have also been raised regarding whether the skills learnt by people with stroke in the indoor setting are transferable to the community (K. A. Walker et al., 2010). However, of the limited RCTs which have been conducted examining rehabilitation for community mobility, one study found that compared to people who received a leaflet about transport services (usual care = 82), participants who received seven intervention sessions focussed on outdoor mobility from an occupational therapist (n = 86) were more likely to get out of the house,

at both four months (RR 1.72, 95% CI = 1.25 to 2.37) and 10 months (RR 1.74, 95% CI = 1.24 to 2.44) (Logan et al., 2004).

Access to appropriate equipment is a consistent recommendation from all international guidelines on stroke rehabilitation (Dawson et al., 2013; National Institute for Health and Care Excellence, 2013; Scottish Intercollegiate Guidelines Network, 2010; Stroke Foundation of New Zealand, 2010; Zorowitz, 2011) and represents a modifiable factor contributing to participation after stroke (Desrosiers et al., 2006). How a healthcare provision system defines ‘appropriate’ and ‘timely’, however, is influenced by a number of systemic and clinical factors (as presented in Chapter 6).

#### **7.4 Shared decision making across different environments: a worthwhile challenge for therapists**

Shared decision making happens when people with disabilities and their health professionals collaborate on how an intervention is provided (Barratt, 2008) and represents one of the ways in which therapists and people with stroke can make decisions together. Alternative approaches to decision making are focussed either on what the therapist believes to be in the best interest of their client (paternalism) or where people with disabilities make decisions about their healthcare with minimal involvement of a health professional (consumerist – interactive) (Charles et al., 2006). The findings of this thesis support the view that shared decision making is an important process during equipment provision. The results from this study showed that shared decision making manifested along a spectrum from being controlled by the therapist to being led entirely by the person with stroke, with the opportunity and interest for people with stroke having more control and input into the equipment provision process often increasing as time went on.

Other studies, using questionnaires to elicit views on whether users of equipment had their preferences taken into account, report similar findings. That most people rated their satisfaction with the equipment prescription services as high is in line with other surveys of stroke populations on these issues (Hesse et al., 1996). Indeed, in comparison to other studies about satisfaction with equipment services (Cowan & Turner-Smith, 1999; Sainty et al., 2009), the results of satisfaction ratings in this thesis were reasonably positive. These rating scales included high satisfaction with elements considered to be vital to shared decision making including having one’s options taken into account and having

one's views and preferences elicited during the equipment provision service. That said, from the qualitative phases of this research, there were many nuances and variations as to what actually constituted shared decision making. Shared decision making was influenced by several factors: a given individual and their preferences for involvement, the environment a person with stroke was in (either hospital or home) and the individual's stage of stroke recovery.

One of the key areas to consider when implementing shared decision making is for therapists to develop an awareness of how cultural preferences can impact decision making for their clients. Research on the impact of cultural preferences in equipment use is in its infancy (Reisinger & Ripat, 2014; Ripat & Woodgate, 2011; Suurmond & Seeleman, 2006). There was an acknowledgement from the therapists that cross cultural understanding could be difficult to attain, but was vital to ensure safe and optimal use of equipment. Participants in this research reported that negotiation and clarification was required around: 1) the expected role of family members (particularly when this support could replace the need for equipment), 2) the level of privacy and cultural protocols associated with certain routine tasks, such as personal care and sleeping proximity to toileting facilities, and 3) the role of older people, where, for some cultures, to be the oldest member in a family meant that one is automatically cared for by others out of respect. These findings are congruent with other research where people of certain cultures have been reported to express a preference for human assistance over equipment use (Resnik et al., 2009). This can produce an additional ethical challenge for healthcare services if personal assistance presents an ongoing cost in comparison to the one-off cost of equipment purchase. As one of the key management strategies for the equipment services in New Zealand is to re-issue equipment where possible (Ministry of Health, 2014a), a further problem arises if such re-issued equipment is considered offensive from a cultural perspective (L. Walker & Friesen, 2015).

Prestige or honour (known as 'mana' in te reo Māori) can be enhanced by equipment (for example, where a walking stick is valued because of its heritage) or can be compromised if the presence of equipment acts as a reminder of incapacity. In Māori culture, certain tasks such as personal care and toileting are tapu (sacred) and to require assistance with these tasks can make someone experience whakaama (shame). The

equipment associated with these personal tasks can also then become tapu or engender a sense of whakaama. Ripat and Woodgate (2011) offer a succinct way of addressing cultural aspects of equipment provision:

Understanding how an individual's culturally defined identity is shaped as an assistive technology user, and the meaning the assistive technology holds to that person and family, is essential to providing culturally appropriate assistive technology services. (p. 87)

This recommendation certainly holds true based on the findings of this thesis. Negotiating how and where one is prepared to be seen with equipment is part of the adjustment process to making the most of life with equipment after stroke. This thesis shared similar findings to others in that equipment can be perceived in ambivalent ways or with fluctuating levels of acceptance (Hagblom-Kronlof & Sonn, 2007; Lund & Nygard, 2003; Mortenson et al., 2012; I. Pettersson, Ahlstrom, et al., 2007).

Importantly, the findings from my research show that a person with stroke is more in control in their own home, and therefore more engaged in selecting and trialling equipment. This is consistent with research about people with stroke returning home and how they engage with their rehabilitation in general (Mitchell & Unsworth, 2005). To be able to take on a more active role in this process and before challenging themselves with more complex activities such as leaving the house, the person with stroke often needed to feel safe first, which the equipment they were provided with initially usually helped them to achieve. The finding from this study, that using adaptive equipment resulted in a heightened perception of safety, is in line with other research (Sainty et al., 2009), as is the potential for the variety of ways in which therapists can set up expectations about equipment. Gramstad et al. (2014) reported that while the need for equipment could feel precautionary rather than absolutely necessary, having equipment translated into feelings of preparedness and therefore hope. Therapists who contributed to this research focussed on the activities their clients hoped to regain competency with and this was most appropriately completed when people had left hospital. The immediate environment influenced how equipment was perceived and how it could be used.

The change observed over time in how people with stroke perceived their equipment aligns with other research on psychological adaptation after stroke. Nanninga et al. (2015)

reported that people with stroke express longing during all phases of rehabilitation, but, what was longed for changed over time. Immediately after leaving hospital, people with stroke were more oriented towards doing their pre-stroke activities in the same way they had always done them, whereas three months later they had begun to consider alternative approaches to these activities, or even replacing them with alternatives. Other authors have noted that the process of being discharged marks an important step in life after stroke and that the person's own perspective of risk is different at home compared to in hospital (Wottrich et al., 2007). These observations fit with the notion of moving from focusing on equipment to enable safety to increasing meaning-making and participation observed in the results of my research.

Feeling that people with stroke could trust their therapist was a key indicator of satisfaction with equipment provision services through all phases of this research. Having trust in their therapist enabled people with stroke to essentially hand over some responsibility for decisions such as which piece of equipment to use and when, a process they valued particularly when they were in the acute stages of recovering. Deciding who made decisions was a fluid process in such a trusting relationship, where autonomy was viewed relative to what else was happening for someone after stroke. The notion of relational autonomy provides a basis on which to understand this finding:

Relational autonomy assumes that the client, and the client's decisional autonomy, is situated and shaped by relationships. From this perspective, health care professionals can engage in a process of communication and deliberation with the client about risky choices, leading towards improved client autonomy. (Hunt & Ells, 2011, p. 961)

Relational autonomy, where therapists used intuition to guide their reasoning when deciding whether they or their clients were responsible for risk and safety issues is something that was particularly highlighted in Phase 3 of this thesis (Chapter 6). Therapists reported, to varying degrees, the importance of making sure their clients had been told about all the risks of not using their equipment. Ensuring that this conversation about risk had been addressed, the therapists could thereafter feel that they had given their clients an opportunity to make an 'informed choice' - an important element to being accountable in the current healthcare environment.

According to a recent study on stroke rehabilitation services in the UK, people with

stroke varied in how they identified their needs and whether they are persistent with continuing to assert these needs (Wolfe et al., 2014). Further, this study identified that how therapists championed for further resource depended on the relationship they had with the person with stroke, the age of the person with stroke and the therapist's perception of how active the person had been previously. In addition:

Most clients trusted that the best decisions were being made for them by the therapists and doctors and were not bothered about not being involved in decisions. (Wolfe et al., 2014, p. 79)

Issues about how and when therapists advocate for resources for their clients is further discussed later in this chapter.

In terms of optimal training on how to use equipment, the findings of this thesis are that learning happens in an ecologically meaningful environment such as one's home and own neighbourhood, in line with recommendations with other stroke-related research about goal directed programmes and home programmes focusing on self-management (F Jones, Livingstone, & Hawkes, 2013; Mastos, Miller, Eliasson, & Imms, 2007; Novak, 2011). People with stroke need tailored solutions to be able to mobilise outside their home, in part because their needs and activity interests change over time (Robison et al., 2009). Of note from the research findings in this thesis is that people with stroke increasingly adapted their equipment, as their confidence grew, to enable participation in activities outside the home. For example, Charles manufactured a tie for his walking stick to keep it attached to his body when he needed two hands in the garden but did not want to drop his stick. People with stroke adapted their activities and planning required for trips outside the house to incorporate their equipment, illustrating a growth in problem solving over time alongside acceptance of equipment which was motivated by their strong desire to take part in valued activities. This indicates support for programmes which focus on self-management and slowly reduce reliance on therapists to develop solutions (as people often desired while inpatients), as people in this study were proud of their own resourcefulness.

There are different equipment training opportunities available when a person with stroke is living in their own home compared to hospital and differences are due in part to who understands most about the rules and norms accorded to the different environments in

which the equipment is being used. While a person with stroke is in hospital the therapist is considered (by both parties) to have the greater knowledge of rules related to equipment, whereas once in their own home again, the person with stroke begins to gain greater control over their own life again. Other studies also have noted the change in perception about equipment use over time, where use is markedly different at home compared to when people are in hospital (Raggi et al., 2010; Sorensen et al., 2003) somewhat due to risk-conscious therapists in the hospital setting influencing how and when equipment is used (Hansson, 2007).

Although this research endorses the general view that shared decision making is an optimal approach for equipment provision services, not all people with stroke in this study wanted to have options and choice. Other research on shared decision making has been critical of a perceived lack of cultural awareness in this process (Reisinger & Ripat, 2014), reporting that it is essential that therapists undergo some mutual value clarification when discussing options with their clients. In addition, clear communication, active listening and the allocation of time are all seen as essential as well as therapists believing in the value of such an approach (Kon, 2010; Makoul & Clayman, 2006; Stacey et al., 2010). While there is demand for client-led services within the disability community (Disabled Persons Assembly New Zealand, 2012), the findings of my research indicate that, similar to others (Charles et al., 1997; Skinner, 1996), some people prefer a more paternalistic approach to decision making at certain stages, and that being presented with too many options could result in distress. Making decisions about the timing and extent of choice offered by therapists may be where the craft of shared decision making lies.

## **7.5 Moral distress of therapists when issuing equipment**

### **Conflicting beliefs about models of stroke care**

When therapists were weighing up whether or not to recommend equipment for someone after stroke, they were often in conflict about whether equipment would actually inhibit physical recovery. As a result of this conflict, therapists appeared in doubt about when, and how much, a person with stroke would benefit from having adaptive equipment. As some of the professional philosophy underlying their practice endorsed the idea that less equipment would encourage more normal movement patterns, these therapists were



left with a sense of unease or even failure when they provided equipment or discharged a person with stroke who was still using equipment.

Some neuro-developmental approaches to stroke rehabilitation have advocated for minimal use of equipment which would change how someone might ‘normally’ move (Lennon, 1996). However, the motivation of a person with stroke to be active as soon as possible and engage with valued activities again, often take priority over this recommendation. To wait before introducing mobility equipment in particular is in conflict with recent guidelines which advocate for people with stroke being encouraged to mobilise as soon as possible and therefore promoting the use of adaptive equipment in early mobilisation (Scottish Intercollegiate Guidelines Network, 2010; Stroke Foundation of New Zealand, 2010). A systematic review completed by Pollock et al. (2014) on mobility rehabilitation after stroke, explored if there was a significant difference between four different physiotherapy modalities categorised as: functional task training, active or passive musculoskeletal intervention, neurophysiological approaches, or training with assistive devices. The outcome of this review was that physiotherapy after stroke resulted in significantly better outcomes than usual care or attention control, regardless of the modality used (12 studies, 887 participants; SMD 0.37, 95% CI 0.20 to 0.55), and that:

No one approach to physical rehabilitation is any more (or less) effective in promoting recovery of function and mobility after stroke. Therefore, evidence indicates that physical rehabilitation should not be limited to compartmentalised, named approaches, but rather should comprise clearly defined, well-described, evidenced-based physical treatments, regardless of historical or philosophical origin. (p. 3)

It should be noted that ‘usual’ care for this systematic review was vaguely defined as no treatment, usual care or attention control or in comparisons of different physical rehabilitation approaches. In practice, few rehabilitation centres could ethically report that they provided no treatment, so the primary dataset must have comprised of comparison across different modalities.

Increasing cardiovascular exercise has been shown through meta-analysis of studies on this topic to improve aerobic capacity for people with mild to moderate stroke (Pang, Eng, Dawson, & Gylfadottir, 2006), however without adequate equipment and encouragement to progressively extend their exercise limits (for example, walking further

from their house) this recovery possibility is reduced for those who require mobility equipment for outside use.

In addition to conflicting advice from different models of practice about when and whether to issue equipment after stroke, there are some acknowledged risks of injury for people who are issued with equipment. This is because of the concentration and change in posture required to use mobility equipment immediately after stroke which can increase the effort required for moving initially (Bateni & Maki, 2005; Hefflin, Gross, & Schroeder, 2005; Stevens et al., 2009). However, the findings of my research correlate with others where the benefits of equipment provision to people with stroke appear to outweigh these risks including safety (Samuelsson & Wressle, 2014; Tyson & Rogerson, 2009) and occupational engagement (C. Pettersson et al., 2014). In a review about novel (for the time) gait re-training after stroke, Hesse (2003) concluded that, regardless of which approach was tried:

To preserve the effects of any of the techniques, the clients and their relatives should be instructed to keep on walking repetitively. With the clients staying idle, effects will wane. In this respect, assistant devices such as walking canes and orthoses are essential. With their help, clients walk faster, more safely, and more efficiently. (p. 123)

Ultimately, it appears that the moral distress experienced by therapists is not warranted: people with stroke do as well or even better with equipment in place sooner rather than later. While therapists can be anxious about the possibility that they are disadvantaging their clients longer term by issuing them equipment, there is evidence that not extending how far they can confidently mobilise (with or without equipment) holds more risk for their health and well-being.

### **Role as equipment assessor: Advocacy versus gatekeeping**

There is a growing demand on therapists to become stronger political advocates for the people they work with (Kirsh, 2015; Layton, 2015). Simultaneously, there is increasing fiscal responsibility expected from therapists by the healthcare sector many are employed within (Chiatti & Iwarsson, 2014; Ministry of Health, 2015a; Williams & Bryan, 2007). The findings of this thesis highlight the moral distress experienced by therapists in their role as equipment providers when balancing these two pressures. The healthcare

system can be perceived by therapists as a constraint on their ability to be client-centred (Hedberg-Kristensson & Iwarsson, 2013) which results in moral distress (Mukherjee et al., 2009) about whether they prioritise the needs of their clients or the requirements of the healthcare system.

In Chapter 6, recommendations about equipment were seen as based on clinical factors such as the ability of a person with stroke to take part in valued activities, their progress to date in rehabilitation and their goals as well as the extent to which they were interested in and capable of discussing what equipment do for them. However, recommendations about equipment shares similarities with other healthcare decisions which eventuate in expenditure for which a therapist feels responsible, which introduces systemic factors such as resource management and being accountable to the health sector and to wider society (Berney et al., 2005; Foster & Tilse, 2003; McGlinchey & Davenport, 2015; McKinlay et al., 1996; Reisinger & Ripat, 2014). Taking on this role of assessor can come into conflict with the trusting relationship which, as discussed, is vital to effective equipment provision services. There appear to be person-centred ideals that therapists try to adhere to during equipment prescription and then there are compromises that need to be made due to systemic factors such as time, suitability of available equipment and their ability to assess people with stroke in different environments.

Alongside respecting relational autonomy during equipment prescription, therapists used a combination of strategies to develop recommendations for equipment use, essentially using tacit reasoning, where decision making is personal, based on context, and difficult to formalise. Often therapists rely on embedded knowledge which fuels them to find ways to over-ride formalised 'one size fits all' categories inherent in eligibility criteria (Greenhalgh et al., 2008). When their clients' presentation was not in line with eligibility criteria for certain equipment, and the therapists believed that the person with stroke would benefit from an item of equipment, the professionals in my research often found ways to subtly subvert the criteria. This is similar to the role therapists can find themselves in when supporting clients to navigate through funding requirements for housing modification processes (Johansson et al., 2009), where their primary role can be to act as translator between how a person with stroke expresses their needs and the narrative required by the funding system to secure appropriate resources. As well as valuing a

person-centred focus, the responsibility of providing information about the health, social and disability system people were entering as a result of their stroke was taken seriously by the therapists, though it did not appear to be the favourite part of their job. Their preferred use of time was to facilitate clients to achieve their goals and the systems they worked within were not always perceived to be similarly motivated. The role of educator about the health service and navigator through the healthcare system is increasingly acknowledged as something therapists do and should do more (Zorowitz, 2011).

The pressure to be financial accountable is increasing in most public healthcare sectors, and equipment provision is no exception (Andrich & Caracciolo, 2007; Chiatti & Iwarsson, 2014; Federici et al., 2014; Howden-Chapman & Ashton, 2000). For example, a recent update from the Equipment and Modification Services, Enable New Zealand (2015) in October 2015 reported that their service planned to audit individual equipment assessors and services:

By comparing prescription patterns of individuals (against their peers) from service utilisation reports and our own internal data. If there are any outliers (i.e., those who prescribe well above the national average) we will undertake discussion with the Equipment and Modification Services Assessor and their Team Leader/Manager to ascertain why. If we still have any concerns following this we will then discuss this further with the Assessor's Team Leader/Manager and the Ministry of Health. (p. 1)

Interestingly, the implication of this report is that 'correct' levels of financial accountability will be judged on the basis of quantity of equipment issued (in comparison to peers) rather than on any evaluation of the clinical decision making applied to individual cases. There is an assumption inherent in this policy that higher levels of equipment prescription are wrong, or at least questionable, without any actual evaluation of the effect of average, low, or high levels of equipment prescription on public health. In other words, this plan is arguably more about cost containment than cost effectiveness. Furthermore, as demonstrated by my research, it is currently very difficult to access data on the cost of equipment at a population level for any given condition such as stroke. This means that it is also very difficult to evaluate the cost effectiveness of equipment prescription patterns without a radical change to routine data collection and reporting methods.

Also inherent in the Equipment and Modification Services' strategy is the

implication (or perhaps threat) of having one's practice monitored more closely if one does not adhere to national equipment prescription rate averages. While a strategy such as this may be deemed necessary from a budget management perspective, these notices emphasise the position of available funding as a primary concern when issuing even basic equipment. Therapists, in general, tended to report that the funding concerns were secondary to their person-centred assessment. This was not a definitive finding, as some therapists did have more awareness than others about the cost of equipment which would be taken into account when recommending an item for their clients. In addition to the person-centred approach, it appears unavoidable that therapists start to consider and record market costs of equipment options as part of their reasoning process (Chiatti & Iwarsson, 2014; Gelderblom et al., 2002). The therapists in my research appeared to have only a vague understanding of equipment costs and preferred to see themselves and the intervention they provided as separate from cost issues, similar to therapists administering equipment in other countries (Blackmer, 2000; Reisinger & Ripat, 2014). When therapists are expected to be responsible for healthcare rationing, they need to be provided with guidelines, forums and support on how to do this, rather than instructions that they just need to 'do it or else'. Otherwise, there is a risk that therapists feel that they are asked to 'put aside their basic commitment and compassion for individual patients' (Blackmer, 2000, p. 52).

Similar to the findings of other researchers who have investigated equipment use and other roles involving various health professionals as gate keepers of public funding (Barbara & Curtin, 2008; Reisinger & Ripat, 2014), this thesis highlights that there can be an unease about presenting the financial constraints and eligibility circumstances to people with whom therapists have invested time in developing a clinical relationship. While there is a call from leaders for therapists to take on greater roles as activists for the public policies which influence their clients (Hammell, 2015), distant policy and activism was seen as too complicated or difficult to change for busy therapists who took part in my research, a finding echoed by other researchers (Barbara & Whiteford, 2005).

Models of clinical reasoning specific to equipment prescription were not mentioned by the therapists who participated in my research, despite their extensive development. This finding has been observed in studies of therapists in different contexts (Angelo et al., 1997; Friederich et al., 2010). Common methods of reasoning of therapists for equipment

recommendations, as already noted, involved more generic processes such as ethical reasoning, using shared decision making principles and consideration of relational autonomy of their clients. So equipment recommendations appear to be more situated within a socio-political environment in conjunction with professional and personal beliefs about fairness and their role in a resource allocation process, as well as their assessment of the needs and wishes of their client (McKinlay et al., 1996). To develop models of reasoning which do not accommodate all of these complex variables risks leaving these important factors unacknowledged (Bornstein & Emler, 2008; Valerie A. Wright-St Clair & Newcombe, 2014).

Finally, despite the development of outcome measures designed specifically to evaluate the impact of equipment provision (S. Kenny & Gowran, 2014; Rust & Smith, 2005), no such outcome measures were mentioned in the clinical reasoning process of therapists involved in this study. It would appear that the concerns of Smith (1996) remain valid two decades later in that therapists still do not have a sense of their role in measuring outcomes resulting from their interventions specific to equipment provision.

## **7.6 Critical evaluation**

### **Strengths**

There are many strengths in the design, implementation and reporting of this research. Maximising choice in managing their experience of research involvement is one ethical way of including vulnerable people in a study (J. Kidd & Finlayson, 2006), which was one key reason why, for the questionnaire in Phase 1, participants were encouraged to choose their preferred medium to complete the questionnaire and had the option of having a support person assist with consenting to take part, completing the questionnaire, or being present while being interviewed in Phase 2. The therapist participants in Phase 3 were likewise supported through the involvement of their professional leaders.

This thesis has enabled an opportunity to gain some insights into how Māori in particular perceive the equipment prescription process where this group was purposively sampled for Phase 2 qualitative interviews. One priority of stroke research in New Zealand is to better engage with Māori, (Dyall et al., 2008; Stroke Foundation of New Zealand, 2010) and there is a paucity of research about how Māori have experienced

disability services such as equipment provision (Ministry of Health, 2012c; Ratima & Ratima, 2007). Ethnicity data was recorded systematically as part of the questionnaire and was collected from all participants using the New Zealand census approved categories for ethnicity (Statistics New Zealand, 2005). This method of collecting ethnicity data involves researcher-assigned ethnicity labels rather than encouraging self-identification of ethnic affiliation, however, pre-set categories are required when ethnicity data is to be used for comparison within a study and in relation to other studies (Bradby, 2003). Another strength of the analysis in this thesis was the involvement of a Māori researcher at all stages, thereby enabling the results to be grounded in cultural reality for Māori and enabling recognition of Māori values and protocol in the collection and interpretation of these findings (S. Walker et al., 2006).

For this thesis, I considered practical ways to increase internal validity, external validity, trustworthiness and credibility as appropriate for the method being used in each phase and over the study as a whole. According to Guba & Lincoln (1982), rigour in research can be categorised into four domains: 1) internal validity (how true are the findings?), 2) external validity (how applicable are the findings?), 3) consistency (how replicable are the methods, and how likely is another researcher going to come to the same result?) and 4) neutrality (how objective has the researcher and the research process been?). Of course, different criteria are required to evaluate qualitative research and quantitative research against each of these domains (Mays & Pope, 2000; Sale et al., 2002). For instance, the criteria about consistency and neutrality in particular are much less relevant and even, in some instances, in conflict with the premise of qualitative research design (Tuckett, 2005; Yardley, 2000). In fact, some researchers contend that it is impossible to impose pre-set criteria regarding rigour on qualitative research as these methods are so diverse (Sandelowski, 1993).

As Morse et al. (2008), argued ‘without rigor, research is worthless,[it] becomes fiction’ (p. 14). As an alternative validity framework, concepts of trustworthiness and credibility have been offered as an indicator of rigour in qualitative research (Curtin & Fossey, 2007; Hammell, 2002; Yardley, 2000). Trustworthiness refers to how much the results of a study reflect the experience of the phenomenon which is being explored Curtin and Fossey (2007) and credibility is defined by Patton (1999) as encompassing three inter-

related areas: 1) rigorously described process, 2) training and reflexivity of the researcher and 3) congruence between the philosophical understanding of the researcher and the methods used. I argue that Patton's standards for credibility have been met in this thesis by the description of the methods undertaken and that trustworthiness was further enhanced in presentation of the results, development of theory and discussion in the rest of this thesis.

In relation to internal validity, a number of strategies have been used which strengthen the trustworthiness of this study. Sampling strategies have been clarified in Chapter 3, alongside the process for developing theoretical sensitivity. Another important technique for enhancing internal validity was triangulation, where the research aim was examined from a range of different perspectives. Incidentally, this is one of the earliest recognised benefits to mixed methods research (Denzin, 1978). One of the strengths of sequential explanatory mixed methods was the triangulation of both data collection techniques and sources of information about provision of equipment. The advantage of triangulation, known as the complementarity of data (Onwuegbuzie & Collins, 2007), is that a comprehensive explanation of a phenomenon can be developed (Johnson et al., 2007).

A recognised risk when using different methodologies together like this is that methodologies can be muddled (Stern, 1994) resulting in diluted or ineffective use of either or both. Researchers who avoid these common methodological mistakes carefully describe their research design and provide examples of their analytical process (Bringer, Johnston, & Brackenridge, 2004; Creswell et al., 2011), which are strategies I have adhered to in Chapter 3. I have argued that the techniques and principles of grounded theory fit comfortably with the tenets of mixed methods research. For example, both grounded theory and mixed methods employ abductive reasoning (Johnson & Onwuegbuzie, 2004) during higher levels of analysis. Abductive reasoning allows for researcher intuition to hypothesise about incomplete observations or varying types of data, in order to reach findings and make recommendations (Wheeldon, 2010). Both grounded theory and mixed methods are also compatible in terms of developing a core concept to explore an aspect of a social system (Morse, 2003) such as the experience of receiving and using equipment after stroke. Grounded theory is also flexible, and can include more than



just interview data, unlike other qualitative approaches such as phenomenology (Suddaby, 2006). Thus, I argue that grounded theory was compatible with the overall structure of this thesis.

While mixed methods research has become increasingly popular, reviewers have noted that many studies fail to integrate the different data they find (Bryman, 2007; Creswell et al., 2011; O'Cathain et al., 2008; Thurston, Cove, & Meadows, 2008). This means that some mixed methods studies present simply as a report of a consecutive series of single studies rather than a cohesive synthesis of different types of data to answer a specific question. This tendency appears most prevalent when data collection happens in an unplanned way (for example, when unexplainable quantitative findings prompt researchers to use qualitative methods to address an issue differently). In comparison, as this thesis had been conceived as a mixed methods project from the outset, the risk of opportunistic and disparate data collection has been low. While the inclusion of both grounded theory and sequential explanatory mixed methods presented challenges in terms of methods design, these two approaches were purposefully and explicitly linked prior to beginning data collection, thereby avoiding the risk of method slurring (Baker, Wuest, & Stern, 1992). The methodology of this thesis has been developed in line with recommendations by Patton (2002a) to select practical methods to answer practical questions that are relevant and meaningful in everyday clinical practice.

Synthesising results from mixed methods studies can be challenging (Joanna Briggs Institute, 2014; Mortenson & Oliffe, 2009). For this research, the results of each phase influenced the succeeding phase in two ways. Sampling changed in response to results from preceding phases. For example, physiotherapists were recruited as well as occupational therapists as the results of Phase 1 and Phase 2 emphasised the importance of mobility equipment as a valued item of equipment. Also, the line of enquiry during qualitative data collection was influenced by the results of preceding phases. So, questions in the qualitative interviewing phase with users of equipment drew on examples and issues that arose in the questionnaire data from Phase 1. For example, while tailored instruction on using equipment was also suggested in early analysis, the information from interview participants provided depth of understanding about how people with stroke themselves took on the process of tailoring their equipment to their activity needs and vice versa.

Interviewees also gave examples of instances where they could not or did not want to participate in shared decision making, due to competing demands for their energy such as planning a return to their home and a overwhelming number of factors in their stroke rehabilitation. Also, concepts related to the importance and effort required to get out of one's immediate environment was a thread which was initially indicated in free text analysis which was strengthened and deepened during analysis of interviewee accounts. Such nuanced explanations were not possible with questionnaire data alone and was not surprising as interviewing people lends itself to them describing their experience chronologically and in a personalised way, rather than in a piecemeal fashion generated during questionnaire responses. This synthesis strategy used in this thesis is known as connecting data (as opposed to merging or embedding data) and it has been endorsed as a valid feature of mixed methods results reporting (Creswell et al., 2011), further illustrating methodological coherence.

The qualitative data presented in Chapters 5 and 6 was richly descriptive, which is vital for trustworthiness in qualitative research (Curtin & Fossey, 2007). Sandelowski (1994) claimed that using quotes is a craft in qualitative reporting, where quotes can clarify ideas and allow the reader to feel that they have heard directly from the participant: 'Quoting is a process that requires the achievement of the proper balance between the obligations of scientific reporting and the taking of artistic license' (p. 479).

Negative case analysis is a strategy primarily used to check for cases which did not fit an established pattern (Harry, Sturges, & Klingner, 2005) and as a concept, this can be applied to both qualitative and quantitative research. An example of using this strategy in quantitative research was in the investigation of outliers or non-respondents and the conditions attached to these cases carefully (where conditions were known). An example from qualitative research was when exploring all data from interview participants which did not fit with the prevailing themes, to see why this was occurring. Both these techniques were relevant and used in this study.

A reflective journal was also used to keep track of decisions made about sampling, analysis and conclusions as the research progressed, in line with recommendations for prompting reflexivity (Curtin & Fossey, 2007; Finlay, 2002). Furthermore, this reflective journal, alongside clear note-keeping in relation to quantitative data management, (for

example, where and why variables were altered during data cleaning), provided an audit trail, which strengthens the credibility of the findings. Theoretical sensitivity to the data in this thesis benefited from my 12 years of occupational therapy experience prior to embarking on this PhD and from my continued involvement in clinical practice during my academic studies.

Peer de-briefing was another important checking mechanism (Curtin & Fossey, 2007), which was used at each stage of data analysis to ensure that preliminary conclusions and plans for any changes to data collection were logical and justifiable. Two of my supervisors were involved in separately coding selected interview and focus group transcripts in Phase 2 and Phase 3 and with designing and testing the questionnaire in Phase 1. This process of peer consultation and review was embedded throughout this thesis with regular meetings with supervisors and written agendas and minutes kept.

One of the strengths of this study related to the range of people invited to participate. People with cognitive and communication difficulties were included, as were people with stroke who lived in residential care. This is a group often missed in questionnaire based research (Okoro et al., 2010) but as there is a growing recognition of the role that equipment and equipment funding can play for this particular group of people (Mortenson et al., 2005), it was important that their perspective was included.

Gathering sensitive data from vulnerable clients is governed by ethical processes which are charted or uncharted (J. Kidd & Finlayson, 2006). Charted areas include informed consent, managing confidentiality and anonymised reporting of results. These are the standard remit of ethics committees and can be planned in advance. Uncharted territory, however, is more difficult to anticipate and needs to be dealt with as it arises:

Researchers, especially those engaging in sensitive human inquiry, must rethink and renegotiate their ethical positions on a daily basis. (J. Kidd & Finlayson, 2006, p. 427)

For example, in this study, while some people with stroke chose to have their family members help them tell their story, the research protocol did not initially allow for support people to provide consent to have their words being used in the reporting of results. Thus when illustrative quotes required the contributing comments of the support people in order to make sense, three people were approached to request their consent for this to happen

retrospectively. Additional ethics approval from the national Health & Disability Ethics Committee (Appendix L) was sought and granted for this amendment to the study protocol.

### **Limitations**

The limitations in my research in many ways highlight the current difficulties associated with researching the application and effects of health policy related to equipment prescription in New Zealand. These limitations are acknowledged here and I recount the ways in which they were managed.

As this was an observational study, the generalisability of findings is potentially limited to the contexts in which the data were collected. Due to privacy issues, I was unable to collect medical or other clinical data about the users of equipment as I was unable to access hospital records for all participants. Part of the reason for this difficulty arose from collection of data across five DHBs, each with its own idiosyncratic rules about data sharing. The questionnaire in Phase 1 was not aligned with other outcome measures making it difficult to compare with other publications, which is a common criticism of research into equipment use (Rust & Smith, 2005). However, another study evaluating equipment after stroke has cited that multiple questionnaires were a limitation for people with stroke, due to the resultant respondent fatigue (Garber et al., 2002).

An important aspect to consider when planning a questionnaire is whether the information required is available elsewhere (Groves et al., 2009). In the case of this study the answer was 'no'. I explored many options for alternative data source with providers of publicly funded equipment, for example Enable New Zealand, and their database of equipment users. They did not hold data on diagnoses such as stroke, they only had data on the type and cost of equipment issued by their service. I also discussed the aims of this research with the New Zealand Stroke Foundation. While supportive of the study, they were unable to assist with recruitment due to their limited time and resources. I liaised with the Ministry of Health which is responsible for managing data from the New Zealand Health Survey, which is a repeated cross-sectional survey collecting data on health conditions and how health resources are used. I was informed by the administrators of this database that, of their survey respondents over a 12 month period (n = 10,000 - 12,000),

only 200 - 280 respondents were likely to have reported that they have had a stroke (J. Fawcett, Group Manager, Health and Disability Unit, Personal Communication, July 2012) and that not all of those people would have agreed to being contacted for further research. Given that over 9,000 people have a stroke in New Zealand in a 12 month period and survive (Stroke Foundation of New Zealand, 2010), the respondent pool from this survey was deemed insufficient to draw on for this research so, in addition to logistical and financial barriers to accessing this data pool, this option was unfeasible. It was therefore a challenge to establish a means of 'finding' people with confirmed stroke severe enough to warrant them needing adaptive equipment.

Ideal strategies such as over sampling in Phase 1 for ethnic minorities (Boynton et al., 2004) were not feasible to implement. Though it would have been ideal (for statistical efficacy) to over sample for Māori during Phase 1 of this study, this was unfortunately not feasible due to logistical and resource constraints. Therefore, Māori perspectives on equipment use and equipment provision services were actively sought at Phase 2. One other group who was omitted from the original questionnaire mail out were people who went to specialist private rehabilitation rather than publicly funded hospitals. Discussions with local stroke rehabilitation services indicate that this would have represented a very small group of people.

The response rate for the questionnaire was 26.7% making results from this phase of the study difficult to generalise to non-respondents. Though screening to remove people who were deceased happened prior to recruitment, it is not surprising some people had passed away since and the total number recorded for people deceased (2.3%, 22/965) is likely to be an underestimation, given that up to 65% of people die in the three years following stroke (Bonita, Ford, & Stewart, 1988; Lofgren et al., 1999). Of note, four people (0.4%, 4/965) reported that they had not had a stroke as far as they knew, with one of this group reporting removal of brain tumour instead. This highlights the possibility of inaccurate ICD-10 coding or that stroke may have been secondary to a more life threatening condition and therefore not prioritised by DHB staff when inputting codes. The other possibility is that the occurrence of stroke was not discussed explicitly with the invitees by medical staff.

People with stroke are not necessarily a stable group as regards their disability, often

declining to take part in research for stroke and non-stroke related reasons (Garber et al., 2002; Wade et al., 1992). It can be difficult to know the effect of co-morbidities on outcomes such as activity limitations and participation restrictions, which is a common challenge when researching people with stroke (Sorensen et al., 2003). Compared to other questionnaires researching utility of equipment with stroke survivors, for example Garber et al. (2002), the response rate in this study was low. One reason for this is the only database available through which stroke survivors could be reached (DHB databases) did not record whether their patients on record actually had equipment or not. This meant that many questionnaires may have reached people without equipment and subsequently discarded on the presumption that they did not relate it to their situation. It is also questionable how well mortality after stroke was recorded in DHB databases. This risk was acknowledged and managed by DHB staff assisting with recruitment checking the databases received from client information services against current records, however, many letters were returned unopened or with a note that a participant had deceased (see Figure 5 in Chapter 4). This is a challenge of conducting research with medium to longer term follow up with stroke survivors in particular (Mann et al., 1995).

While reasons for non-response (where known) were provided in Chapter 4, with many people having passed away or being too unwell, no reason for non-response was known for 58.8% of people and these results may not apply to these people. Those who did respond were a self-selected group, who were likely to be able to read and write or more likely to have a support person to encourage or complete questionnaire for them or with them. There was no assessment of people with regards to cognition or other impairments - this was unavoidable given the self-selecting process offered to all people with stroke. Recall bias was an issue for some where, for example, 1.3% (2/156) of respondents did not know how long it had been since their stroke and 6.4% (10/156) did not know if they had had equipment options explained to them or not.

There is evidence that people with more complex disability are more likely to be critical of the healthcare system but this group are also less likely to be able to complete a mailed questionnaire (Jackson, Chamberlin, & Kroenke, 2001) and so their experience may have been not well represented by the findings of this thesis. Certainly the people with stroke in this thesis reported much less frustration and disadvantage than a recent

large study about equipment availability and funding in Australia (Layton et al., 2010). This could be due to the population in this thesis being older and less critical of the health service or less disabled and therefore less reliant on a range of services.

It is difficult to measure and research 'satisfaction' as a concept as it holds such a variety of meanings (Atwal & Caldwell, 2005) and satisfaction surveys targeting people who have used healthcare services need to be considered carefully in relation to time that may have passed since the healthcare interaction of interest. In general, it is acknowledged that satisfaction increases as an individual's expectations are met as their symptoms resolve and when communication with therapists is clear (Jackson et al., 2001). For most people with stroke who took part in this research, between 12 and 18 months had passed since their original stroke before they took part in the survey, and longer still for those who volunteered to contribute to qualitative interviews.

Logistic regression is more flexible than other techniques for modelling outcomes as it does not require data to be normally distributed and it produces results that are similar to other statistical methods that analyse binary variables in that it is based on the odds of an event rather than the probability (Kirkwood & Sterne, 2003; Tabachnick & Garrett, 2013). The more factors you enter into a regression model, generally, the wider the confidence intervals will be, so how many variables should be included in a model is an important consideration when using this strategy (Bagley, White, & Golomb, 2001). There are practical issues to consider in this decision, such as which variables will give a good estimation accuracy, which variables relate to primary concerns (for example, things you are interested in and you will get a reasonable answer for in your analysis) and technical concerns to do with stable model development (in that the more groups you have, the more technical difficulties you have). Confounding factors which were not available which would likely have impacted on equipment provision include severity of disability, which has been identified as one of the strongest predictors of equipment use (Agree & Freedman, 2000) and poor overall health and obesity, which have been noted as weaker but also correlated factors (Mann, 2005; Pressler & Ferraro, 2010).

There were also limitations with the binomial logistic regression model used for addressing the research objective about whether receiving equipment after stroke can be predicted by ethnicity. When comparing receipt of equipment between New Zealand

Europeans and non-New Zealand Europeans, the limiting factor for ethnic comparisons was the absolute size of the smallest group ( $n = 156/176$  for New Zealand European and  $n = 20/176$  for non-New Zealand European). This means that the model had imprecise answers in terms of estimating the population values (Bagley et al., 2001). Without having the resources to strategically sample and increase the response from, minority ethnic groups, it was not possible to increase the size of these groups. These low numbers have affected the precision of the model sufficiently that performing further goodness of fit tests such as the Hosmer-Lemeshow test (Archer, Lemeshow, & Hosmer, 2007) were deemed unhelpful and were not completed. Finally, a rating for the activity limitations of the participants as a confounding factor would ideally have been included in the model (Gosman-Hedstrom & Blomstrand, 2003) but this was not obtainable.

The use of software for qualitative data analysis is not without controversy (Goble, Austin, Larsen, Kreitzer, & Brintnell, 2012), with concerns noted regarding how transcripts are formatted, analysis potentially becoming routine and a risk that reflective engagement may be dampened (P. Kidd & Parshall, 2000). However, in practice many researchers use such software primarily to help them organise large amounts of data (Bringer et al., 2004) and analysis alternates between wholly viewing data using the software and in printed and audio form (Welsh, 2002), as was the case with this study. Using software to record coding was also helpful in ensuring transparency, particularly for grounded theory studies (Bringer et al., 2004).

There are known limitations to the equipment cost figure supplied in Chapter 4. Gross estimates of pooled public funding for equipment, housing and personal care costs in 2012 were requested and supplied from Disability Support Services unit at the Ministry of Health (Sarah Hamlin, personal communication, May 2015). However, the way in which this data was reported made it incomparable with my research objectives. Instead, the companies which supplied each of these items were contacted (20 suppliers in total) to request information on cost to the public for these items. The true cost to the publicly funded bodies was not available as suppliers tender for contracts for common items and this information was therefore commercially sensitive. This kind of challenge has been noted in other research estimating cost of publicly funded equipment (Andrich & Caracciolo, 2007) and given the access to equipment for people to purchase privately,



separating out public from private costs regarding adaptive equipment remains a challenge for research in this arena (Wilson et al., 2009).

Furthermore, the cost outlined is for the equipment only and does not include goods and services tax, freight or other maintenance costs. These issues would have contributed to an inaccurate estimate of the true cost of equipment in the result presented in Chapter 4, with the extent of this inaccuracy being unknown. Additionally, in some cases it had been over three years between the equipment being issued and the data being sought, meaning that some suppliers no longer existed, had been merged with others, or equipment was being imported and supplied by different companies. During interviews I observed expensive equipment such as power wheelchairs (in two situations) and a hospital bed (in one situation) used by study participants, and these items were not listed in the equipment database supplied by Enable New Zealand. Given the cost of this equipment and the context of these people's lives it seemed highly unlikely that these items had been privately purchased. This casts further doubt on the accuracy of the data received on the cost of equipment.

## **7.7 Recommendations**

### **Research**

Participation in one's community appeared to be highly valued by people with stroke and therapists in this and other research on this topic (Hartman-Maeir et al., 2007; Logan et al., 2004; Lord et al., 2004; Reed et al., 2012; Woodman et al., 2014). Further research is required to highlight the health benefits of this aspect of life in order to convince funding bodies of the tangible cost benefits of supporting people with stroke to participate. Large observational studies examining the relationship between equipment use, extent of community access and participation, and biomedical markers of health (such as cardiovascular fitness) would be useful in this instance. Regarding participation measures, Harris (2007) offers guidance on how participation-focussed measurement tools related to the ICF categories could be developed for adaptive equipment, though measures which meet all of these criteria would be a challenge to design:

- 1) participation measures need to be device-specific; 2) measures ought to capture both 'capacity' and 'performance'; 3) methods need to be sensitive to those factors that impact mobility device use over time; 4) methods

need to be sensitive to the complexities of both the social and physical environment as they impact device use; and 5) measures need to reflect the impact of multiple mobility device use. (p.137)

Questions about whether the equipment provision services are providing equitable access for all groups in New Zealand society remains an important question which has been unanswered by this thesis. The use of logistic regression analysis to quantitatively investigate the odds of receiving equipment by ethnicity remains a valid way to address this query. However, the way in which equipment-related data is gathered would need to change to be able to use this approach effectively to produce significant findings. Having a database where ethnicity, health conditions and other data on impairments, activities and participation were contained alongside equipment details and its cost would enable this and other areas of scientific enquiry to be better addressed. Much of this information is in fact already routinely gathered in clinical practice. The key issue here is establishing reporting and recording systems to make better use of these data.

There has been a focus on use and non-use as ways to measure successful equipment provision services. I join in the argument of others such as Papadimitriou (2008) and Verza et al. (2006) that measuring an equipment item as successful or not based on use is a one-dimensional and flawed way of evaluating outcomes as a result of equipment provision. I suggest instead a shift in prioritising how equipment provision services are evaluated towards addressing client satisfaction with equipment provision processes, the reported therapeutic relationship with their therapists, and perceptions of shared decision making reported by people who live with disability, alongside measures of risk, safety and health consequences of equipment use, such as impact on participation levels.

The ICF continues to offer useful tools such as the core set for stroke (I. Pettersson, Pettersson, & Frisk, 2012; Sivan et al., 2014) and the WHO-DAS II is a way of incorporating more participation-focussed measures of equipment use when evaluating the effectiveness of equipment provision (Raggi et al., 2010). However, my research furthers concept development, which has been noted by Sivan et al. (2014) as lacking in the ICF, regarding the nature of user preferences and the interaction of the therapists with people with stroke, ideas about equipment provision and the role of allied healthcare professionals within the provision process.

In terms of research on the consequences of equipment use, there has been a call over the last 15 years for the investment of time and resources into the development of equipment-specific models of practice such as the Matching Person and Technology model (Scherer et al., 2007) and equipment-specific outcome measures and assessment processes (Fuhrer, Jutai, Scherer, & DeRuyter, 2003). The findings of my research endorse the need for measures which accurately reflect the outcomes achieved by equipment provision and for such measures in turn to be recognised by funding bodies. Given the lack of uptake of measures in the clinical arena, as reported in this thesis, investment in how these measures relate to the New Zealand context is required.

Alongside including measures which address participation and equipment use, it is also necessary to advance recommendations of Hocking (1999) where encouraging reflective, ethically reasoned practice and client-centred assessment is key. However, as argued earlier in this chapter, these models of reasoning ought to explicitly incorporate and acknowledge financial and systemic concerns related to equipment provision. In this regard, using standardised outcome measures (such as measuring social participation, mobility range in a community, and physical activity levels) to evaluate health consequences of equipment use are also likely to be of benefit, even if these measures are not equipment-specific.

As outlined in Chapter 2, there has been a focus in assistive technology research on better predicting who will use equipment after stroke, for understandable reasons to do with the economic accountability required from healthcare services (Finlayson & Havixbeck, 1992; Wielandt et al., 2006). The results of my research question whether this is a battle which can be won by developing measurement tools alone, which make presumptions about the linear nature of the relationship between equipment provision and equipment use, given all of the influencing factors outlined in the results of all three phases of this study. Taking a mixed method approach to equipment provision service evaluation, though challenging in terms of planning for systems, offers a more realistic way to approach development of equipment provision services. This is a shift from recent models of research in this area and a change in my thinking since the beginning of this thesis, where I had anticipated being able to predict equipment use far more readily than has proved to be the case.

Other research designs can be considered to advance knowledge in this field. Given that questionnaire and qualitative interview methods are limited when researching the experiences of people with communication difficulties (Lloyd et al., 2006; Sneeuw et al., 1997), non-language based methods of data collection such as is employed in Photovoice or Photo elicitation might be useful for extending understanding of equipment use from this groups' perspective (Wang & Burris, 1997). These methods could be particularly appropriate for equipment use in relation to people who have had a stroke (Levin et al., 2007). Scherer (2014) makes the point that RCTs and comparison group studies are often ethically inappropriate ways of addressing research objectives to do with equipment prescription. Well-designed pre-post study designs may offer better ways of illustrating how equipment affects people, where comparisons can be made over time, rather than comparing individuals (Tomsone, Haak, & Lofqvist, 2015).

### **Clinical Practice**

Clinical practice guidelines which explicitly address and support the tenets of shared decision making could offer a way to make explicit the type of communication and responsibility sharing that is required when it comes to making recommendations for equipment purchase and use. To further understanding in this area, a more consistently used model of shared decision making could be considered. In this regard, Makoul and Clayman (2006) offer one integrated model which is compatible with the findings of this thesis where essential elements (for example, present options and clarify understanding), ideal elements (present evidence and reach mutual agreement) and general qualities (partnership and information exchange) could be outlined between the person with stroke and the therapist. Development of decision aids specific to equipment provision holds potential benefit for this area. In a recently updated Cochrane review, Stacey et al. (2014) reported that:

There is high-quality evidence that decision aids compared to usual care improve people's knowledge regarding options, and reduce their decisional conflict related to feeling uninformed and unclear about their personal values. There is moderate-quality evidence that decision aids compared to usual care stimulate people to take a more active role in decision making, and improve accurate risk. (p. 3)

Many therapists rely on their own expertise when making decisions about what to

recommend for their clients, using outcome measurement data to support rather than direct their actions (Greenhalgh et al., 2008). Outcome measures which could be helpful, such as the Psychosocial Impact of Assistive Device Scale (Jutai & Day, 2002), ‘have the compelling feature of assigning sovereignty to users’ judgments as opposed to the judgments of payers, clinicians, or researchers’ (Fuhrer, 2001, p. 531). This scale is designed to capture the competency and adaptability of a person using equipment whereas outcome measures such as the Wheelchair Outcome Measure, the Goal Attainment Scale, the Functioning Every-day in a Wheelchair measures are more focussed on the activity and participation concepts as defined by the ICF (S. Kenny & Gowran, 2014). As with recommendations for research priorities, measurement tools which focus specifically on participation could be used more in clinical practice to highlight the difference which is made in people’s lives by allocation of equipment (Harris, 2007).

Given the importance of people with stroke being able to access their community, interventions which maximise the application of equipment to this end are also required. From the rights-based perspective alone, funding is arguably required specifically to achieve this objective. A recent systematic review and meta-analysis of ‘real world’ walking after stroke reported that interventions which included behaviour change approaches, collaborative support and practice in real-world contexts were more effective than interventions which focussed on exercises alone found that studies where only exercise was used had a smaller point estimate (0.01 [-0.24, 0.26]) in comparison to interventions which included behavioural change techniques (0.25 [0.12, 0.38]) (Stretton et al., 2014). Highlighting and implementing further research on this highly valued aspect of life after stroke could assist with justifying time and money spent supporting clients in this regard.

No specific model of reasoning was mentioned by therapists when it came to equipment provision services. Based on the findings presented in this thesis, I would encourage the inclusion of training on the ethical and financial dimensions of equipment provision for therapists. Ethical reasoning tends to be a subject that is addressed in occupational therapy and physiotherapy education. However, a recent study by Laliberte et al. (2015) reported that 65% of educators in Canada for these programmes have no specialised ethics training and there is a wide range of pedagogy being applied in this part

of the curricula. Given the potential stress for therapists associated with ethical tensions, the impact of these issues on the people they work with, and the wider systems they work within, I endorse the recommendation by Laliberte et al. (2015) to map the content of ethics teaching in courses and compare these findings internationally. This would stimulate debate and discussion on this area and better prepare therapists for this aspect of their practice. Models of ethical reasoning, which negotiate the balance between scientific drivers of allied health intervention and more qualitative issues like those presented by Taff et al. (2014) require closer examination and warrant widespread discussion. This ethical reasoning model is entitled the 'Accountability - Well-being - Ethics' model and would appear to fit with the needs of the health service outlined in the research presented in this thesis. There will likely always be a divide between an ideal outcome regarding equipment options and what is going to be funded (Ferguson-Pell et al., 2005), however, operationalising an ethical framework for equipment provision services should enable all relevant stakeholders to be considered.

### **Policy**

Part of the aim of this thesis was to address if the current policy for equipment provision was fit for purpose. As was introduced in Chapter 1, the Ministry of Health in New Zealand has prioritised value for money, being person-centred, ensuring equity, timeliness and effectiveness and sustainability of health services (Ministry of Health, 2013a). Considering this statement as the aims of policy in this area, the findings of this thesis indicate that the current services are striving to be person-centred and timely (as indicated by data from all three phases of collection), but that long term value for money is potentially not being achieved and, with current available data, it is impossible to determine if the equipment provision service is equitable. The issue of 'effectiveness' of policy in this area is a complex one, where the current system may be effective at keeping people safe, but also seen as ineffective at enabling community mobility.

Since beginning my doctoral studies, funding systems in New Zealand have begun to collect data on the client's perspective of their needs and the potential benefits that could arise as a result of receiving equipment. This assessment is then scored and used to determine if a person meets a set threshold for funding for equipment, with the result being either that 'funding is available' or 'funding is not available'. While this effort to actively

include the perspective of the person with a disability is commendable, this kind of approach runs the risk that people who have experienced entrenched deprivation or those without the guile or language ability to advocate for themselves are disadvantaged in terms of accessing financial support for equipment (Menzel et al., 2002).

From the findings of this research, people who have complex disability or recent onset of a chronic condition like stroke, particularly those with cognitive and communication difficulties, relied heavily on their therapist to advise them when navigating through the funding process to trial equipment. This finding is congruent with other research where people who live with disability may not always advocate as honestly or strongly for themselves as one who is an expert in the ways of the healthcare system (Johansson et al., 2009). Equipment funding should be based on what is known to help people stay well and out of hospital and while advocacy (either via therapists or people with disabilities themselves) should be encouraged to ensure that people who would actually benefit from equipment use are not silent about their potential need.

Though in a relatively early stage of development, easy to use cost calculators such as the SIVA<sup>27</sup> cost analysis instrument (Andrich & Caracciolo, 2007) could offer a way for therapists to factor in the cost of equipment to decision making rationale. This tool ‘distinguishes social costs (the sum of all material and human resources mobilised by the intervention) from the financial plan (the actual disbursement of money over time by involved actors)’ (Andrich & Caracciolo, 2007, p. 20). As such, this tool offers the means to calculate cost for each potential equipment solution, considering purchase cost, maintenance, services use and assistance alternatives alongside other clinical decision making. This provides one avenue for policy makers and therapists to explore when considering the cost-benefit of equipment provision. This tool would require therapists to upskill in calculating these costs and given current resistance in this area, it is unclear how likely they would be to take this up without a lot of support and encouragement. However, the advantage of tools such as the SIVA cost analysis instrument is that it could provide empirical information to help health professionals meet their increasingly expected responsibilities regarding accountability for fair financial management of public funding.

Essentially, any approach to funding allocation and equipment provision needs to

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<sup>27</sup> Italian term, not further defined in the publication

consider best use of resources of the client, funding agency, and societal resources (Peterson & Murray, 2006). There are a number of different ethical frameworks that could be applied to making these decisions. The current equipment provision service directs therapists to aim for an agreed upon minimum standard of ability to take part in activities and to participate, to enable the most people possible to reach that minimum standard with the resources available. One potential approach for policy makers is to consider a more utilitarian approach to making funding distribution decisions. In this situation, all potential costs and benefits could be considered during funding decisions rather than just safety and risk. In such a situation consideration of reduced physical endurance and social isolation (and related health problems) associated with not funding equipment to enable participation outside the home could have a clearer place in funding decisions (Levack, 2009). Another alternative is for the policy in this field to be directed by a capabilities approach (Sen, 1992), where equal capabilities (or freedoms as an outcome of health service intervention) are distributed fairly, rather than resources. There is increasing interest in how the ICF aligns with capabilities theory, making this potentially a good fit for equipment provision and therapists, where Siegert and Ward (2010) argue that:

The advantage of the concept of capabilities is that it is intimately tied to the ideas of dignity and human rights and makes it clear that practitioners have an important moral obligation to help individuals develop their capabilities to live dignified lives, ones that they are able to shape for themselves. (p. 2144)

Regardless of which framework is adopted, by supporting prescribing therapists to be able to understand and articulate their clients' needs using ethical reasoning, complex issues like inequities and the role of advocacy and empowerment within the disability community can be better recognised. To achieve increased participation of people with stroke, ultimately, more funding is required. This resource needs to specifically target (and therefore protect) the participation aspirations of people with stroke which specialised equipment can enable. One potential way to ensure that participation focussed goals are explicitly addressed would be to have a ring-fenced pool of funding available specifically for these types of equipment. This dedicated pool would be accessed using established criteria but not compete with funding already allocated for equipment designed to keep people safe at home, which is a priority for funders, therapists and people with stroke



alike.

People who use mobility devices make fewer trips outside their home than those without (Harris, 2007) and Māori and Pacific people report a greater unmet need for adaptive equipment than New Zealand Europeans (Office for Disability Issues and Statistics New Zealand, 2010). In addition, it has been established that people from minority ethnic backgrounds experience greater impact on their life as a result of stroke than other groups (McNaughton et al., 2011; Stansbury et al., 2005). These inequities need to continue to be rigorously examined where possible and the healthcare system needs to allocate additional resource appropriately. Recommending that the equipment provision service prioritises equity of outcome (rather than equity of access to equipment) could increase the complexity and the cost of the current equipment provision service, however, addressing these issues should remain priorities for the public health system as a whole.

### **Summary**

The aim of this thesis was to explore if the services that provide equipment after stroke are fit for purpose at maximising safety, independence and choice. Given the weight of evidence present from this thesis that the policy for provision of equipment for community mobility is unjust in terms of actually enabling community mobility, this policy warrants urgent review. Further recommendations, as discussed in this section, are summarised in Table 7-1. This table has been developed to enable organisations to effectively make use of the findings of this thesis.

**Table 7-1 Summary of recommendations**

<b>Objective</b>	<b>Finding</b>	<b>Recommendation</b>
Who receives equipment after stroke and what outcomes do they achieve?	With current data collection processes in the Ministry of Health, it is not possible to adequately address this objective.	<p>Re-structure of data collection process to include ethnicity data and a record of outcomes achieved after equipment provision.</p> <p>Review of the policy and related processes to better provide equipment for community mobility and therefore, participation.</p>
How do people experience the process of receiving and using equipment?	People engage to varying degrees in the equipment provision process after stroke, with this ability to engage increasing with time and adjustment to life after stroke.	<p>Principles of shared decision making need to be incorporated into the assessment and provision process.</p> <p>The differences over time in how people engage with equipment and equipment provision processes need to be acknowledged.</p>
What influences the reasoning of therapists on decision making?	Therapists are influenced by clinical and non-clinical factors and rarely use outcome measures to evaluate the effect of providing equipment.	<p>Therapists need to be explicit to funders and their clients about non-clinical factors.</p> <p>Therapists need to explore and include relevant outcome measures to justify their decision-making and recommendations. Consideration of the outcome measures under development within the ICF may be useful.</p>

ICF = International Classification of Function

## 7.8 Conclusion

This thesis has drawn attention to the factors inherent in the prescription and use of equipment which are often alluded to in literature on this area, but rarely explored in depth and presented a comprehensive overview of how the current equipment provision service works, from the perspective of those who receive equipment and those who prescribe these items. The topics explored in this thesis should be a priority consideration for those working in the healthcare service as well as policy makers.

Overall, people with stroke who use equipment in New Zealand are satisfied with this service. They value the equipment that they received and the relationships with therapists who prescribed them their equipment. Equipment primarily supported people after stroke to feel safer and has the potential to support people to participate in their community. The findings identified a discrepancy between policy objectives and funding criteria for equipment supporting participation, despite participation being a highly valued outcome by both people with stroke and their therapists.

Shared decision making offers a pathway to addressing the concerns of the funder, the therapist and the client, but this requires there being a therapeutic relationship and sufficient time for people with stroke to test and evaluate their changed abilities during equipment provision. There will inevitably be ethical reasoning and compromises required (in terms of therapist time) when prescribing equipment, for which they could be better prepared and supported. In addition, decision-makers in funding require greater clarity on how money is spent on equipment provision after stroke, to assist in planning future service delivery and to target inequities. Finally, given that supporting people with stroke to mobilise outside of their houses can increase physical activity and reduce social isolation, the current provision system of equipment is potentially being short-sighted in how it limits funding for equipment to address these needs.

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Please note: Where possible a DOI has been supplied and if none available, a URL to a journal home page or Pubmed, except where journal home page URLs no longer existed.

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## Appendix A: Summary of research on equipment use and stroke

### Search history

Source	Screened	Reviewed against inclusion criteria and studies already selected
Cochrane Database of Systematic Reviews	9	0
TRIP Database	48	2
VISTA-Rehab	6	0
OT Seeker	66	3
Medline	100	14
CINAHL	124	0
Pedro	23	0
(Used allied health seeker function, includes PsychBITE and speechBITE databases)		
Checking reference lists		10
Total publications selected for review		29

#### Notes on key literature table in Appendix A

Research reported in various publications are grouped by study number (left hand column) and indicated also by shading for the first eight studies. Thereafter each study was reported in one publication only and so no further shading is used.

Where more than one publication was found relating to the same core study, the publications are numbered ‘a’, ‘b’ etc. to assist with making it clear where populations, methods or findings overlapped and/or were duplicated across publications. There is a guide to all outcome measures at the end of the table

Study No.	Reference(s)	Sample	Study Design	Analysis	Core finding	Critical Commentary
1 (a)	Hass et al. (1995)	38 people with stroke	Prospective, observational study over 9 months (1987-1988) using demographic data, equipment provision, care needs. Outcome measures: Costs, BI and NHP.	Regression analysis to identify variables which explained outcomes and costs. Descriptive analysis of qualitative and quantitative data.	Average cost per patient SEK (Swedish Krona) 204,409 (approx.. NZD \$ 43,708 in 1995 or NZD \$ 63,054 in 2016 when adjusted for inflation). Costs for accommodation were 70% of total with equipment cost 1 %. Divorced people and those with higher needs had higher total costs.	<p><b>Strengths</b> Included key variables for analysis such as functional ability, demographics and cost.</p> <p><b>Limitation</b> Cost data collection was pragmatic and descriptive rather than a true cost effectiveness or cost utility analysis. Data was collected at a unit with a strong Bobath philosophy where authors' acknowledge that equipment was often discouraged.</p> <p><b>Relevance</b> Cost figures useful but now 27 years old.</p>
1 (b)	Hass et al. (1996)	38 people with stroke	Qualitative interviews using a structured schedule.	Descriptive qualitative analysis to explore the selection process for equipment.	People with stroke reported having little choice of equipment items and follow up varied, but did use their equipment as intended.	<p><b>Strength</b> Variety of sources of data (qualitative and quantitative) enabled a potentially broad range of informative results.</p> <p><b>Limitation</b> Interview schedule was highly structured and results are reported quantitatively.</p> <p><b>Relevance</b> First qualitative study to explore how people with stroke decided whether and how to use equipment and model components of this decision making</p>
2 (a)	Mann et al. (1995)	35 older people with stroke, living at home.  Sampled from the CAS, a 10 year cohort study.	Descriptive study comparing changes over one year for equipment ownership, use and satisfaction with items, based on twice yearly qualitative (interview) and quantitative data (OARS, FIM, JFPI , CAATU).	Means and SDs were reported for time 1 and time 2 on the clinical and demographic measures as well as descriptive report on responses to the CAATU.	Functional ability rose by 4% however, there was no difference on psychosocial measures. Three case studies are presented to illustrate how these people used equipment when coping with the effects of stroke.	<p><b>Strengths</b> Measures were valid. The CAATU was used to separate analysis of factors related to equipment ownership, use, and satisfaction.</p> <p><b>Limitations</b> Loss to follow up (20%) was a concern for the CAS as a whole. Due to small sample size, options for statistical testing were limited.</p> <p><b>Relevance</b> Though the findings are not generalisable, they do suggest that people with stroke became more dependent on their equipment and expanded their pool of items during the 12 month post stroke.</p>



Study No.	Reference(s)	Sample	Study Design	Analysis	Core finding	Critical Commentary
2 (b)	Prangrat et al. (2000)	12 people with stroke	Descriptive study based on a sample selected from the CAS dataset, alongside structured interviews, unilateral neglect tests and an observation checklist of the person moving with equipment.	Mann-Whitney U test to compare group means, and Chi-square for nominal data. 3 people with neglect and 1 without were analysed as case studies.	Rate of equipment use to equipment ownership was less in people with unilateral neglect, who also had more difficulties using mobility aids and locating aids when on their neglect side.	<p><b>Strengths</b> Considerable data available to describe the small group from their involvement with the CAS project.</p> <p><b>Limitations</b> Study had to be amended from its original plan due to poor response to invite to participate (15/30) and then not having enough people with stroke who also had neglect as they would have preferred (n = 3) making findings difficult to generalise to all people with neglect.</p> <p><b>Relevance</b> One of only two studies to look at the impact of unilateral neglect on equipment use.</p>
3 (a)	Gitlin et al. (1996)	28 people with stroke	Prospective cohort study measuring how much equipment was used by people with different conditions, factors which led to equipment use and if demographic or health conditions predicted use.  Outcome measures: FIM, PGMS, BRMS	Pearson product-moment correlation co-efficient was used for predictor variables before a hierarchical linear regression model was performed, with equipment use at month 1 as the dependent variable. McNemar test was used to assess changes over time on paired nominal data.	<p>Patients' expectation about using equipment was an independent predictor of use. No socio-demographic characteristic predicted use,</p> <p>Each person with stroke received on average two bathing items and three dressing items and expressed satisfaction with the training they received.</p>	<p><b>Strength</b> Collected and compared equipment use across different condition groups with appropriate statistical modelling to test for predictor variables. Measurement tools were a mixture of standardised assessments and questionnaires developed by the researchers.</p> <p><b>Limitation</b> Of the 250 people eligible to take part, 94 declined most often due to ill-health and of 156 people first interviewed, only 86 had complete data (including pre-discharge base line information) for analysis.</p> <p><b>Relevance</b> Pre-disposition to equipment use was highlighted as a predictor of use.</p>

Study No.	Reference(s)	Sample	Study Design	Analysis	Core finding	Critical Commentary
3 (b)	Schemm and Gitlin (1998)	19 OTs who provided training to n = 28/86 patients over 55 with stroke.	Data collected on type of equipment issued, teaching methods used (where applicable), perceptions from therapists about patient knowledge and therapists' expectation of equipment future use. Outcome measures: FIM, JFP Index the Reinforcement Scale and Affect-Balance Scale.	Descriptive statistics to report on training practices of therapists. Differences between people with different conditions (stroke versus non-stroke) using <i>t</i> tests for independent samples. Pearson product-moment correlations to examine the relationships between characteristics of instruction and patient self-report factors. Analysis of equipment issued, teaching methods and therapist perceptions about patient knowledge expectation of equipment future use.	Average training time: 9 mins for bathing and 10 mins for dressing. People with stroke received more equipment items than others (mean = 10.8 ± 3.8). No significant differences noted on instruction for groups with different conditions.	<p><b>Strength</b> Measurement tools were a mixture of standardised assessments and questionnaires developed by the researchers.</p> <p><b>Limitation</b> Data collected was categorical and self-reported by therapists and people with stroke – potential for bias on both counts.</p> <p><b>Relevance</b> Considers and illustrates the potential mis-match between health professional of potential use for equipment.</p>
4 (a)	Reid et al. (2001)	16 people with stroke over 65 with 15 caregivers	Descriptive study comparing occupational performance for both a person with stroke who used a wheelchair.  Outcome measures: COPM (both) and the SMAF (caregiver only).	Descriptive data were described using mean, standard deviations and frequency counts. Differences between number and type of problems identified by the COPM were tested using the Mann-Whitney U Test and the Wilcoxon Signed Ranks Test.	Self-care was rated as a priority for both people with stroke and their caregivers and the inability to walk was reported to be a significant barrier to occupational performance.	<p><b>Strength</b> Measures chosen were appropriate for the research question and two groups' perspectives were included.</p> <p><b>Limitation</b> Small cohort (16 people with stroke and 15 caregivers) and 12/16 were male, 15/16 were married and white, making findings difficult to generalise.</p> <p><b>Relevance</b> Mobility issues ranked highly as occupational performance barriers, particularly in self-care – thereby highlighting the importance of mobility equipment at reducing difficulties.</p>

Study No.	Reference(s)	Sample	Study Design	Analysis	Core finding	Critical Commentary
4 (b)	Rudman et al. (2006)	16 people with stroke over 65 with 15 caregivers	Qualitative data gathered of the impact on occupation of wheelchair provision, via in-depth interviews.	Inductive analysis using grounded theory principles	Two themes related to occupation: living in a restricted occupational world and challenges to participation in occupation. Results indicated a relationship between occupation, one's identity and having a sense of control in relation to equipment use.	<p><b>Strength</b> Two researchers were involved with peer coding data and the results are well presented with quotations from participants.</p> <p><b>Limitation</b> Lack of detail on how grounded theory strategies were used in analysis of the data in the Rudman (2006) paper, in particular how accounts by care givers were considered in relation to those from people with stroke.</p> <p><b>Relevance</b> Control of one's body and one's environment was important, as well as the impact equipment could have on one's occupational identity.</p>
5 (a)	Gosman-Hedstrom, Claesson, and Blomstrand (2002)	249 people with stroke aged over 70 years  Sampled from a larger 12 month study of 248 people in the Goteburg 70+ stroke study  (Goteburg is an area of Sweden)	To compare the prescription, frequency, costs, types, and impact of equipment on daily activities. The hypothesis was that the patients at a stroke unit (SU, n = 166) would be better equipped with equipment, at a lower cost and with a higher impact than the patients on general wards (GW, n = 93). Outcome measure: questionnaire designed for this study and costs.	Frequency differences were calculated with a 95% confidence interval (CI) based on binominal distribution. The Mann-Whitney U non-parametric test was used to analyse differences in costs between the groups and the chi-square test for categorical data.	Statistically significant difference in prescribing simple and inexpensive equipment items between the SU and the GW within the first 3 months after stroke. However, no significant difference in cost at later stages. The low cost items had a high impact on these people's life.	<p><b>Strength</b> Randomised comparison where intention to treat analysis was used to account for loss to follow up for the whole study (comparing stroke unit care with general care on a range of outcomes). No significant demographic differences between groups were noted at baseline assessment.</p> <p><b>Limitation</b> Costs gathered were for equipment items only, rather than the time spent by health professionals prescribing and training people on use. One third of people in both the SU and GW group had equipment prior to their stroke, making data about impact of equipment after stroke difficult to interpret and group allocation was not controlled introducing confounding factors.</p> <p><b>Relevance</b> People in the stroke unit had equipment prescribed at an initial lower mean cost than those in the GW. Reinforces earlier research studies where the total cost of equipment after stroke is small compared to other costs (Hass et al. 1995).</p>

Study No.	Reference(s)	Sample	Study Design	Analysis	Core finding	Critical Commentary
5 (b)	Gosman-Hedstrom, Claesson, Blomstrand, Fagerberg, et al. (2002)	Identical to earlier publication (5a)	Identical to earlier publication (5(a)).	Identical to earlier publication (5(a)).	Identical to earlier publication (5(a)).	Identical to earlier publication (5(a)).
5 (c)	Gosman-Hedstrom and Blomstrand (2003)	121 elderly people who used equipment compared to 30 who did not use equipment. Sampled from 12 month study of 248 people in the Goteburg 70+ study	Longitudinal cohort study to describe dependence in daily activities and quality of life 3 months and 12 months after stroke. Outcome measures: FIM and NHP	Continuous variables were compared using the Mann-Whitney U test and x2 was used to compare proportions	Many people who were dependent on others for personal care used equipment (63%) and this group reported significantly lower health-related quality of life in many of the items in the NHP.	<p><b>Strengths</b> Longer follow up time since stroke than other studies in this area. Details of FIM assessors given as experienced OTs and that FIM was conducted in people's own home.</p> <p><b>Limitation</b> Those most likely to be excluded were people with dysphasia.</p> <p><b>Relevance</b> The researchers' hypothesise that the dependence levels of the equipment users was the reason for their lower HRQoL, rather than the use of equipment.</p>
6 (a)	Barker et al. (2004)	10 people with stroke	Qualitative descriptive study. Semi-structured, in-depth interviews that were conducted with 10 participants, ages 70 to 80 years old, who had used a wheelchair for a mean of 5.6 years.	Constant comparative inductive method of analysis.	Three categories of acceptance of wheelchair use: reluctant, grateful, and internal. Increased mobility, varied social response, and loss of valued roles common to all categories. As the wheelchair provided opportunity for increased continuity in life, it was accepted more fully and viewed more positively.	<p><b>Strength</b> Considers pre-stroke lifestyle and personal preferences explicitly in data collection and analysis and uses continuity theory as a framework for understanding the data.</p> <p><b>Limitation</b> Only 2 participants were female and only 2 participants had powered mobility.</p> <p><b>Relevance</b> Proposes new ideas that stroke as a catastrophic event from which one recovers means that this population embraces mobility equipment more readily than people with progressive conditions.</p>

Study No.	Reference(s)	Sample	Study Design	Analysis	Core finding	Critical Commentary
6 (b)	Barker et al. (2006)	Identical to 6(a)	Identical to 6(a)	Re-interpretation of original data collected in 2004, mapping concepts onto the ICF categories.	Whether manual or power, wheelchairs were enablers of community participation among the participants. However, they also created difficulties, such as restricting destinations and creating increased dependence on others. The researchers propose a balance scale model address how factors affecting community participation manifest for this group.	<p><b>Strength</b> Similar to Barker et al. (2004), in Barker et al (2006) continuity theory was used as a framework for understanding the data, alongside the recently developed (at the time) ICF categories. Barker et al. (2006) was one of the first studies to explore how the experience of using equipment relates to ICF categories.</p> <p><b>Limitation</b> Questionable secondary analysis of a small qualitative study in Barker et al. (2006) – methods description was identical to Barker et al. (2004) but rationale was presented differently to relate to the ICF. This made for confusion regarding the methods - for example, 2 participants took part in member checking of results, however, it appears this was for original findings in 2004 and not for the re-interpretation in 2006.</p> <p><b>Relevance</b> One of the first studies to explore how the experience of using equipment relates to ICF categories.</p>
7 (a)	Pettersson et al. (2006)	32 people with stroke who used power wheelchairs.	Pre and post design to compare limitations and participation restrictions before and 3-5 months after receiving a powered wheelchair. Outcome measures: IPPA and WHODAS II.	Effect size was calculated for the IPPA per individual participant (mean change/weighted mean SD of 32 participants at pre-assessment) and per activity and participation domain in the ICF (mean change/mean SD at pre-assessment – of the overall scale and subscales, respectively).	Powered wheelchairs have a positive effect on activity and participation assessed with IPPA, at both the group (ES = 2.6) and the individual level. Most problems categorised ‘Community, social and civic life’ according to the ICF, and the effect size in this domain was large (ES = 2.4) after the participants had used the wheelchair.	<p><b>Strength</b> Appropriate study design and measures chosen to address the research question.</p> <p><b>Limitation</b> WHODAS II has had limited testing in this type of design, more typically used in cross sectional studies. Small sample limited statistical testing of findings.</p> <p><b>Relevance</b> Linking equipment use after stroke to domains under the ICF and showing a sizeable positive effect in terms of activity and participation.</p>

Study No.	Reference(s)	Sample	Study Design	Analysis	Core finding	Critical Commentary
7(b)	Pettersson, Ahlstrom, et al. (2007)	Identical to 7(a)	Pre and post design to investigate quality of life and psychosocial impact of equipment between 3-5 months after receipt of a powered wheelchair. Outcome measures: EuroQol-5D, PIADS and other data collection tools devised for this study.	For ordinal variables, Wilcoxon signed-ranks test (two tailed) was used, the within-group effect size was calculated (mean change divided by the mean standard deviation at pre-test). A Mann-Whitney U test (two tailed) was used to detect changes in scores on the EQ-5D index, the mean of specific dimensions of the EQ-5D, and the mean of the PIADS total scale and subscales and for two ordinal five-point scaled variables, a Kruskal-Wallis test was performed.	Improved quality of life was observed with respect to the items competence, independence, capability, quality of life, well-being, happiness, and self-esteem on the PIADS as well as usual activity dimension on the EuroQol-5D. Those who drove their powered wheelchair at least once a day in the summer showed a more positive score on the total PIADS competence subscale than persons who drove less.	<p><b>Strength</b> Previously validated measures appropriate for the research question were used.</p> <p><b>Limitation</b> Relatively small sample size making results difficult to generalise.</p> <p><b>Relevance</b> Powered wheelchair mostly has a significant positive impact on quality of life for people with stroke.</p>
7(c)	Pettersson, Appelrosi, et al. (2007)	22 people with stroke.	Qualitative study using conversational interviews regarding daily experiences using equipment.	Hermeneutic-phenomenological research approach.	A dual experience exists with equipment use which is complex and contradictory. The equipment was seen as necessary for well-being but at the same time, the equipment gave rise to negative feelings because of the restrictions implied by their use.	<p><b>Strength</b> Clear inclusion criteria for participants and well described analysis pathway and helpful use of case scenarios to illuminate core themes.</p> <p><b>Limitation</b> As with most qualitative research and stroke, people with communication difficulties were excluded.</p> <p><b>Relevance</b> Furthers the idea that equipment becomes part of how people interact with their world, their bodies and their social relationships and that equipment use can be associated with contradictory feelings.</p>

Study No.	Reference(s)	Sample	Study Design	Analysis	Core finding	Critical Commentary
8 (a)	Winkler, Ripley, et al. (2010)	12,046 veterans with stroke during fiscal years 2001 and 2002.	Retrospective population-based cohort study to examine regional variation in provision of equipment and whether variation can be explained by patient characteristics or Veterans Health Administration region. Outcome measures: Provision of 8 equipment categories.	z Scores and corresponding p values to determine whether provision at the local level was significantly different than national level. Logistic regression models were fitted and run for 8 of the 11 equipment categories.	Significant variation was observed in the provision of equipment post-stroke, where patient characteristics accounted for only 6.2% of the variation. Local administrative region and disability severity accounted for equivalent amounts of the variation.	<p><b>Strength</b> Statistically significant explanation of variance, well described methods for data management and extraction from multiple relevant databases. Large dataset with few missing key variables.</p> <p><b>Limitation</b> Not easily generalisable outside of the American healthcare system.</p> <p><b>Relevance</b> A seminal study showing how administration processes differ across regions and how they can affect distribution of equipment.</p>
8(b)	Winkler, Vogel et al. (2010)	Identical to 8(a)	Retrospective study to examine equipment provision policy by comparing Medicare and Veterans' affairs. Outcome measures: Frequency of provision of equipment by purchase price and capped rental payments across the two services.	Descriptive comparison of key outcomes in two services including frequency counts and report of mean, median and percentages.	39% received no equipment, 56% received equipment from the VA only, 1% received equipment from Medicare only, and 3% received equipment from both the VA and Medicare. Most equipment was for activities of daily living, followed by walkers/canes/crutches. In specific equipment comparisons, VA costs were lower than Medicare for purchased items and slightly lower than Medicare for capped rental payments.	<p><b>Strength</b> Retrospective design limits bias and large sample size enhances the validity of the findings.</p> <p><b>Limitation</b> Differences in how costs were managed (i.e. VA do not rent items for people, whereas Medicare do in some cases) made some cost comparisons difficult. Problems with the accuracy of administrative coding of data and VA population tend to be older and in poorer health were acknowledged.</p> <p><b>Relevance</b> Ambitious attempt to compare the impact of two different funding and policy structures, illustrating that despite Medicare's policy to provide many items for 'in-home' use only, the VA system provided a broader range of equipment items at a lower cost.</p>

Study No.	Reference(s)	Sample	Study Design	Analysis	Core finding	Critical Commentary
8(c)	Winkler et al. (2011)	Identical to 8(a)	Retrospective study using administrative records at the Veteran's Affairs (VA does not limit provision of equipment to in-home use) to determine how the provision of equipment relates to ongoing utilisation and costs of services for veterans 12 months post-stroke when. Outcome Measures: FIM, inpatient days, outpatient visits, inpatient and outpatient costs during first year post-stroke.	Bivariate ( <i>t</i> -test) and multivariate (analysis of covariance). Multivariate analyses on subset who were 65 years at admission. The independent variable was provision of equipment. Outcome variables were inpatient days and outpatient visits and costs of VA services post-stroke.	Motor gain for veterans receiving equipment was higher than for veterans not receiving equipment (20 vs 9 FIM points, $p < 0.001$ ). Receiving a low-end manual wheelchair was associated with increased inpatient days and costs (both $p < 0.001$ ). Receiving a power wheelchair was associated with increased inpatient ( $p = 0.03$ ) and outpatient costs ( $p < 0.001$ ). Provision of a scooter was associated with increased outpatient visits and outpatient costs (both $p < 0.001$ ). Scooters, walking aids, and power wheelchairs associated with increased outpatient visits.	<p><b>Strength</b> Large sample size</p> <p><b>Limitation</b> FIM scores were only available for 5,519 (46%) of the cohort as this tool was only mandatory since 2002 and there was no way of knowing if equipment was issued specifically due to stroke related difficulties or other disabilities.</p> <p><b>Relevance</b> When people with stroke receive mobility equipment in particular, this predicts greater functional gain while in the hospital and greater frequency of outpatient visits.</p>



Study No.	Reference(s)	Sample	Study Design	Analysis	Core finding	Critical Commentary
9	Cushman and Scherer (1996)	17/47 people on a rehabilitation ward with stroke (36% of study population).	Cohort study where functional data and information on equipment and peoples' disposition towards their equipment was collected 3 months post discharge. Outcome measures: FIM and ATDPA administered with people with stroke and their health, FoneFIM at 3 months.	Rates of use and non-use were grouped descriptively by area of function and responses on the ADTPA between health professionals and people with stroke.	Equipment which was most frequently abandoned was adapted grooming aids (55%), quad canes (43%), walkers (36%), and manual wheelchairs (36%), given most frequently was that equipment was no longer needed. Functional improvement at follow-up corresponded with non-use of equipment for half the items. Discrepancy in perception noted between therapists and users regarding aesthetics	<p><b>Strength</b> Considers both people with stroke and their health professionals' perspectives on equipment use and measures function with validated FoneFIM which may be easier for people with writing/reading difficulties. Mixed population but the authors did report on condition specific findings.</p> <p><b>Limitation</b> Primarily descriptive data collected within a short follow up time for people with stroke.</p> <p><b>Relevance</b> Considers right and left hemisphere stroke and whether this impacted on continued equipment use and also highlights differences in how therapists and users perceive the aesthetic qualities of equipment.</p>
10	Gitlin (1998)	103 people with stroke in rehabilitation.	Qualitative approach to describe equipment perceptions of people recruited from a larger longitudinal study on equipment use.	Structured qualitative approach, drawing on ethnographic and interpretative philosophy.	Dimensions identified were the operation and utility of equipment, social contexts and consequences, and attributions of cultural meanings of use. Equipment use posed cultural value dilemmas initially, due to discrepancies between sociocultural beliefs and normative expectations.	<p><b>Strength</b> Large qualitative study, well written and substantiated themes.</p> <p><b>Limitation</b> Reasonably broad exclusion criteria including n 'perceptual distortions, moderate attention deficits, aphasia, mental confusion, psychoses, or dementia'.</p> <p><b>Relevance</b> Heavily cited for research in this area (over 101 on Google Scholar), appears a seminal article addressing these issues.</p>

Study No.	Reference(s)	Sample	Study Design	Analysis	Core finding	Critical Commentary
11	Hesse et al. (1996)	121 people with stroke	Retrospective cross sectional study using questionnaires sent to the homes of 194 people at home six to ten months after discharge. Medical records were also hand searched to estimate cost of equipment for this group.	Descriptive analysis of questionnaire data.	121 (62.3%) questionnaires were returned. From the 466 people discharged following stroke in 1992, 194 (42%) received at least one item of equipment, with a mean of 2.1 items per person, totalling ECU 690 per person. Ninety-four people with stroke used equipment regularly, 19 occasionally and eight had stopped due to improvement and/or poor fit. 85% had over 50% satisfaction with services.	<p><b>Strengths</b> Reasonably high response rate to questionnaires and unlike much research in this area, these researchers were able to target people issued with equipment.</p> <p><b>Limitations</b> The questionnaire was designed for this study and not validated and people with poor communication after stroke would have been excluded from questionnaire based data collection.</p> <p><b>Relevance</b> The cost figures are difficult to interpret in the New Zealand context, particularly given how long since the study was conducted (over 30 years ago).</p>
12	Garber et al. (2002)	49 veterans who have had a stroke.	Cross-sectional descriptive study investigating extent to which wheelchairs prescribed during rehabilitation are used and meet individuals' mobility, functional, psychological and social needs. Outcome measures: questionnaire designed for the study, VAS for pain, AS, HOISF-LO and FoneFIM, GDS, MMSE, CHART, HSQ-2 and Major Life Events Scale.	Means, standard deviations (SDs) and ranges calculated for continuous variables, <i>t</i> -tests were used where one variable was continuous and one was categorical and Chi-squared analysis when both variables were categorical.	Fifteen people (31%) stopped using their wheelchairs due to improved function or use of other mobility aids, they used them for on average 13 weeks. Participants who retained use of the wheelchair were satisfied with its performance. Almost 45% of the participants had impaired socialisation, 80% had severely compromised occupations, and 41% had depression.	<p><b>Strength</b> Collected data on a wide range of possible contributing variables such as contractures.</p> <p><b>Limitations</b> Specific stroke population and therefore system (Veterans) making the results difficult to generalise and results were primarily descriptive. The age at stroke onset in this study was 89-99 which is relatively old (average age of stroke in New Zealand = 76 for NZ Europeans) and there was a wide variation in time since stroke onset.</p> <p><b>Relevance</b> Alongside reporting o satisfaction and use of wheelchairs, these researchers collected and described psychological symptoms after stroke which affected equipment use.</p>

Study No.	Reference(s)	Sample	Study Design	Analysis	Core finding	Critical Commentary
13	Lampinen and Tham (2003)	8 people with stroke with visuospatial agnosia.	Participants were interviewed twice in one week. The first interview was open ended and informal, the second interview included the participant performing a kitchen task and they and the interviewer reflecting on how they used items in this task.	Empirical phenomenological psychological (EPP) method.	Three themes arose, each with 2 sub-themes: Experiences of an unfamiliar world (do not recognise familiar things and perceiving more or less than before), Experiences of interacting with the physical world (perceiving objects as obstacles and perceiving the wheelchair as unruly) and Adaptation to the new problematic world (constant striving for mastery and striving to be a whole person again).	<p><b>Strength</b> Commendable relationship building with first interview making second interview with practical equipment use less stressful for participants and the steps of analysis were well described and appear trustworthy.</p> <p><b>Limitation</b> Due to the nature of the methods, it was not possible to separate visuospatial agnosia concerns from other stroke related impairments like weakness or poor balance.</p> <p><b>Relevance</b> Rich qualitative data which described how objects can seem to have a life of their own and how one conceptualises ones' body differently in relation to objects after stroke.</p>
14	Sorensen et al. (2003)	155 consecutive people with stroke at a rehabilitation service.	Longitudinal study regarding participants recruited from a larger randomised study of post discharge follow up for people with stroke between 1996 and 1998. Identified by an OT who reviewed home discharge reports and a home visit 3-5 years post-stroke, where 76 people were still alive and eligible for follow up. Outcome measures: questions on use of equipment, the SSS and the BI.	Chi-squared analysis for class variables and gamma analysis for ordinal variables. A t-test was used to analyse means and SDs for continuous variables and ANOVA was used to when compare differences between groups.	75% of those discharged received equipment at that time and 80% were still using equipment or had received more 6 months after discharge. Statistically significant difference in the number of equipment items issued where people had a home visit pre-discharge compared to those without ( $p = .003$ ).	<p><b>Strength</b> Original group (related to larger study) represented 20% of all people discharged with stroke in Denmark – however, not all of this group needed or received equipment. Findings correlate with other Scandinavian research on this topic (Gosman-Hedstrom, 2002 and Hass, 1995).</p> <p><b>Limitation</b> Opportunistic data analysis made data collection and follow up somewhat limited and inflexible.</p> <p><b>Relevance</b> Hearing aids and grab-rails were included, which makes the finding that most people still alive 3-5 years later were still using equipment unsurprising. The findings do encourage the use of pre-discharge home visits to increase access to a range of equipment.</p>

Study No.	Reference(s)	Sample	Study Design	Analysis	Core finding	Critical Commentary
15	Chiu and Man (2004)	53 adults with stroke discharged from a rehabilitation ward.	Prospective pre- and post-test RCT design, where the intervention group (n = 30) received an extra home based intervention on how to use the equipment given on discharge. Outcome measures: FIM and the QUEST as primary outcome measures.	Descriptive statistics and <i>t</i> test to compare mean differences in independence and satisfaction between, and within, the two groups.	The intervention group showed improved function ( $t = 3.89$ ; $df = 51$ ; $p = .01$ ) and satisfaction with equipment ( $t = 69.8$ ; $df = 29$ ; $p = .01$ ) after intervention and they had a higher rate of using bathing equipment (96.7% compared to 56.5%).	<p><b>Strength</b> Clear randomisation process for intervention and control groups, referring OTs were blinded appropriately and appropriate outcome measures were used.</p> <p><b>Limitation</b> 3 month follow up was quite a short period of time for stroke recovery and single centre only in the trial. Small sample size further limits generalisability and researchers acknowledge that costs were higher for the intervention group, but does not state by how much.</p> <p><b>Relevance</b> The only RCT to compare enhanced training with equipment with functional outcome and the authors identified the need for more long term studies and that more in-home training increased uptake of equipment.</p>
16	Jutai et al. (2007)	316 people with confirmed initial stroke.	Longitudinal study estimating the extent to which clinical and functional features of stroke relate to the use of mobility equipment. Intervention: Equipment for mobility (canes, walkers, wheelchairs). Outcome measures: Equipment use and mobility capacity using SF-36 PF scale, BI, MMSE, SIS mobility subscale and CNS mentation subscale.	Chi-square tests to examine the association of clinical features with use or non-use, single or multiple equipment use, and primary equipment type (cane, walker, or wheel-chair). Spearman correlations were used to examine the strength of relationship between functional measures and age. Logistic regression analyses was used to predict equipment use.	135/181 people received a mobility assistive equipment. Equipment use significantly associated with mobility (SF-36 PF) (OR = .97; 95% CI, .96–.98), functional independence (BI) (OR=.96; 95% CI, .95–.98), and cognitive status, measured by the CNS mentation subscale (OR = 1.46; 95% CI, 1.03–2.07) and the MMSE (OR = .03; 95% CI, 1.01–1.06) (R <sup>2</sup> = .48; percentage correctly classified, 79.4%).	<p><b>Strengths</b> Relatively large sample size for this type of questionnaire and multiple valid measures of mobility.</p> <p><b>Limitations</b> Details on the exact type of equipment issued to people and the nature and extent of the rehabilitation they received before and during the month long intervention period were unknown.</p> <p><b>Relevance</b> This study indicates that equipment allocation and likelihood of use could be modelled effectively and that commonly used measures in stroke rehabilitation such as the MMSE, the SF-36 PF and BI are reliably associated with use of equipment.</p>

Study No.	Reference(s)	Sample	Study Design	Analysis	Core finding	Critical Commentary
17	Tyson and Rogerson (2009)	20 non-ambulant stroke rehabilitation patients at inpatient units of 3 UK hospitals.	Randomised crossover trial Interventions: Five walking conditions: (1) Walking with no equipment (the control condition), (2) walking with a walking cane, (3) ankle foot orthosis, (4) slider shoe, and (5) a combination of all 3. Outcome measures: Functional mobility categories, speed, step length of the weak leg, and patients' opinions.	Friedman test for the categorical data and a 1-way ANOVA for continuous data Where significant differences were found, Mann-Whitney U tests and paired t tests identified where significant differences lay. Additional calculations included ([meantreatment meancontrol]/ SD) and percentage change.	Functional mobility improved with all equipment ( $P < .0001$ – $.005$ ; effect sizes 1.68–0.52; number needed to treat =2–5). Walking impairments were unchanged ( $P < .800$ – $.988$ ). Participants were positive about equipment, that their walking, confidence, and safety improved and the equipment were acceptable to them. They would rather walk with the equipment than delay walking until a normative gait pattern was achieved.	<p><b>Strengths</b> One of the few studies to use intervention trial methods to evaluate these commonly prescribed walking aids.</p> <p><b>Limitations</b> Small sample group which means that differences may have existed due to chance or confounding factors. Also early in stroke rehabilitation (mean time since stroke was 6.5 weeks (SD = 5.7).</p> <p><b>Relevance</b> People with stroke expressed a preference to walk with aids soon into their rehabilitation, prioritising speed and safety of mobility over normal gait patterns.</p>
18	Allet et al. (2009)	25 people with hemiparesis after stroke, in early stages mobility rehabilitation	Cohort study where on 3 consecutive days, participants used 1 of 3 walking aids: 4-point cane, simple cane with ergonomic handgrip, and Nordic stick. Outcome measures: Maximal walking distance in 6 minutes, commercial electronic gait analysis system GAITRite and patients' ranked preference.	Regression modelling for repeated measures and Spearman's correlation coefficient to examine the relationship between mobility status and subjective ranking for each aid.	Walking distance was greatest with simple cane with ergonomic handgrip (mean walking distance, 115.48m), followed by the 4-point cane (mean walking distance, 101.40m; $p = .021$ ). Gait velocity was higher with cane with ergonomic hand grip than 4 point cane (mean difference, 3.58cm/s; $p = .018$ ). Simple cane with ergonomic handgrip was patients' preferred aid.	<p><b>Strengths</b> Objective measures were well used alongside patient preference data to objectively evaluate a clinical intervention which is often highly subjective.</p> <p><b>Limitations</b> Relatively small and homogenous sample, findings apply to people with stroke who do not require assistance (as well as equipment) to mobilise.</p> <p><b>Relevance</b> Researchers considered objective ambulation measures alongside patient preferences for gait aids and the simple cane with an ergonomic handgrip was both the preferred aid for most people and enabled them to walk the greatest distance at the highest velocity.</p>

Study No.	Reference(s)	Sample	Study Design	Analysis	Core finding	Critical Commentary
19	Skolarus et al. (2014)	892 stroke survivors and n= 6,709 from a smoke free group.	Cross sectional study sampled from National Health and Aging Trends Study (2011) comparing demographic characteristics, accommodation-enabling and need-related factors. Outcome measures: self-reported data on cognition, demographic detail and equipment use from NHATS questionnaire.	Multinomial logistic regression models predicting type of accommodation and logistic regression models predicting unmet need.	Stroke survivors used more equipment and received more personal assistance and had greater unmet need than stroke-free controls. Measures of physical and cognitive capacity (both p< .01) were most important in adjusted models in predicting accommodations.	<b>Strength</b> Large cohort with people with no stroke as control group and well-conceived statistical modelling with accounting for most key confounding variables. <b>Limitation</b> Secondary analysis of national cross-sectional survey data, where the original survey did not include people living in residential care, thereby excluding people with more complex stroke. <b>Relevance</b> Illustrates increasing trend to determine if equipment use can be statistically predicted (it can) and that further research is warranted on how to increase the use and reduce unmet need, which continues to be substantial.

CAATU – Consumer Assessments Assistive Technology used

OARS – Older Americans Research and Service Centre instrument

JFPI - Jette Functional Plan Index

Bobath philosophy - to promote motor learning for efficient motor control for people with neurological disability through specific patient handling skills to improve participation and function.

PGMS – Philadelphia Geriatric Morale Scale

BRMS – Bruno’s Reinforcement Motivation Survey

SMAF - Functional Autonomy Measurement System

COPM - Canadian Occupational Performance Measure

WHODAS - II World Health Organization Disability Assessment Schedule II

IPPA - Individually Prioritised Problem Assessment

EuroQol 5D - standardised instrument for use as a measure of health outcome

PIADS – Psychosocial Impact of Assistive Devices Scale

FoneFIM - Telephone version of the Functional Independence Measure

ATDPA - Assistive Technology Device Pre-disposition Assessment

FIM - Functional Independence Measure

AS – Ashworth Scale for spasticity

HOISF-LO - Health Outcomes Institute Stroke Form--Later Outcomes

CHART - Craig Handicap Assessment and Reporting Technique

HSQ - Health Status Questionnaire

SSS – Scandinavian Stroke Scale

QUEST - Quebec User Evaluation of Satisfaction with Assistive Technology

CNS Canadian Neurological Scale

SIS - Stroke Impact Scale  
MMSE - Mini-mental State Exam  
SF-36 PF - Medical Outcomes Study 36-Item Short-Form Health Survey physical functioning  
NHP - Nottingham Health Profile  
BI - Barthel Index  
OT - Occupational therapist  
VA - Veteran Affairs

## Appendix B: Ethics approval



### Health and Disability Ethics Committees

Ministry of Health  
1 the Terrace  
PO Box 5013  
Wellington  
6011  
0800 4 ETHICS  
hdec@moh.govt.nz

15 March 2013

Ms Pauline Boland  
Rehabilitation, Teaching and Research Unit  
University of Otago,  
Newtown, Wellington  
6242

Dear Ms Boland

<b>Re: Ethics ref:</b>	<b>13/NTA/31</b>
Study title:	Prescription and management of assistive technology after stroke.

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

The main ethical issues considered by the Committee were as follows.

- The Committee considered that the letter of invitation should be sent from the researcher on University of Otago letterhead, rather than from the DHB, which could be potentially confusing. This letter should also confirm ethics approval for the research.
- The Committee considered that the study should avoid potential participants who have other conditions, especially those that may impact on capacity to consent (eg, dementia). This could be inferred from some aspects of the application. However, the PISCF would more appropriately refer to people *who are assisting in supporting* participants, rather than those *who are legally responsible for* participants.
- The Committee noted that consent for image release should make clear that images will contain no identifying information, and refer to "monetary" rather than "corporate" benefit.
- The Committee noted multiple typographical errors in the PISCFs for this study, which may detract from readability, and suggested that these be corrected.

#### Conditions of HDEC approval

HDEC approval for this study is subject to the following conditions being met prior to the commencement of the study in New Zealand. It is your responsibility, and that of the study's sponsor, to ensure that these conditions are met. No further review by the Northern A Health and Disability Ethics Committee is required.

Standard conditions:

1. Before the study commences at *any* locality in New Zealand, all relevant regulatory approvals must be obtained.



2. Before the study commences at a *given* locality in New Zealand, it must be authorised by that locality in Online Forms. Locality authorisation confirms that the locality is suitable for the safe and effective conduct of the study, and that local research governance issues have been addressed.

After HDEC review

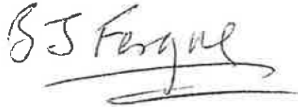
Please refer to the *Standard Operating Procedures for Health and Disability Ethics Committees* (available on [www.ethics.health.govt.nz](http://www.ethics.health.govt.nz)) for HDEC requirements relating to amendments and other post-approval processes.

Participant access to ACC

The Northern A Health and Disability Ethics Committee is satisfied that your study is not a clinical trial that is to be conducted principally for the benefit of the manufacturer or distributor of the medicine or item being trialled. Participants injured as a result of treatment received as part of your study may therefore be eligible for publicly-funded compensation through the Accident Compensation Corporation (ACC).

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

Yours sincerely,



Dr Brian Fergus  
Chairperson  
Northern A Health and Disability Ethics Committee

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

**Appendix A**  
**Documents submitted**

<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of scientific review: Record of consultation with a peer from neighbouring department who is not involved with this project	1	25 February 2013
CV for CI: CV for CI	1	27 February 2013
CVs for other Investigators: CV for primary supervisor Dr William Levack	1	27 February 2013
CVs for other Investigators: CV for secondary supervisor Dr Fiona Graham	1	27 February 2013
Covering Letter: Cover letter to HDEC about this study	1	27 February 2013
PIS/CF: Participant Information Sheet for Phase 1	1	27 February 2013
PIS/CF: Participant Information Sheet for Phase 2	1	27 February 2013
PIS/CF: Participant Information Sheet for Phase 3	1	27 February 2013
PIS/CF: Consent Form for Phase 1	1	27 February 2013
PIS/CF: Consent Form for Phase 2	1	27 February 2013
PIS/CF: Consent Form for Phase 3	1	27 February 2013
Protocol: Study Protocol	1	27 February 2013
Survey/questionnaire: Survey questionnaire	1	23 February 2013
Focus Group Schedule (for Phase 3)	1	16 January 2013
Interview Schedule for people with stroke (phase 2)	1	01 February 2013
Cover letter to accompany mail questionnaires from the DHB	1	27 February 2013
Consent form to release photos	1	28 February 2013
Application		

**Appendix B**  
**Statement of compliance and list of members**

Statement of compliance

The Northern A Health and Disability Ethics Committee:

- is constituted in accordance with its Terms of Reference
- operates in accordance with the *Standard Operating Procedures for Health and Disability Ethics Committees*, and with the principles of international good clinical practice (GCP)
- is approved by the Health Research Council of New Zealand's Ethics Committee for the purposes of section 25(1)(c) of the Health Research Council Act 1990
- is registered (number 00008714) with the US Department of Health and Human Services' Office for Human Research Protection (OHRP).

List of members

Name	Category	Appointed	Term Expires	Present on 12/03/2013?	Declaration of interest?
Dr Brian Fergus	Lay (consumer/community perspectives)	01/07/2012	01/07/2015	Yes	No
Ms Susan Buckland	Lay (consumer/community perspectives)	01/07/2012	01/07/2015	Yes	No
Ms Shamim Chagani	Non-lay (health/disability service provision)	01/07/2012	01/07/2014	Yes	No
Mr Kerry Hiini	Lay (consumer/community perspectives)	01/07/2012	01/07/2014	Yes	No
Assoc Prof Wayne Miles	Non-lay (intervention studies), Non-lay (health/disability service provision)	01/07/2012	01/07/2013	Yes	No
Dr Etuate Saafi	Non-lay (intervention studies)	01/07/2012	01/07/2014	Yes	No
Ms Michele Stanton	Lay (the law)	01/07/2012	01/07/2014	Yes	No

<http://www.ethics.health.govt.nz>

## Appendix C: Māori consultation

NGĀI TAHU RESEARCH CONSULTATION COMMITTEE  
TE KOMITI RAKAHAU KI KAI TAHU

Tuesday, 23 April 2013.

Ms Pauline Boland,  
Dunedin School of Medicine - Rehabilitation Teaching and Research Unit,  
WSM&HS.

Tēnā Koe Ms Pauline Boland,

### **Prescription and management of assistive technology for people with stroke.**

The Ngāi Tahu Research Consultation Committee (The Committee) met on Tuesday, 23 April 2013 to discuss your research proposition.

By way of introduction, this response from The Committee is provided as part of the Memorandum of Understanding between Te Rūnanga o Ngāi Tahu and the University. In the statement of principles of the memorandum it states "Ngāi Tahu acknowledges that the consultation process outline in this policy provides no power of veto by Ngāi Tahu to research undertaken at the University of Otago". As such, this response is not "approval" or "mandate" for the research, rather it is a mandated response from a Ngāi Tahu appointed committee. This process is part of a number of requirements for researchers to undertake and does not cover other issues relating to ethics, including methodology they are separate requirements with other committees, for example the Human Ethics Committee, etc.

Within the context of the Policy for Research Consultation with Māori, the Committee base consultation on that defined by Justice McGechan:

*"Consultation does not mean negotiation or agreement. It means: setting out a proposal not fully decided upon; adequately informing a party about relevant information upon which the proposal is based; listening to what the others have to say with an open mind (in that there is room to be persuaded against the proposal); undertaking that task in a genuine and not cosmetic manner. Reaching a decision that may or may not alter the original proposal."*

The Committee considers the research to be of importance to Māori health.

As this study involves human participants, the Committee strongly encourage that ethnicity data be collected as part of the research project. That is the questions on self-identified ethnicity and descent, these questions are contained in the 2006 census.

2010 Statistics suggest that Stroke mortality was over one-and-a-half times higher for Māori than for non-Māori. The Ministry of Health website <http://www.health.govt.nz/publications> contains a list of Māori health publications. The Committee recommends you review the Māori health publications on this website, eg. Unequal Impact II: Māori and Non-Māori Cancer Statistics by Deprivation and Rural-Urban Status 2002-2006 and Tatau Kahukura: Māori Health Chart Book 2010. Another Publication, Hauora: Māori Standards of Health IV (2000-2005), has its own website, <http://www.hauora.maori.nz/>. These publications provide information on a range of Māori health issues and will assist in ensuring your research has an

appropriate Māori health focus.

The Committee suggests dissemination of the research findings to Māori health organisations regarding this study.

We wish you every success in your research and The Committee also requests a copy of the research findings.

This letter of suggestion, recommendation and advice is current for an 18 month period from Tuesday, 23 April 2013 to 12 October 2014.

Nāhaku noa, nā



PP. NTRCC

Mark Brunton  
Kaiwhakahaere Rangahau Māori  
Research Manager Māori  
Research Division  
Te Whare Wānanga o Otāgo  
Ph: +64 3 479 8738  
Email: [mark.brunton@otago.ac.nz](mailto:mark.brunton@otago.ac.nz)  
Web: [www.otago.ac.nz](http://www.otago.ac.nz)



Research Advisory Group – Māori  
Māori Partnership Board, Capital & Coast DHB

## RESEARCH ADVISORY GROUP MĀORI (RAG-M)

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01 May 2013

Pauline Boland  
Rehabilitation Teaching and Research Unit  
Wellington School of Medicine and Health Science  
PO Box 7343  
Wellington South 6242

### **RAG-M 2013/249- Letter of Endorsement**

Tēnā koe Ms Boland

I write on behalf of the Research Advisory Group Māori in relation to the proposed study of experience with adaptive equipment used by people after stroke.

We note that the research has been referred for ethical approval and Whanau Care Services information.

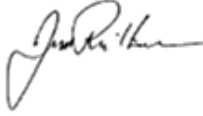
The significance to Maori of stroke research and rehabilitation is very high, particularly because the average age of stroke onset among Maori is quite low, compared with stroke incidence among European-origin people in Aotearoa, and there is also evidence that post-stroke dependency is comparatively high and that the whole stroke experience causes much anxiety to whanau.

*We feel some concern, because of the disparities I have mentioned, that the number of Maori subjects may be no greater than in the general population mix, and this may be a factor for you to consider during the research. Another aspect is that service providers such as physiotherapists and OTs, and the rehabilitation equipment they may recommend, may be less accessible to Maori living in smaller towns and rural areas.*

Your PhD project appeals greatly in terms of improving rehabilitation and we trust that the evaluation of adaptive equipment and its use will also include concern for good accessibility and the involvement of whanau and primary caregivers in its best use.

We wish you every success in this study project and we would appreciate being advised of its outcomes.

Nāku noa nā,

A handwritten signature in black ink, appearing to read 'Jack Rikihana', written in a cursive style.

**Jack Rikihana**  
**Chair RAG-M**



14 May 2013

Ms Pauline Boland  
Dunedin School of Medicine-Rehabilitation Teaching and Research Unit

**RE: Letter of Support for research project titled:**  
Prescription and management of assistive technology for people with stroke.

Tēnā Koe

Thank you for submitting the above proposal to the Waikato DHB Te Puna Oranga Maori Health Research Committee for review.

The committee acknowledges that research applications may at times be governed by international protocols as the study may not have originated in New Zealand, therefore, the committee would expect that consideration has been given to engaging with other indigenous peoples and researchers in other countries. Indigenous peoples are concerned about exploitation, confidentiality and control over research, informed consent, usefulness of research, ownership and control of data. We trust that the other countries part-taking in your research have also involved indigenous people.

Based on the information provided and the review conducted by the committee, we are very pleased to provide support to your research with an invitation to:

- a. Provide progress updates to Te Puna Oranga regarding the study and a copy of the results at the completion of the study

Te Puna Oranga can offer cultural support and guidance to this research process, particularly with regards to working with Maori patients and their whanau during your trials. We can also provide the links regarding Maori providers to support an increase in Maori participation with these trials.

Please feel free to contact Manaaki Nepia, Service Manager if you need assistance.

We are committed to building on-going relationships with researchers in the hope of improving Maori health, we wish you well with the study/trial and should you have any further queries please feel free to contact me.

Noho ora mai ra

A handwritten signature in black ink that reads "Manaaki Nepia".

Manaaki Nepia  
Service Development Manager  
Te Puna Oranga-Maori Health Service  
[Manaaki.nepia@waikatodhb.health.nz](mailto:Manaaki.nepia@waikatodhb.health.nz)  
07 834 3628  
021 415 062





06 May 2013

Pauline Boland  
BSc (Hons) OT, MHealSci (Rehabilitation), Phd candidate,  
Rehabilitation Teaching and Research Unit,  
Wellington School of Medicine and Health Science,  
PO Box 7343  
Wellington South 6242

Dear Ms Boland

**re: Research Application: Equipment use after stroke**

I am happy to confirm that this proposal has been reviewed by the Hutt Valley DHB Maori Health unit as part of the DHB's approval process. The Maori Health Unit is fully supportive of this research application and has no outstanding concerns.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Kuini Puketapu', written in a cursive style.

Kuini Puketapu  
MAORI HEALTH UNIT

Hutt Valley District Health Board  
High Street Private Bag 31907  
Lower Hutt 5040 New Zealand  
Telephone +64-4-566 6999  
Fax +64-4-570 9228  
Fox Hospital +64-4-570 9001

## Appendix D: Peer review

### HDEC scientific peer review

**Project title:** Prescription and management of assistive technology for people with stroke

**Primary researcher:** Pauline Boland

**Reviewer:** Dr Meredith Perry, School of physiotherapy, University of Otago – Wellington

**Date of original review:** 9.1.2013

(Documents reviewed: Research proposal, questionnaire draft, focus group schedule and interview schedule)

**Response from Pauline Boland to Dr Perry's comments sent on 06/02/13**

**Review on these comments received from Dr Perry on 25/02/12**

The proposed study utilises a mixed method quantitative → qualitative design to investigate whether the policies and procedures for provision of assistive technology to people with stroke are fit for purpose.

The research consists of three interlinked studies. Initially a postal questionnaire sent to 1000 people (from five District Health Board's) who have had a stroke and were admitted to a rehabilitation ward. Up to twenty people who complete this questionnaire will be purposefully selected and invited to attend semi-structured interviews. The purpose of the interviews is to explore their experiences of assistive technology assessment, provision and use more deeply. Thirdly, health professionals from three District Health Boards who are authorised to prescribe assistive technology will be invited to attend focus groups.

#### ***Merit of the research***

The background clearly identifies why this research is relevant and justifiable. The incidence of stroke in New Zealand (particularly in Māori people) and the costs of supporting people following a stroke with chronic disability are significant. This research seeks to identify whether the assessment, and then provision of assistive devices meets users' needs. Consultation with end users and equipment assessors will ensure that any recommendations from this research are meaningful and easily adapted into practice.

#### ***The design and methods:***

The use of mixed methods is appropriate with the objectives of this research. Furthermore, the use of grounded theory (constructivist approach) for the qualitative aspects (Phase two and three of the research) will enable the design of a model from which service recommendations might be made. Conversely, as one aim of the research is to compare experiences of people who are highly satisfied and have high utility of their assistive devices with low users and to compare experience by ethnicity a methodology such as phenomenography.

**Response**

Although questions regarding experience are often addressed using phenomenology we have chosen Grounded theory because it is also suitable to explore and understand shared experiences AND it is frequently used by social researchers who are trying to discover the underlying processes which shape interaction (McCallin, 2003). The principal authors of grounded theory methodology, Glaser, Strauss and Corbin and Charmaz have all used grounded theory to explore experience. What will distinguish this work as grounded theory (as opposed to phenomenology or phenomenography) will be: the use of theoretical sampling, some consideration of sample size from the perspective of theoretical saturation, and the synthesis of findings into a single model of some kind, preferably with a central theme. The strength of Grounded theory is in its ability to give a framework to examine the relationships (rather than differences) between satisfaction and utility and other variables to develop a substantive theory (for instance) about how people become more satisfied or less satisfied with equipment prescription/use .

This is a useful and timely question from the peer reviewer and description of methodology and justification for same has been made clearer in the proposal.

More clarification on how much/little results from previous phases will be incorporated into subsequent phases is required.

**Response**

As the primary strength and purpose of mixed methods research is to build from one mode of inquiry to another, this is a salient point. The data for each phase will be related though not necessarily inter-related, so the perspectives of users of equipment and those who prescribe it will be explored individually as well as in relation to findings from earlier phases. For example, the results from Phase 1 quantitative phase will be used to further develop the interview schedule (currently in draft) for Phase 2 qualitative interviews. The results from AT users in phase 1 and 2 will form the core questions for discussion in the focus groups in phase 3 and this has been made more explicit in the proposal. Also, while earlier results will be examined from a different angle at each stage of the study, as is appropriate for mixed methods, the perspectives of individuals and groups will emerge at both Phase 2 and Phase 3 until data saturation is reached, and this will not necessarily confirm or deny earlier results, but provide another perspective to contribute to the overall model.

In addition, there is a lack of specificity with respect to the recruitment and the sampling method of the quantitative study (Phase one). It is unclear whether patients will be identified from ward admission records or from District Health Board databases.

**Response**

Patients will be identified from DHB databases and cross referenced with DHB records for admission to rehabilitation wards (or slow stream medical wards, for DHBs which may not have specific rehabilitation wards). This has been trialled as a search strategy in CCDHB and from early conversations with other DHBs, this data exists in an easily identifiable format elsewhere in the country.

Some more consideration/specificity on how to ensure generalizability/representativeness of the results is also required. All three phases of the study require some additional clarity of who is eligible to participate.

**Response**

Eligibility for each phase has been made more explicit, earlier in the proposal, as follows:

**Eligibility to participate**

**Phase 1 – people who have had a stroke in 2012 who were admitted to a rehabilitation ward following their stroke and who live in the local DHB area.**

**Phase 2 – people with stroke who had 1) mixed experiences and 2) diverse demographic profiles (range of age, gender, ethnicity, social status and morbidity) who volunteered to be contacted about an in-depth interview and possible use of photo-voice to give depth and context to the findings from phase 1**

**Phase 3 – people who are allied health professionals (occupational therapists and physiotherapists) at different stages of career who are working with people with stroke and who are involved with equipment assessment and provision.**

***The feasibility of the research:***

Overall this research is feasible, has been carefully thought through and is likely to contribute to better services and health outcomes. However, there are some issues which might affect the validity of the results and hence require addressing or further justification/clarification.

1 The estimated return rate for the questionnaire appears optimistic. Additional thought as to the use and timing of follow up methods of increasing response rate might be worthwhile.

**Response**

The response rate mentioned (80%) from previous similar research with a similar population was to illustrate that this topic has had reasonable interest from users of equipment in the past despite the challenges for this population (and people generally!) when it comes to written questionnaires. The actual anticipated response rate is 50% from a mail out to 1000 people who meet eligibility criteria and plans for statistical analysis are based on this expectation.

In an effort to maximise response rate there will be 3 mail outs (2 with full questionnaire and one 'reminder card) each a month after the last. Participants will be included in a draw for a \$50 grocery voucher and the university logo will be clearly displayed (to increase credibility of researchers), Respondents can complete the questionnaire on paper, over the telephone, or on an electronic version (survey monkey) and questionnaire can also be completed by proxy. The risks of different methods of

**data collection affecting the nature of data collected is offset by the opportunity to maximise the response rate for this population.**

At present the questionnaire being used in phase one of the research is 13 pages long. While carefully laid out, participant burden should be considered further. Questionnaire fatigue can lead to survey non-completion, poor return rate and hence affect validity of results. Clarifying which variables (at present there are a lot of variables – some of which are closely related) are of most importance might help to decrease the questionnaire length.

**Response**

The comments from this peer reviewer on specific aspects of questionnaire have been taken into account – thank you. The questionnaire has been condensed to 8 pages, (4 pages if double sided) with some 'desirable rather than essential' variables removed and the concern about respondent fatigue is noted. To manage fatigue the number of 'please explain' requests has been kept to the most essential questions, particularly as much more meaningful qualitative data can be collected in Phase 2 interviews rather than in the questionnaire. 2 equipment users (who do not have stroke) have trialled the questionnaire and found that it took 15 minutes to complete. Given the cognitive and comprehension challenges experienced by people with stroke, having a well laid out, if slightly longer questionnaire, may be more advantageous than one which is more tightly spaced and difficult to navigate.

The questionnaire will be trialled with 4-5 people with stroke who are in the community in the next month, where the actual 'time to complete' and cognitive demand for this population will become clearer and help determine the final draft.

Phase two of the research aims to explore/compare experiences by ethnicity. Recruitment of Māori and Pacific island people can be difficult. It is not mentioned in the methodology whether translators/interpreters might be employed and whether whanau or support persons will be welcome. Consideration of these strategies might improve recruitment of these specific groups of people and enable a more meaningful comparison of experiences.

**Response**

Engaging a range of people at all stages of the research is important and I am keen to maximise inclusion of Maori and Pacific island people. Whanau and support people are welcome at both interviews and to support participants with stroke to decide to complete the questionnaire and to ask questions. The use of translators (possibly over the phone) will certainly be considered where and if appropriate.

**24/02/13 – Reviewer response to outlined amendments**

Thank you for your very detailed and considered replies. I believe the justifications you have made in response to my queries are satisfactory. The changes or additions that you have outlined have made the study aim and methodology much clearer and therefore stronger. I wish you all the best with this work.

Kind regards,

  
Dr Meredith Perry

## Appendix E: Consultation with Burwood End-User consultation committee



C/o - The Burwood Academy of  
Independent Living,  
Burwood Hospital,  
Private Bag 4708  
Christchurch,  
New Zealand  
Email: [cuconsult@burwood.org.nz](mailto:cuconsult@burwood.org.nz)  
Phone: +64 3 383 6871

2<sup>nd</sup> June 2, 2013

Dear Miss Boland,

**Re proposal titled: Prescription and management of assistive technology for people with stroke.**

The End User Consultation Committee met with our end-user reference group on May 29<sup>th</sup> 2013 to discuss your research proposal. Your topic was considered very interesting and relevant, and the end-user group could see how your research will benefit those living with stroke. The follow suggestions are not mandatory and do not replace any issues highlighted by other ethical or cultural consultations that this research has been subject to. The Committee asks that you read the following suggestions in good faith and with an open mind.

Comments & suggestions:

- Will participants be followed up by the same DHB in which they were admitted to? Will the follow-up be different in different DHB areas?
- There was discussion regarding your focus on AT that is publicly funded.
  - Does this provide a limited range of AT compared to all AT available on the open market?
  - Does publicly funded AT differ from privately funded AT in terms of quality and effectiveness?
  - Would this potentially influence the outcomes you are exploring?
- The Committee were also pleased to see you are to collect data by proxy in cases of cognitive and/or high-level physical impairment, but asked that you be aware of caregiver family influencing responses.
- Regarding phase 2, will you explore if any participants preferred not to have or use AT, and the reasons why?
- When organising interviews in phase 2, please consider the best time of day for participants in terms of morning routines and possible fatigue.
- Regarding phase 3, a suggestion was made regarding how allied health professionals of different ages may potentially have different opinions and levels of enthusiasm for AT.
- Suggestions regarding potential dissemination include Age Concern, The Association of Occupational Therapists, Physiotherapy New Zealand, Neurological Foundation, and Enable.

We wish you every success in your research and ask that you supply the Committee with a copy of the research findings upon completion.

Yours sincerely,

John Bourke  
Chair  
End User Consultation Committee

Response to Suggestions raised by EU consult group – Pauline Boland, PhD Candidate

- *Will participants be followed up by the same DHB in which they were admitted to? Will the follow-up be different in different DHB areas?*

Yes, I need to make this clearer. Part of the aim of phase one (quantitative) is to compare across DHBs. It is hoped that as part of sampling to maximise diversity, some participants from all DHBs will be represented in Phase 2 interviews/photovoice but this will be somewhat dependent on costs to travel for interviewer.

*There was discussion regarding your focus on AT that is publicly funded.*

- *Does this provide a limited range of AT compared to all AT available on the open market?*

There are 2 points here

1 In some ways, yes. However, as the core question is if public funding for provision of equipment is fit for purpose, questioning for the majority of the questionnaire focuses on publicly funded equipment. Such equipment, by definition, is limited by contracts, approved suppliers and other principles employed by MoH contracted agencies to make their budget go as far as possible for as many as possible (similar to Pharmacs).

2 However, as the first half of the questionnaire focuses on the 'most important item to YOU', this is independent of whether it is publicly funded or not – it may be that a hearing aid or something people made themselves or bought is their most important item and opinions on the most important item and whether or not it was publicly funded can be captured at analysis. Also, this area can and most likely will be explored during qualitative data collection at Phase 2

- *Does publicly funded AT differ from privately funded AT in terms of quality and effectiveness?*

Effectiveness in this particular arena is highly debatable as a construct. Does an increase in safety increase effectiveness of an item or would an increase in control on one's daily life constitute it being effective? For those who I interview who indicate that they have both privately (or lottery etc) funded equipment I can explore this issue further with the qualitative arm of this study!

- *Would this potentially influence the outcomes you are exploring?*

Issues of choice, ability to have things 'tailored' and when that clashes between principles of individualised AND equitable delivery of service are some of the expected themes which will be explored in particular in Phase 2 (qualitative arm).

- *The Committee were also pleased to see you are to collect data by proxy in cases of cognitive and/or high-level physical impairment, but asked that you be aware of caregiver/family influencing responses.*

Agreed. I find this particularly interesting as I have read a lot in favour of using proxy and not using proxy but that on balance, despite the potential for introducing a different voice/perspective, it is worth the effort in order to have the views of people with cognitive or communication difficulties somewhat represented as they are all too often excluded from research. Your thoughts on this are particularly useful to me as I develop protocol around collecting and analysing data from this group, so thank you.

- *Regarding phase 2, will you explore if any participants preferred not to have or use AT, and the reasons why?*

One of the indicators for inclusion in the qualitative arm is people with 'low utility' of AT – this may be because they are trying to live without it, do not like it or do not think it is worth it to their sense of self OR who are not happy with what has been provided through public funding. So yes, it is likely that this group will have some representation.

- *When organising interviews in phase 2, please consider the best time of day for participants in terms of morning routines and possible fatigue.*

Agreed. Every effort will be made to place least inconvenience on participants and maximise their ability to contribute to the process.

- *Regarding phase 3, a suggestion was made regarding how allied health professionals of different ages may potentially have different opinions and levels of enthusiasm for AT.*

I plan to include a population of AHPs with a range of experience, years qualified (not always the same thing!), cultural background and clinical background. Some AHPs identify strongly as equipment providers first and foremost, while other take a different starting point for their intervention – I expect and plan to have a smattering of both in my focus groups and will sample accordingly.

- *Suggestions regarding potential dissemination include Age Concern, The Association of Occupational Therapists, Physiotherapy New Zealand, Neurological Foundation, and Enable.*

Enable are already somewhat involved and are hopefully going to provide me with access to costs (for those who consent for me to find this out). The New Zealand Association of Occupational Therapy have contributed 2,600 towards research costs and will be kept updated throughout, with potential for this research to be presented at the NZAOT organised Asia Pacific Occupational Therapy Conference in Rotorua in 2015. I had not directly considered Age Concern or the Neurological Foundation but will now add them to my list of people to disseminate the results to.



## Appendix F: Participant information sheet and consent form: Phase 1, Questionnaire



### Equipment use after stroke

#### Participant Information Sheet for individuals with stroke and their family

Locality: **X DHB**

Ethics committee ref: **13/NTA/31**

Lead investigator: **Pauline Boland**

Contact phone number: **04 385 5541 ext 6564**

You are invited to take part in a study on how people use the adaptive equipment that they have after they have a stroke. Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason, and it won't affect the care you receive. If you do want to take part now, but change your mind later, you can pull out of the study at any time.

This Participant Information Sheet will help you decide if you'd like to take part. It sets out why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what will happen after the study ends. You may also want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this.

If you agree to take part in this study, you will be asked to sign the Consent Form attached to the questionnaire. Alternatively, if someone else who supports you helps you to participate in this research, they can sign the consent form if this is more appropriate. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep.

#### Why are we doing the study?

Each year many people in New Zealand have a stroke. As part of their rehabilitation, they often use equipment which helps them to do the things that they need to and want to do in their day. Examples of this equipment include walking frames, wheelchairs, seats to raise the toilet height and items to help people to cook and eat. Some people buy equipment while many others get it through the hospital and health service. You are receiving this invitation as you were identified as having a stroke in 2012 by X DHB records.

Health professionals spend a lot of time assessing for and providing equipment for people with stroke, however there is a lack of understanding about what people with stroke do with this equipment and also how they feel about it. To better understand this area of rehabilitation after stroke, we are conducting three phases of information gathering. These phases will be to find out about how people with stroke feel about their equipment; how it affects their life and how the people who organise equipment feel about their role. You are being asked to participate in the first phase of this three part study.

The information gathered will be of use to the people who work in rehabilitation for people with stroke in hospitals and community centres as well as for those who plan policy and services for providing adaptive equipment to people after stroke. This study is being undertaken as part of a PhD which Pauline Boland is completing over the next 3 years through the Rehabilitation, Teaching and Research Unit. This PhD is supervised by Dr William Levack and Dr Fi Graham and is funded by a University of Otago Scholarship. This study has received ethics approval from the Northern A Health and Disability Ethics Committee (Ref no. 13/NTA/31).

#### **What would your participation involve?**

Taking part in the first phase involves completing the questionnaire which you have just received. If the questions apply to you (even if only one or two apply), please complete this questionnaire and return it in the stamped addressed envelope provided. The information gathered with this questionnaire will be used to describe what equipment people are given when they have a stroke and how useful they find the equipment. It will also describe where they got the equipment from and how they found the experience of getting the equipment from the health service (where relevant). Information from this questionnaire will be collected over the next 3 months. If you have any difficulty completing this questionnaire on paper, you are welcome to complete some or all of it over the telephone (speaking to a researcher) or by computer.

For the second phase of this study, a small number of people will be invited to take part in interviews. The interview will be about their experience with equipment that they received after their stroke and the health service which provided the equipment. You can choose (on the consent form) to volunteer to be contacted about this second phase. You do not have to volunteer for the second phase and may only complete the first phase if you wish.

#### **What are the possible benefits and risks to you of participating?**

There are no expected risks to you taking part in this research. You may find the questionnaire tiring. You may find the questionnaire difficult to understand and you can ask someone you trust to help you fill it out. You can also complete the questionnaire by telephone (number at the end of this information sheet). All participants who choose to share their contact details will be entered into a draw for \$50 grocery voucher.

#### **What would happen if you were injured in the study?**

If you were injured in this study, which is unlikely, you would be eligible for compensation from ACC just as you would be if you were injured in an accident at work or at home. If you have private health or life insurance, you may wish to check with your insurer that taking part in this study won't affect your cover.

#### **What are the rights of participants in the study?**

Taking part in this study is entirely voluntary. You are free to decline to participate, or withdraw from the research at any stage, without it affecting your healthcare provision in any way. You have a right to access to the information collected about you as part of this study and a summary of the findings will be made available to you should you want it. All details that could identify you will be removed or changed before any publication or report about this study. Electronic files will be stored in password protected computers. Information on paper

will be stored in a locked filing cabinet for 10 years, after which it will be destroyed, which is the policy at the University of Otago. Only the primary researcher (Pauline Boland) and her supervisors (Dr William Levack and Dr Fi Graham) will have access to your information with your details intact. The information will be used to answer the aims of this study only and your details will not be available to the DHB or health service.

**What will happen after the study ends, or if you pull out?**

The information you supply will be stored at the University of Otago, Wellington for up to 10 years. Electronic files will be protected by a password known only to the researcher and her supervisors. Once all information from the questionnaire has been analysed, a report will be available to anyone who indicates (with a tick) on the consent form that they would like to receive a report AND provides an address (either electronic or postal address). As this study is running for the next 2 years, the results may not be available until the end of 2014.

The results of this study may be published and the results will be available at the University of Otago Library.

**Where can you go for more information about the study, or to raise concerns or complaints?**

If you have any questions, concerns or complaints about the study at any stage, you can contact:

*Name: Pauline Boland, PhD Candidate and Lead investigator*  
*Telephone number: 04 385 5541 ext 6564*  
*Email Pauline.Boland@otago.ac.nz*

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050  
 Fax: 0800 2 SUPPORT (0800 2787 7678)  
 Email: advocacy@hdc.org.nz

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone: 0800 4 ETHICS  
 Email: hdec@moh.govt.nz

If you live in the Wellington area only and would like advice or support about participating in this study from Whānau Care services, please contact

Whānau Care Services, Level 2, New Regional Hospital  
 Riddiford Street, Newtown,  
 Phone (04) 806 0948 Fax (04) 385 5421  
 Email wcs@ccdhb.org.nz



## Equipment use after stroke

Consent form for individuals with stroke and their family

**PLEASE KEEP THIS COPY FOR YOUR OWN RECORDS**

### Declaration by participant (i.e. the person with the stroke):

I have read, or have had read to me in my first language, and I understand the Participant Information Sheet. I have had the opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this study.

I have been given a copy of the Participant Information Sheet and Consent Form to keep.

I consent to the researcher accessing Ministry of Health data so that they can find out how much my equipment costs.

Participant's name: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

**If the person with the stroke needs help with physically signing this consent form (i.e. having someone else sign on their behalf), could the supporting person please complete the following INSTEAD of the section above.**

**THIS BOX CAN BE LEFT BLANK IF THE PERSON WITH THE STROKE HAS BEEN ABLE TO SIGN ON THEIR OWN BEHALF ABOVE.**

### Declaration by person supporting the participant with stroke:

I have read, or have had read to me in my first language, and I understand the Participant Information Sheet. I have had the opportunity to ask questions and I am satisfied with the answers I have received.

I have discussed this study and the Participant Information Sheet with the person with the stroke, whose name is: \_\_\_\_\_ (Insert name here)

This person with the stroke has said they agree to participate in this study. They have been given a copy of the Participant Information Sheet and Consent Form to keep.

The person with the stroke has said they consent to the researcher accessing Ministry of Health data so that they can find out how much the equipment which belongs to them costs.

Support person's name: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

## Appendix G: Participant information sheet and consent form: Phase 2, Qualitative interviews



### Equipment use after stroke

#### Participant Information Sheet for individuals with stroke and their family

Locality: X DHB

Lead investigator: **Pauline Boland**

Ethics committee ref: **13/NTA/31**

Contact phone number: **04 385 5541 ext 6564**

You are invited to take part in a study on how people use adaptive equipment after they have a stroke. You are receiving this letter as you filled in a survey about this topic in 2012 and indicated that you would be willing to be contacted about an interview. Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason, and it won't affect the care you receive. If you do want to take part now, but change your mind later, you can pull out of the study at any time. This Participant Information Sheet will help you decide if you would like to take part. It sets out why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what will happen after the study ends. You may also want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this.

If you agree to take part in this study, you will be asked to sign the Consent Form attached to the questionnaire. Alternatively, if someone else who supports you helps you to take part in this research, they can sign the consent form if this is more appropriate.

#### Why are we doing the study?

Each year many people in New Zealand have a stroke. As part of their rehabilitation they often use equipment; this helps them to do the things that they need to do and want to do in their day. Examples of this equipment include walking frames, wheelchairs, seats to raise the toilet height and items to help people to cook and eat. Some people buy equipment while many others get it through the hospital and health service. You are receiving this invitation as you were referred to the Stroke service in 2012 in X DHB and you completed a questionnaire on this topic and indicated you would be willing to be contacted for a follow up interview.

Assessing for and providing this equipment is what many health professionals working in rehabilitation do, however, there is a lack of understanding about what people with stroke do with this equipment and also how they feel about it. In order to understand this area of rehabilitation after stroke better, we are conducting three phases of information gathering. These phases will be to find out about how people with stroke feel about their equipment, how it affects their life and how the people who organise equipment feel about their role. You are being asked to participate in the second phase of this three part study.

The information gathered will be of use to the people who work in stroke rehabilitation as well as for those who plan policy and services for providing equipment to people after stroke. This study is being undertaken as part of a PhD which Pauline Boland is completing over 3 years through the Rehabilitation, Teaching and Research Unit. This PhD is supervised by Dr William Levack and Dr Fi Graham and is funded by a University of Otago Scholarship. This study has received ethics approval from the Northern A Health and Disability Ethics Committee (Ref no. 13/NTA/31).

**What would your participation involve?**

Taking part in the first phase of this study involved completing the questionnaire which you have done – thank you. The information gathered with this questionnaire will be used to describe what equipment people have when they have a stroke and how useful they find the equipment, as well as how they found the process of getting the equipment from the health service. Information from this questionnaire has been collected over the last 12 months.

For the second phase of this study, a small number of people are being invited to take part in interviews about their experience with equipment that they used after their stroke and the health service which provided the equipment.

You are invited to take part in an in-depth interview with the main researcher, Pauline Boland. This interview can take place at a time and location that suits you and you are welcome to have a support person present. The researcher will ask about what equipment you have. The interview will be different for each person, depending on your equipment and how you feel about the service you received it from. The interviews are not expected to take longer than 40 minutes to complete and they will be recorded and later they will be typed up.

Your interview will be analysed along with the interviews of others who take part. A summary of the findings will be mailed to you to give you the chance to comment on the results, to ensure that the researchers have understood your views.

**What are the possible benefits and risks to you of participating?**

There are no expected risks to you taking part in this research. You may find the interview tiring. All participants who take part in the interview will receive a \$20 grocery voucher to compensate for their time.

**What are the rights of participants in the study?**

Taking part in this study is entirely voluntary. You are free to decline to participate, or withdraw from the research at any stage, without it affecting your healthcare provision in any way. You have a right to access to the information collected about you as part of this study and a summary of the findings will be made available to you should you want it. All details that could identify you will be removed or changed before any report about this study is published. Only the primary researcher (Pauline Boland) and her supervisors (Dr William Levack and Dr Fiona Graham) will have access to your information with your details intact. The information will be used to answer the aims of this study only and your contact details will not be available to the DHB or health service.

**What will happen after the study ends, or if you pull out?**

The information you supply will be stored at the University of Otago, Wellington for up to 10 years. Electronic files will be protected by a password known only to the researcher and her supervisors. Once all information from all three phases of the study has been analysed, a report will be available to anyone who indicates (with a tick) on the consent form that they would like to receive a report AND provides an address (either electronic or postal address). As this study is running for the next 2 years, the results may not be available until the end of 2014. The results of this study may be published and the results will be available at the University of Otago Library

**Where can you go for more information about the study, or to raise concerns or complaints?**

If you have any questions, concerns or complaints about the study at any stage, you can contact:

*Name: Pauline Boland, PhD Candidate and Lead investigator*  
*Telephone number: 04 385 5541 ext 6564*  
*Email Pauline.Boland@otago.ac.nz*

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050  
 Fax: 0800 2 SUPPORT (0800 2787 7678)  
 Email: [advocacy@hdc.org.nz](mailto:advocacy@hdc.org.nz)

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone: 0800 4 ETHICS  
 Email: [hdecs@moh.govt.nz](mailto:hdecs@moh.govt.nz)



## Equipment use after stroke

### Consent form for individuals with stroke and their family

**PLEASE KEEP THIS COPY FOR YOUR OWN RECORDS**

**Declaration by participant (i.e. the person with the stroke):**

I have read, or have had read to me in my first language, and I understand the Participant Information Sheet. I have had the opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this study.

I have been given a copy of the Participant Information Sheet and Consent Form to keep.

Participant's name: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

**If the person with the stroke needs help with physically signing this consent form (i.e. having someone else sign on their behalf), could the supporting person please complete the following **INSTEAD** of the section above.**

**THIS BOX CAN BE LEFT BLANK IF THE PERSON WITH THE STROKE HAS BEEN ABLE TO SIGN ON THEIR OWN BEHALF ABOVE.**

**Declaration by person supporting the participant with stroke:**

I have read, or have had read to me in my first language, and I understand the Participant Information Sheet. I have had the opportunity to ask questions and I am satisfied with the answers I have received.

I have discussed this study and the Participant Information Sheet with the person with the stroke, whose name is: \_\_\_\_\_ (Insert name here)

This person with the stroke has said they agree to participate in this study. They have been given a copy of the Participant Information Sheet and Consent Form to keep.

Support person's name: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_





## Equipment use after stroke

Consent form for individuals with stroke and their family

**PLEASE COMPLETE AND RETURN THIS COPY TO THE RESEARCHER**

### Declaration by participant (i.e. the person with the stroke):

I have read, or have had read to me in my first language, and I understand the Participant Information Sheet. I have had the opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this study.

I have been given a copy of the Participant Information Sheet and Consent Form to keep.

Participant's name: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

**If the person with the stroke needs help with physically signing this consent form (i.e. having someone else sign on their behalf), could the supporting person please complete the following INSTEAD of the section above.**

**THIS BOX CAN BE LEFT BLANK IF THE PERSON WITH THE STROKE HAS BEEN ABLE TO SIGN ON THEIR OWN BEHALF ABOVE.**

### Declaration by person supporting the participant with stroke:

I have read, or have had read to me in my first language, and I understand the Participant Information Sheet. I have had the opportunity to ask questions and I am satisfied with the answers I have received.

I have discussed this study and the Participant Information Sheet with the person with the stroke, whose name is:

\_\_\_\_\_ (Insert name here)

This person with the stroke has said they agree to participate in this study. They have been given a copy of the Participant Information Sheet and Consent Form to keep.

Support person's name: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

**Appendix H: Questionnaire**

# Use of equipment after stroke



Please read the information sheet before completing this survey  
and tick all boxes that apply to you.

### Use of Equipment after Stroke

Did someone help you with this survey?

Yes  No

If yes, how do you know them? (their relationship to you) \_\_\_\_\_

Were you offered any equipment through the health service when you had your most recent stroke?

Yes  No

Do you currently have any equipment?

Yes  No

If you ticked 'no' please **DO complete section 3 and RETURN THE SURVEY** as this is very useful for us to know

### Section 1

**If you have received equipment from the health service, please tell us what equipment you have NOW. Please tick as many as you have.**

- Electric bed
- Hoist
- Wheelchair you or someone else pushes
- Wheelchair with motor (electric)
- Walking frame with wheels and seat
- Walking frame without seat
- Walking stick
- Crutch (es)
- Board for the bath
- Other seat for the bath
- Seat for the toilet
- Frame for the toilet
- Stool for the shower
- Commode chair
- Stool for the kitchen
- Pick up stick
- Trolley for the kitchen
- Special kitchen equipment
- Other (please give details)

### Use of Equipment after Stroke

Did you have any equipment before you had your most recent stroke?

Yes  No

**Have you been given equipment by the health service since your stroke that you no longer use?**

Yes  No

If yes, tell us about why you no longer use the equipment. If there were different reasons for different equipment, please include them all.

**Thinking about the most important piece of equipment you currently have, tell us more about how you got it and why it is useful.**

**Equipment item (write name here) → \_\_\_\_\_**

**How often do you use this equipment?**

Every hour  Every day  A few times a week  Less than once a week

**Does someone else help you so that you can use this equipment?**

Yes  No

**Who paid for this equipment?**

I paid for it myself  The hospital  
 My family bought it for me  ACC

Other (please specify)

**What would happen if you didn't have this equipment?**

*(tick all that are true for you)*

I would feel unsafe  
 I would need more help from others  
 I couldn't live where I am  
 I would get tired more easily  
 I don't know

Other (please describe)

## Use of Equipment after Stroke

**How satisfied are you with all of the equipment you have?**

- Very satisfied  
 Reasonably satisfied  
 Couldn't say either way  
 Dissatisfied  
 Very dissatisfied

**How much do you think that all the equipment you have . . .**

**Increases your safety doing things you need to do?**

- A lot       A little       Makes no difference

**Increases how much control you have doing things when and how you want?**

- A lot       A little       Makes no difference

**Increases your confidence in doing things?**

- A lot       A little       Makes no difference

**Increases how much you can take part in doing things you enjoy?**

- A lot       A little       Makes no difference

**Increases how easy it is for others to help you?**

- A lot       A little       Makes no difference

**Increases your ability to do things without needing help from others?**

- A lot       A little       Makes no difference

## Section 2

This section is for people who got some or all of their equipment **from the health service**. Do not complete if this does not apply to you **BUT** please complete Section 3 we can describe the people who took part in this study.

**Did you receive written information on using any of your equipment?**

- Yes       No

## Use of Equipment after Stroke

**Did you receive a demonstration on using any of your equipment?**

Yes  No

**Would you say that in general your experience of being assessed for equipment by the health service was . . .**

Excellent  Good  Fair  Poor  No opinion

Reasons for answer chosen -

**Would you say that *in general* your experience of being taught to use the equipment has been . . .**

Excellent  Good  Fair  Poor  No opinion

Reasons for answer chosen

**Would you say that *in general* your experience of receiving equipment (quality and delivery of equipment) was . . .**

Excellent  Good  Fair  Poor  No opinion

Reasons for answer chosen

**Do you think that your views and preferences were taken into account by the health professionals giving you the equipment?**

Absolutely  Mostly  A little  Not at all  Don't know

Reasons for answer chosen

**Do you think the health professionals explained options about equipment to you?**

Absolutely  Mostly  A little  Not at all  Don't know

Reasons for answer chosen

### Section 3

So we can describe people doing this survey, tell us about yourself.

Age (in years) \_\_\_\_\_

Gender  Male  Female

**Ethnicity**

- |   |                                  |
|---|----------------------------------|
| <input type="checkbox"/> NZ European        | <input type="checkbox"/> Tongan  |
| <input type="checkbox"/> Māori              | <input type="checkbox"/> Niuean  |
| <input type="checkbox"/> Samoan             | <input type="checkbox"/> Chinese |
| <input type="checkbox"/> Cook Islands Māori | <input type="checkbox"/> Indian  |

Other, please state \_\_\_\_\_

**Current relationship status**

- |  |                                    |
|--|------------------------------------|
| <input type="checkbox"/> Living with partner         | <input type="checkbox"/> Separated |
| <input type="checkbox"/> Married or in a civil union | <input type="checkbox"/> Divorced  |
| <input type="checkbox"/> Single                      | <input type="checkbox"/> Widowed   |

Other, please state \_\_\_\_\_

**Who do you live with?**

- |                                      |  |
|--------------------------------------|--|
| <input type="checkbox"/> With family | <input type="checkbox"/> With my spouse only |
| <input type="checkbox"/> Alone       | <input type="checkbox"/> With a flatmate     |

Other, please state \_\_\_\_\_

**Do you live in a rural or urban area?**

- |                                |                                |
|--------------------------------|--------------------------------|
| <input type="checkbox"/> Rural | <input type="checkbox"/> Urban |
|--------------------------------|--------------------------------|

**Where do you live?**

- |  |  |
|--|--|
| <input type="checkbox"/> In my own home          | <input type="checkbox"/> In rented accommodation |
| <input type="checkbox"/> In a retirement village | <input type="checkbox"/> In a rest home          |
| <input type="checkbox"/> In hospital level care  |  |

Other, please state \_\_\_\_\_





## Use of Equipment after Stroke

Contact Details	
Name	
Address	
Phone Number	
Email	
Date survey completed	

For us to better understand what you liked or did not like about your equipment and the process you went through to get it, we will ask some people to take part in a face to face interview. If you are happy to be considered for such an interview, please tick here.

I would be happy to be contacted about an interview with a researcher about this topic

**THANK YOU** for taking the time to tell us what you thought. Your responses will make this research relevant and meaningful and your time is much appreciated. Again, if you have any queries, do not hesitate to contact me or my supervisors using the contact details in the information sheet.

Kind Regards,

**Pauline Boland BSc (OT) Hons, M(HealSci) Rehabilitation**  
Supervised by Dr William Levack and Dr Fiona Graham

**Please put the completed survey in the addressed envelope supplied and return along a signed copy of the consent form.**

**Appendix I: Cognitive interview prompt questions (adapted from Collins, 2003)**

Think-aloud/general

How did you go about answering that question?

Tell me what you are thinking?

I noticed you hesitated before you answered - what were you thinking about?

How easy or difficult did you find this question to answer?

Why do you say that?

Comprehension

What did the term X mean to you?

What did you understand by the term Y?

Retrieval

How did you remember that?

Did you have a particular time period in mind?

What helped you to remember/ what made it hard?

Confidence judgment

How *well* do you remember this?

How *sure* do you feel about this answer?

Response

What does the term equipment/stroke etc. mean to you?

How did you feel about answering this question?

**Appendix J: ICD-10 codes list**

I610	Intracerebral haemorrhage in hemisphere, subcortical
I611	Intracerebral haemorrhage in hemisphere, cortical
I612	Intracerebral haemorrhage in hemisphere, unspecified
I613	Intracerebral haemorrhage in brain stem
I614	Intracerebral haemorrhage in cerebellum
I615	Intracerebral haemorrhage, intraventricular
I616	Intracerebral haemorrhage, multiple localised
I618	Other intracerebral haemorrhage
I619	Intracerebral haemorrhage, unspecified
I629	Intracranial haemorrhage (non-traumatic), unspecified
I630	Cerebral infarction due to thrombosis of pre-cerebral arteries
I631	Cerebral infarction due to embolism of pre-cerebral arteries
I632	Cerebral infarction due to unspecified occlusion or stenosis of pre-cerebral arteries
I633	Cerebral infarction due to thrombosis of cerebral arteries
I634	Cerebral infarction due to embolism of cerebral arteries
I635	Cerebral infarction due to unspecified occlusion or stenosis of cerebral arteries
I636	Cerebral infarction due to cerebral venous thrombosis, non-pyogenic
I638	Other cerebral infarction
I639	Cerebral infarction, unspecified
I64	Stroke, not specified as haemorrhage or infarction

## Appendix K: Cover letter accompanying questionnaire

DHB letter head

Date

*Participant name*

*Address line 1*

*Address line 2*

*Address line 3*

Dear Sir/Madam

**Re: Equipment use after stroke**

The DHB in <insert DHB name> has identified you as having had a stroke in 2012. Pauline Boland, a Phd student with the Rehabilitation, Teaching and Research Unit with the University of Otago in Wellington is conducting a study, recruiting people with stroke to tell us about the equipment that they got after they had a stroke and how they use it.

You are invited to participate in the first part of this study. This involves a questionnaire, which should take about 15 – 20 mins to complete. You are also invited to express interest in volunteering for the second part of the study which is an in-depth interview.

The aim of this study is to better understand how people with stroke feel about the equipment they use after their stroke. The results will also inform the therapists and funders of this equipment and help to develop the processes and services in relation to equipment.

If you are interested in helping with this study, please read the attached information sheet about the study. If you wish to participate, there are three options available to you.

1. Complete and return the questionnaire in this envelope
2. Contact Pauline Boland via the contact details provided to complete the questionnaire by telephone (you can e-mail if you would prefer that she rang you or ring her and she will ring you right back).
3. You can access the survey at. <https://www.surveymonkey.com/s/FMNNBM6>. The first question of the survey checks that you are satisfied with your understanding of the study and consent to participate. Please note that you can save your on-line questionnaire and return at a later time to complete.

Regardless of your choice to participate in this study, could you please indicate your choice on the attached form and return in the stamped envelope provided. This will let us know whether we can contact you again or not.

This research has received ethics approval from the Northern A Health and Disability Ethics Committee through the Full Review Pathway (Ref no: 13/NTA/31).

If you have any questions about the study, please contact either

Pauline Boland, Research Fellow, RTRU

[Pauline.boland@otago.ac.nz](mailto:Pauline.boland@otago.ac.nz) Phone +64 4 385 5541 extn 6564

Or *<insert DHB contact person's details>*

Thank you in advance for considering this request and assisting with this research.

Kind regards

DHB employee name

DHB employee contact details

**Equipment use after stroke**

I have received the information about this study and DID / DID NOT (please circle) choose to participate. Declining to participate means that you should receive no further correspondence regarding this study

Name \_\_\_\_\_

Date \_\_\_\_\_

## Appendix L: Ethics amendments approvals



Health and Disability Ethics Committees  
 Ministry of Health  
 1 The Terrace  
 PO Box 5013  
 Wellington  
 6011  
 0800 4 ETHICS  
 hdec@mh.govt.nz

30 April 2013

Ms Pauline Boland  
 Rehabilitation, Teaching and Research Unit  
 University of Otago,  
 Newtown, Wellington 6242

Dear Ms Boland

Re:	<b>Ethics ref:</b>	<b>13/NTA/31/AM01</b>
	Study title:	Prescription and management of assistive technology after stroke.

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.

- The first phase of this study involves the mail out of questionnaires to people with stroke in 5 DHBs. For Canterbury and Dunedin (locality assessments currently under negotiation) this mail out will be completed by DHB staff in order to preserve privacy of patient information. As these staff are clinicians who are busy, I propose that when they receive the list of people from patient information services, this list is checked and sent to an administrator working in the School of Medicine in Wellington to complete Mail merge with cover letters to accompany questionnaires. These cover letters are then sent to clinicians to check, sign and post out to patients. I (as primary researcher) would still not see patient details and the spreadsheet with same can be password protected. This would need to happen 3 times as there are 3 mail outs. The administrator in Wellington works with patient details as she supports 4th, 5th and 6<sup>th</sup> year med students and she is familiar with confidentiality protocols. In addition to this amendment to protocol, I would like to notify the ethics committee of two minor changes to the PIS/CF forms for Phase 1. One amendment clarifies why there is request for MOH data regarding equipment cost and the other is a reformatting of the Consent form so that the role of people supporting those to take part is more clear (as recommended by HDEC in their approval letter).

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



Health and Disability Ethics Committees  
 Ministry of Health  
 Freyberg Building  
 20 Aitken Street  
 PO Box 5013  
 Wellington  
 6011

0800 4 ETHICS  
 hdocs@moh.govt.nz

01 April 2015

Ms Pauline Boland  
 Rehabilitation, Teaching and Research Unit  
 University of Otago,  
 Newtown, Wellington 6242

Dear Ms Boland

Re: <b>Ethics ref:</b>	<b>13/NTA/31/AM03</b>
Study title:	Prescription and management of assistive technology after stroke.

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.

The main issues considered by the HDEC in giving approval were as follows.

- The Participant Information Sheet was not uploaded with the consent form.
- The Consent form has two pages of the same consent form.
- In the present state the Consent form is not very clear about the request.

Points for clarification:

1. Please ensure the Participant Information Sheet is uploaded with the Consent Form, particularly in this case as the Consent Form you provided refers to the PIS.
2. A bit puzzling but the Consent Form has two pages of the same consent form. Was this done in error?
3. In the present state the Consent Form is not very clear about the request. Please ensure this is improved.

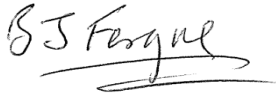
Non-standard conditions must be completed before commencing the changes submitted for your study. Non-standard conditions do not need to be submitted to or reviewed by HDEC before commencing your study. Do not submit non-standard conditions as a post approval form (PAF).

For information on non-standard conditions please see section 128 and 129 of the Standard Operating Procedures at <http://ethics.health.govt.nz/home>.



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

Yours sincerely,

A handwritten signature in black ink, appearing to read "B J Fergus", with a horizontal line underneath.

Dr Brian Fergus  
Chairperson  
Northern A Health and Disability Ethics Committee

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

**Appendix A**  
**Documents submitted and approved**

Document	Version	Date
Covering letter: Cover letter to significant others who supported their partners in interviews asking permission to use their words when reporting on the study	2	03 March 2015
PIS/CF: Consent form for significant others, explicitly about using their words in reports for the whole study.	2	18 March 2015
Post Approval Form	03	18 March 2015

**Appendix B**  
**Statement of compliance and list of members**

Statement of compliance

The Northern A Health and Disability Ethics Committee:

- is constituted in accordance with its Terms of Reference
- operates in accordance with the *Standard Operating Procedures for Health and Disability Ethics Committees*, and with the principles of international good clinical practice (GCP)
- is approved by the Health Research Council of New Zealand's Ethics Committee for the purposes of section 25(1)(c) of the Health Research Council Act 1990
- is registered (number 00008714) with the US Department of Health and Human Services' Office for Human Research Protection (OHRP).

List of members

Name	Category	Appointed	Term Expires
Dr Brian Fergus	Lay (consumer/community perspectives)	01/07/2012	01/07/2015
Dr Karen Bartholomew	Non-lay (intervention studies)	01/07/2013	01/07/2016
Ms Susan Buckland	Lay (consumer/community perspectives)	01/07/2012	01/07/2015
Ms Shamim Chagani	Non-lay (health/disability service provision)	01/07/2012	01/07/2015
Dr Christine Crooks	Non-lay (intervention studies)	01/07/2013	01/07/2015
Mr Kerry Hiini	Lay (consumer/community perspectives)	01/07/2012	01/07/2015
Mr Mark Smith	Non-lay (intervention studies)	01/09/2014	01/09/2015
Ms Michele Stanton	Lay (the law)	01/07/2012	01/07/2015

<http://www.ethics.health.govt.nz>

## Appendix M: Interview schedule

### Interview schedule Users of equipment

Introduction (re-iterate goals of study, re-assure re confidentiality and discuss role of support person (if present) in regards to assisting communication vs contributing their perspective. Discuss audio-recorder, how data will be managed, that I may ask about their questionnaire responses in more detail as well as what they bring up today and answer questions.

Warm up: Tell me about how life has changed since you've had your stroke

#### Equipment

- In your response to my survey you said that you had got the following equipment to help you following your stroke: X,Y, Z etc... Is that correct? Is there any other equipment the you use, of that you have used, that I haven't mentioned in that list?"]
- How long have you had your (*ask about different items mentioned in questionnaire, NEXT QUESTIONS MAY RELATE TO MULTIPLE ITEMS AND HAVE DIFFERENT RESPONSES*)
- Tell me about having a [name of equipment]? (Prompt: how do you use it in your life?)
- Why do YOU think you have/need this equipment?
- What is difficult, if anything about having X equipment?
- If you could change it in any way, what would that be and why? )
- Refer to questionnaire responses, *particularly neg and positive ones of interest*

#### Process

- Can you tell me where you got it from?
- Can you tell me what it was like being assessed for this equipment?
- How did the assessor (nurse/physio/OT) talk about the equipment?
- What other options were discussed with you before you got this equipment?
- Tell me about what do you do if equipment breaks down or you need something different?
- If you could change one thing about the assessment process and the way you received your equipment (delivery, fitting, set up etc), what would it be?
- Refer to questionnaire responses about process, *particularly neg and positive ones of interest*

Wrap up

## Appendix N: Participant information sheet and consent form: Phase 3, Focus Groups



### Equipment use after stroke

#### Participant Information Sheet for Allied Health Professionals

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Locality: X **DHB**

Ethics committee ref: **13/NTA/31**

Lead investigator: **Pauline Boland**

Contact phone number: **04 385 5541 ext 6564**

---

You are invited to take part in a study about people using assistive technology (or adaptive equipment) after they have a stroke. Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason. If you do want to take part now, but change your mind later, you can pull out of the study at any time.

This Participant Information Sheet will help you decide if you'd like to take part. It sets out why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what would happen after the study ends. You may also want to talk about the study with other people, such as family, whānau, friends, or employers and work colleagues. Feel free to do this.

If you agree to take part in this study, you will be asked to sign the Consent Form on the last page of this document. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep.

#### **Why are we doing the study?**

Each year many people in New Zealand have a stroke. As part of their rehabilitation, they often use equipment which helps them to do the things that they need to do and want to do in their day. Examples of this equipment include walking frames, wheelchairs, seats to raise the toilet height and items to support people to cook and eat. Some people buy equipment while many others get it through the hospital and health service. You are receiving this invitation as you are an Allied Health Professional working for X DHB AND you have worked with people who have had a stroke to assess them for, and provide them with, equipment.

Health professionals spend a lot of time assessing for and providing equipment for people with stroke, however there is a lack of understanding about what people with stroke do with this equipment and also how they feel about it. To better understand this area of rehabilitation after stroke, we are conducting three phases of information gathering. These phases will be to find out about how people with stroke feel about their equipment, how it affects their life and how the people who organise equipment feel about their role. The first two phases involved a questionnaire and interviews with people who have had a stroke and who are using equipment. You are being asked to participate in the third phase of this study.

Lay study title: Use of equipment after stroke

Page 1 of 5

PIS version no.:

1

Dated: 2/11/2015

The information gathered will be of use to people who work in stroke rehabilitation, both in hospitals and the community as well as for those who plan policy and services for providing adaptive equipment to people after stroke. This study is being undertaken as part of a PhD which Pauline Boland is completing over the next 3 years through the Rehabilitation, Teaching and Research Unit. This PhD is supervised by Dr William Levack and Dr Fi Graham and is funded by a University of Otago Scholarship. This study has received ethics approval from the Northern A Health and Disability Ethics Committee (Ref no. 13/NTA/31).

#### **What would your participation involve?**

You are being invited to take part in a focus group to share your thoughts and feelings about the role of equipment after stroke. You can be involved in this phase of the study if you are an Allied Health Professional (either an occupational therapist or a physiotherapist) who is involved with people with stroke.

The first two phases involved people with stroke. In the first phase they completed a questionnaire about their use of equipment. A group were then selected who had volunteered to discuss via face to face interviews about the equipment they had, how they used it and how they found the service which provided this equipment.

If you decide to take part in a focus group, the results from these first two phases will be presented to you to discuss what this feed-back from users of equipment means in relation to your practice. It is hoped that you will contribute your thoughts and feelings about how the assessment for and provision of equipment affects your everyday practice. There will also be some broad questions about the role of equipment in rehabilitation after stroke and how (or if) it may be possible to involve the users of equipment in the process of acquiring equipment. The discussion will be reasonably open.

#### **What are the possible benefits and risks to you of participating?**

There are no expected risks to you taking part in this research. You are welcome to bring a support person to this focus group discussion. Morning or afternoon tea will be provided and the results from the first two phases of this study (as well as the eventual results from phase three which you are participating in) will be shared with you. This is an opportunity to reflect on an area of practice which is key to the working lives of many allied health professionals.

#### **What are the rights of participants in the study?**

Taking part in this study is entirely voluntary. You are free to decline to participate, or withdraw from the research at any stage, without it affecting your healthcare provision in any way. You have a right to access to the information collected as part of this study and a summary of the findings will be made available to you should you want it. All details that could identify you will be removed or changed before any report about this study is published. A typist (who will type up the recorded group discussions) will have access to the information you provide but he or she will sign a confidentiality agreement.

Electronic files will be stored in password protected computers. Information on paper (transcripts of focus groups) will be stored in a locked filing cabinet for 10 years, after which it will be destroyed, which is the policy at the University of Otago. Only the primary researcher (Pauline Boland) and her supervisors (Dr William Levack and Dr Fi Graham) will

have access to your information with your details intact. The information will be used to answer the aims of this study only and your contact details will not be available to the DHB or health service.

**What will happen after the study ends, or if you pull out?**

The information you supply will be stored at the University of Otago, Wellington for up to 10 years. Electronic files will be protected by a password known only to the researcher and her supervisors. Once all information from the questionnaire has been analysed, a report will be available to anyone who indicates (with a tick) on the consent form that they would like to receive a report AND provides an address for us to send it to (either electronic or postal address). As this study is running for the next 2 years, the results may not be available until the end of 2014. The results of this study may be published and the results will be available at the University of Otago Library

**Where can you go for more information about the study, or to raise concerns or complaints?**

If you have any questions, concerns or complaints about the study at any stage, you can contact:

*Name: Pauline Boland, PhD Candidate and Lead investigator*  
*Telephone number: 04 385 5541 ext 6564*  
*Email Pauline.Boland@otago.ac.nz*

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050  
 Fax: 0800 2 SUPPORT (0800 2787 7678)  
 Email: advocacy@hdc.org.nz

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone: 0800 4 ETHICS  
 Email: hdec@moh.govt.nz



## Equipment use after stroke

### Consent Form for allied health professionals – Copy for your records

#### **Declaration by participant:**

I have read, and understand the Participant Information Sheet. I have had the opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this study.

I have been given a copy of the Participant Information Sheet and Consent Form to keep.

Participant's name: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_



## Equipment use after stroke

### Consent Form for allied health professionals – Copy for Researcher

---

**Declaration by participant:**

I have read, and I understand the Participant Information Sheet. I have had the opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this study.

I have been given a copy of the Participant Information Sheet and Consent Form to keep.

Participant's name: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_



## Appendix O: Focus group schedule

### Schedule for Focus Groups – Allied Health Professionals

#### Intro

#### Warm up

When I say 'equipment' give me some words that come to mind?

Tell me about the **types of equipment** you give people after stroke?

How do you decide who gets what? What influences this decision?

Do you think you **can predict who may need equipment** long term and/or short term?

*(my data so far suggests you can't, apart from age – tie into ideas about transition time and not knowing what you'll need until you are home) How do you feel about that?*

What do **you think these devices do** for people (*safety, choice etc*).

*People who I've spoken to have nominated their mobility aid as their most important item – what do you think about that?*

How do you feel when **clients modify or purchase their own equipment?** (*many do and value their own tailoring/input to the thing*). Based on analysis of interview data

Which do you think (*safety, choice, participation*) you **consider most important or relevant when assessing this group** (may vary across setting).

*People I've spoken to have talked a lot about valuing being able to access the world outside their house as well as be safe inside their house – what do you think about that (in relation to system)*

What teaching skills (if any) do you use when educating people on using their equipment

Are there some people you spend more/less time doing training with and why?

**When/where do you experience conflicts about equipment provisions (in your own clinical reasoning, with patients, with the system?).**

**Do you think there are any cultural issues at play here – if so give examples, if not, fine.**

Can you give me (*OR 'thinking about' if examples given*) some **examples of such conflicts** and how you resolved them (or not)

Do you think you consult the people with stroke using AT?

(Are able to as much as you would like, give them choice/s)

If so, **how** do you do consult?

If not, **why not?**

If there was one thing about the process of assessing for AT you could change what would it be?

If there was one thing about the process of equipment provision (wider system), what would it be?

Wrap up

**If it hasn't come up prompt re**

Trials –organising choice when limited by time

Where/how does the system support and constrain the **choices available to you** as a clinician?

Where **does the family fit in** – when/with whom do you focus your efforts on training people using equipment?

## Appendix P: Form for demographic details for therapists

### Allied Health Professional Data Collection

Age (in years)	
Gender	
Ethnicity	
Qualification	
Year first qualified	
Country where qualification received	
Working with people with stroke	Please circle CURRENT / PREVIOUS  <u>Years</u> working with people with stroke -
Hours per week employed	

**Appendix Q: Early qualitative analysis based on free text data**

Effective equipment services offer guidance on equipment choice and tailored instruction	
Relationship with, and trust in, therapist was important for shared decision making	Ownership of decision making varied according to client ability and interest
<p>‘Not necessary to explain options, I was given what they (therapists) thought I needed.’</p> <p>‘They (therapists) made sure everything was suitable for my needs.’</p> <p>‘The physio helped me a lot with selecting the right mobility scooter for me.’</p> <p>‘They let me choose one just for me after several trials.’</p> <p>‘They listened and understood.’</p> <p>‘They were prompt to phone and just as prompt to come and assess what was needed.’</p> <p>‘Occ Therapists/Physiotherapists were very</p>	<p>‘As I have basic/fundamental equipment there wasn't the need for in-depth knowledge/teaching/preference of these items.’</p> <p>‘I was on the move with equipment from the moment I could get out of bed. I have never been a slacker and the state I was in as a stroke victim didn't go down well with me.’</p> <p>‘Wasn't aware of equipment order. Possibly wouldn't have understood at the time after severe stroke.’</p> <p>‘I just consented to what they thought I needed.’</p> <p>‘If the client was always fully given their preferences they might not end up as well off (given their depressed state at the time).’</p>

Effective equipment services offer guidance on equipment choice and tailored instruction	
Relationship with, and trust in, therapist was important for shared decision making	Ownership of decision making varied according to client ability and interest
<p>helpful and competent.’</p> <p>‘Great people with good knowledge of what was needed.’</p> <p>‘OTs and PTs were all skilled teachers.’</p>	<p>‘Can’t remember, nothing to complain about.’</p> <p>‘I can’t remember the assessment as I got very ill and that period of my life is hazy.’</p> <p>‘I fully understood without being told.’</p>

**Appendix R: Syntax conventions for extracts**

The transcripts for this study reflected as closely as possible the actual words and speech patterns of the interview participants. Interview extracts have been edited to illustrate points for the purposes of this paper, but all editing has occurred with the intent of retaining the original meaning of the speech. Ellipses ( ... ) have been used to indicate where speech was omitted. Square brackets [ ] were used to insert editorial notes or words not present on the audiotape. Rounded brackets ( ) were used to indicate where nonverbal sounds such as laughter occurred on tape. Em dashes (–) were used in the place of hanging phrases resulting in an incomplete sentence, interruption by another speaker, or where the speaker made a meaningful pause.