# Walking for wellbeing after stroke:

# Building a treatment theory

# to improve

# real-world walking

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> *To the One in whom we live and move and have our being, who came to bring light to the darkness, hope to the hopeless, freedom to the captives-guide us on our path to knowledge and direct our steps.*
>
> *In the name of the Father, the Son and the Holy Spirit*
>
> *Amen*
>
> *Ki a ia, e ora nei tātou i a ia, e haere nei tātou i a ia, tō tātou tino kaitiaki, i haere mai nei ki te kawe mai i te mārama ki te pouri, i te tumanako ki te hunga i te hākerekeretanga o ngā whakaaro, ki te whakawātea hoki i ngā herehere.  Kia tiaho mai tōu māramatanga ki te ara e tae ai mātou ki te mātauranga, arahina hoki ō mātou hikoiranga katoa.*
>
> *I te ingoa o te Matua, o te Tama, o te Wairua Tapu.*
>
> *Āmene*

# Contents

# List of Abbreviations

| | |
|---|---|
| **AM** | Autonomous Motivation |
| **ASCQ** | Ambulatory Self-confidence Questionnaire |
| **BREQv2** | Behavioural Regulation of Exercise Questionnaire Version 2 |
| **CM** | Controlled Motivation |
| **CMO** | Context-Mechanism-Outcome |
| **CSD** | Clinically Significant Difference |
| **HEP** | Home Exercise Programme |
| **ICF** | International Classification of Functioning, Disability & Health |
| **LEAPS** | Locomotor Experience Applied Post-Stroke |
| **MDC** | Minimum Detectable Change |
| **MRC** | Medical Research Council |
| **PWS** | Person with Stroke |
| **SIPSO** | Subjective Index of Physical and Social Outcomes |
| **SMD** | Standardised Mean Difference |
| **SRHBAI** | Self-Report Habit Index- Automaticity Index |
| **NEADL** | Nottingham Extended Activities of Daily Living |

# List of Figures

# List of Tables

# Abstract

This thesis explored ways to enable people with stroke to walk more in the real-world. The starting point for this work was the lack of sustained change in real-world walking following clinic-based interventions after stroke. This lack of translation of gains from physical training into real-world settings is known as a lack of carryover. As recommended by the Medical Research Council guidelines, this thesis employed both quantitative and qualitative methods to iteratively develop an understanding of the likely change process behind sustained change in real-world walking after stroke. Informed by a realist research philosophy, I developed a treatment theory to propose specific intervention components; contextual factors; mechanisms of action; and desired outcomes to address this clinical problem. First, this thesis aimed to determine the effectiveness of current interventions and whether benefits were sustained. Second, it aimed to clarify what real-world walking meant to people with stroke and how they thought it could be better. Third, it sought to build a treatment theory and operationalise this theory into an intervention. Finally, it evaluated the intervention to clarify the processes needed to produce carryover.

The systematic review in Phase 1 showed sustained change in real-world walking was possible but certain key components appeared important: collaborative goal planning and context specific training. The qualitative enquiry in Phase 2 found walking in the real-world was a demanding but inherently motivating activity that required significant concentration. Data analysis in Phase 3 indicated active ingredients behind the process of carryover included planning, automaticity, mastery, and normalisation mechanisms. Based on the principles of self-determination theory, the intervention appeared to produce a virtuous cycle of confidence building for some participants that produced gains in physical and social integration through mechanisms of motivational transfer. A key contribution of this thesis is the elucidation of learning-related mechanisms behind sustained change. Three mid-range theories were identified: Control Theory, Self-Determination Theory and Normalisation Process Theory. Collectively these theories helped to explain study findings in Phase 3 and how each of the intervention components worked.

In conclusion, this thesis provides support for the importance of self-regulated learning in promoting sustained change in real-world walking. This arguably should prompt a rethinking of current physiotherapy interventions for walking after stroke. Interventions that use collaborative planning, context specific training and caring connections appear to contain the active ingredients needed to build confidence and create carryover, to help people with stroke walk more, and keep on walking.

# Chapter 1  Introducing the research

## 1.1  Background

This research introduces and explores the concept of *real-world walking* within the context of physiotherapy interventions for community-dwelling stroke survivors. Evidence is mounting that walking regularly is likely to produce notable long-term benefits in body and brain health after stroke (Billinger et al., 2014; Cumming, Tyedin, Churilov, Morris, & Bernhardt, 2012; Towfighi, Markovic, & Ovbiagele, 2012). However gains in walking ability from clinic-based interventions do not necessarily translate to sustained change in real-world walking (Ada, Dean, & Lindley, 2013; Duncan et al., 2011; Mudge, Barber, & Stott, 2009; Pang, Eng, Dawson, McKay, & Harris, 2005).

This thesis starts with two key assumptions. First, optimal interventions to improve walking need to help people with stroke integrate gains in walking skill into their usual daily routines in order to produce change that is sustainable. Second, those tasked with improving interventions need an in-depth understanding of *how* particular intervention components can produce change and the underlying mechanisms of action responsible (Davidoff, Dixon-Woods, Leviton, & Michie, 2015).

My interest in this topic can be traced to the findings of a previous PhD study (Mudge, 2008). That study aimed to improve usual walking after stroke using a clinic-based exercise programme. The intervention produced small gains in walking endurance when measured in the clinic using routine clinical measures in line with the author's expectations. Mudge also measured real-world walking using an activity monitor. Unexpectedly, and despite gains in walking endurance for the intervention group, no change in usual walking was reported. Over the next three months, even the small gains in walking endurance dissipated. I remember my dismay and disappointment at the findings. I asked myself: "why did the observed clinical changes not carry over into sustainable real-world change?These findings challenged my assumption about how physiotherapy worked, and I started to wonder how physiotherapists could optimise the real-world impact of physiotherapy interventions.

In response to these questions, I commenced this PhD with the goal of developing a theoretically informed and practically effective intervention that could lead to sustained change in usual walking for stroke survivors. However it soon became clear that although there was considerable literature on the effectiveness of rehabilitation following stroke, there appeared to be limited engagement with theory on the relevant change processes (Wade, 2005, 2015; Whyte, 2008). Again, there is an extensive body of literature on walking after stroke, but there is limited theoretical explanations about how physiotherapy interventions can actually lead to any changes in real-world settings let alone sustained change in real-world-walking behaviours (Barclay, Stevenson, et al., 2015; Pollock et al., 2014). It would seem most applied health research, including the field of rehabilitation, has focused on whether something works, not *how* it works (Lipsey, 1993; Siegert, McPherson, & Dean, 2005).

Existing treatment theories that do attempt to explain how physiotherapy interventions work to improve walking after stroke are drawn from the exercise sciences and focus on progressive overload and motor skill learning (Carr & Shepherd, 2010; Shumway-Cook & Woollacott, 2012); or the neurosciences and focus on use-dependent neural plasticity (e.g. Dobkin, 2009; Kleim & Jones, 2008; Kreisel, Hennerici, & Bazner, 2007). Much of the research informing these fields is undertaken in controlled indoor settings such as clinics or gyms. These existing treatment theories explain how gains in strength, endurance and skill may improve motor skills through short term physiological adaptations (Adkins, Boychuk, Remple, & Kleim, 2005), however, they provide little insight for physiotherapists keen to promote sustained changes in real-world walking behaviours. This omission has the potential to significantly limit the real-world impact of physiotherapy interventions.

Rehabilitation interventions have been described as complex interventions with many interacting ingredients or components (Wade, 2005, p. 811). Trying to understand how these ingredients work together has been likened to trying to peer into a black box (Lipsey, 1993; Whyte & Hart, 2003). This analogy explains the situation where little is known about which ingredients really matter (i.e. the active ingredients) and how these ingredients interact with each other and work

together to create change. In order for physiotherapy interventions to produce sustained change in walking behaviours, the problem of inactivity after stroke needs to be more clearly understood and a coherent explanation of the underlying processes behind sustained change developed (Medical Research Council, 2006).

For people with stroke, walking is the most preferred type of exercise and is essential to reengagement in personally valued activities (Robison et al., 2009; Simpson, Eng, & Tawashy, 2011). Walking is also accessible and due to its familiarity, likely to be relatively easier to integrate into daily routines than other types of physical activity such as gym attendance or structured exercise programmes (Aarts, Paulussen, & Schaalma, 1997; Lee & Buchner, 2008). Helping stroke survivors become more active, by changing their daily walking habits and routines, could provide long term gains in mobility. This thesis aims to construct a treatment theory that can be used to inform future interventions on ways to support sustained change in real-world walking behaviours. To this end it will identify the active ingredients behind this process so that clinicians can select the correct intervention components for the right reasons thus optimising the real-world impact of physiotherapy interventions for walking after stroke.

## 1.1   Definition of real-world walking

In this thesis *real-world walking* is viewed as a subset of other types of physical activity behaviours (Michie & Johnston, 2012). The term "behaviour" describes "activities a person does in response to internal or external events" (Michie, Atkins, & West, 2014, p. 234). Figure 1 describes the relationship between physical activity, exercise and real-world walking behaviours. Real-world walking refers to *actual walking in usual settings*. This definition was developed to overcome the conceptual ambiguities and related measurement difficulties of the various walking-related terms identified in the rehabilitation literature (these are discussed further in Chapter Eight in section 8.2.3). Walking behaviours include walking for exercise or transport as well as incidental walking during daily activities. Real-world walking is the walking a person actually does rather than the walking he or she has the physical capacity to do (Holsbeeke, Ketelaar,

Schoemaker, & Gorter, 2009; World Health Organisation, 2002). It involves locomotor movement of the legs, habitually occurs during daily routines and takes place in a person's usual environmental settings.

In addition, real-world walking typically has the following features:

- It occurs in a range of environmental contexts, from own homes or residential settings to out and about in various community venues.
- It requires a range of walking patterns for a variety of purposes. Such patterns include turns and transitions that occur during incidental walking (e.g. during housework, or for transportation); and walking for leisure or exercise. It may include running or stair climbing because these are locomotor activities. The definition does not include physical activity behaviours that are not part of locomotion (e.g. Tai Chi); nor activities that primarily use external objects for transport (e.g. biking or using a wheelchair); nor activities which use both arms and legs for propulsion (e.g. swimming).
- It is measured through the use of activity monitors or appropriate self-report measures. The latter focus on real-world walking activities and record walking that has actually occurred. They are likely to include the phrase, "how often do you?" in the question. Outcome measures that ask, "can you?", "how difficult?" or "how much assistance?" are not considered a measure of actual walking behaviour but reflect instead perceptions of difficulty and/or the amount of assistance required.

Figure 1. Relationship between physical activity, exercise and real-world walking

## 1.2 Research questions

This research aimed to address a clinical problem; walking inactivity following stroke. It sought to develop theoretical and empirical support for a treatment theory to help people with stroke walk more by guiding physiotherapists in ways they can support their clients integrate gains in walking skills into daily routines. The specific questions were:

1. How effective are current interventions at improving real-world walking and can benefits be sustained? (Phase 1: Systematic Review - see Chapter Four).

2. What does real-world walking mean to people with stroke and how do they think it could be improved? (Phase 2: Qualitative Enquiry - see Chapter Five).

3. How can physiotherapists intervene to support sustained change in real-world walking behaviours? (Phase 3a: Building Treatment Theory - see Chapter Six).

4. What is the potential for impact of a theoretically-informed intervention? If it appears to work, how and why does it work? Did the expected mechanisms of action operate? Were there any unexpected mechanisms of

action? What features of context prevented anticipated mechanisms of action from being activated? (Phase 3b: Refining the treatment theory - see Chapter Seven).

## 1.3 Thesis structure

This mixed methods thesis is divided into four parts - an introductory section (Chapters Two and Three) and three phases of research (Chapters Four to Seven). Chapter Two sets the scene for this project by analysing the problem of walking inactivity after stroke and provides the context for the research in later phases. In Chapter Three, drawing on the recommendations of the Medical Research Council (MRC) for the development of complex interventions (Medical Research Council, 2006), a systematic and phased approach is detailed. In the first of the three phases of research, Phase 1 was a systematic review which examined the effectiveness of current interventions on real-world walking (Chapter Four). Phase 2 was an inductive qualitative study which provided insights on the perspectives of people after stroke toward real-world walking (Chapter Five). Phase 3 involved the iterative development and refinement of a treatment theory for improving real-world walking after stroke which was then operationalised into an intervention and evaluated (Chapters Six and Seven). This third phase used a realist lens and case study methodology to identify likely active ingredients by considering the relationship between contextual features, mechanisms of action and outcomes. Throughout this thesis and particularly in Chapters Six and Seven, tables were used to communicate key information relating to intervention development and, where appropriate, particularly lengthy tables were included as appendices rather than embedded in the text. In Chapter Eight, I revisit the original aims of the research, discuss the findings of the project as a whole, consider the strengths and limitations of the research and explore the application of the findings to rehabilitation interventions to improve real-world walking after stroke.

# Chapter 2  Setting the scene

The purpose of this chapter is to set the scene for the research that follows and inform the intervention development process by identifying pertinent factors influencing walking inactivity after stroke. I examine the clinical problem of walking inactivity after stroke and explore possible reasons for this inactivity. Then I discuss the potential benefits and challenges of walking more in the real-world and the distinctive features of real-world walking behaviours. Finally, I examine how researchers and clinicians have previously tried to address this problem.

This narrative review drew on literature identified through a broad search strategy that sought to identify all literature relevant to real-world walking behaviour and related interventions following stroke. In the absence of literature specific to stroke, research exploring real-world walking in healthy and/or older adult populations was also drawn on where appropriate. Likewise, literature relevant to the broader context of physical activity was considered where evidence specific to real-world walking was not available. Appendix A provides examples of the search terms used.

## 2.1  Walking inactivity after stroke

Research suggests most stroke survivors are relatively inactive (English, Manns, Tucak, & Bernhardt, 2013; Paul et al., 2016; Rand, Eng, Tang, Jeng, & Hung, 2009; Roos, Rudolph, & Reisman, 2012; Tieges et al., 2015) even when compared to others with chronic conditions (Tudor-Locke, Washington, & Hart, 2009). A comprehensive  review by English et al. (2013) found the average stroke survivor takes 50% less steps per day than others their age. Activity counts for healthy people fall between 6000-8000 steps per day (Tudor-Locke et al., 2011). Those with chronic conditions usually take between 3500-5,500 steps, and people with stroke consistently fall at the lowest end of this range (English et al., 2013; Tudor-Locke et al., 2009). The way people with stroke structure their day seems to differ (Paul et al., 2016; Roos et al., 2012). For example, activity profiles of healthy older adults often show an active period in the morning and again in the afternoon whereas people with stroke tend to have just a single active period (typically in

the morning) with prolonged uninterrupted periods of sitting in the afternoon and evening. This may partly explain the low number of daily steps. One study found community dwelling stroke survivors spent almost three more hours per day sedentary (e.g. sitting or lying) than control participants (Paul et al., 2016). This pattern of uninterrupted inactivity does not seem to change throughout the first year after stroke (Tieges et al., 2015). Not only do people with stroke take less steps, they also seem to walk less often and sit for longer than others the same age.

Adaptive biological responses to prolonged sitting after stroke include alterations to the structure of muscle leading to increased proportion of fat and alteration of muscle fibre type (Ivey, Macko, Ryan, & Hafer-Macko, 2005). These changes mean leg muscles become more prone to fatigue, which leads to less efficient walking patterns (Kramer, Johnson, Bernhardt, & Cumming, 2016). Other consequences of inactivity include changes to the cardio-respiratory, metabolic and inflammatory systems leading to reduced physical fitness (Billinger, Coughenour, Mackay-Lyons, & Ivey, 2012; Ivey et al., 2005). Evidence for adaptive cognitive changes after stroke are still emerging (Cumming, Marshall, & Lazar, 2013; Cumming et al., 2012) but there is substantial support for the deleterious impact of physical inactivity on cognitive functioning for older adults (Daly, McMinn, & Allan, 2015; Lista & Sorrentino, 2010; Sofi et al., 2011). Adverse physical and cognitive adaptive changes due to an inactive lifestyle are likely to influence walking disablement after stroke.

### 2.1.1 Exploring reasons for walking inactivity after stroke

Walking inactivity and, by extension, walking disablement are likely due to a range of physical, cognitive, emotional, social and environmental factors (Barclay, Ripat, & Mayo, 2015; Barnsley, McCluskey, & Middleton, 2012). Such factors can include, (but are not limited to): reduced physiological reserve (Ivey et al., 2005), loss of executive functioning affecting cognition (Cumming et al., 2013), a loss of confidence (Horne, Lincoln, Preston, & Logan, 2014), fear of adverse events (Lord et al., 2004), fatigue (Choi-Kwon & Kim, 2011), and environmental barriers such as the overly protective attitudes of others (Barnsley et al., 2012; Pound, Gompertz,

& Ebrahim, 1998). It is likely these factors interact (Glouberman & Zimmerman, 2002; Shiell, Hawe, & Gold, 2008).

Table 1. Comparison of different perspectives to understanding walking disablement

| Discipline | Dominant/ significant theoretical framework(s) | Primary explanation for walking inactivity after stroke |
|---|---|---|
| **Physiotherapy** | Biomedical<br>Biomechanical<br>Biopsychosocial | Focuses primarily on direct and indirect impairments (usually biological) after stroke and how these affect walking patterns (e.g. Carr & Shepherd, 2011; Mayo, et al., 1999) |
| **Health Psychology** | Behavioural | Focuses primarily on behavioural (observable) outcomes and cognitive processes influencing decisions to be active (e.g. Dixon & Johnston, 2008) |
| **Disability studies** | Ecological models | Focuses on contextual factors such as social attitudes and features of the built environment that affect accessibility (e.g. Garcia et al., 2015; Heinemann et al., 2015) |

A variety of theoretical perspectives can be used to explain walking inactivity. To illustrate this variety, Table 1 compares three different schools of thought on walking disablement. One perspective, common to the profession of physiotherapy (Nicholls & Gibson, 2010; Wade, 2015), explains walking disablement by focusing primarily on the impact of physical impairments after stroke (e.g. Carr & Shepherd, 2011; Mayo et al., 1999). Other professions, like health psychology, tend to focus more on the impact of cognitive processes influencing decision making processes (e.g. Dixon & Johnston, 2008; Rhodes & Nigg, 2011). An ecological perspective focuses on the interaction between the person and the environment and the way that context enables or constrains walking (e.g. Heinemann et al., 2015; Magasi et al., 2015; Noreau & Boschen, 2010). An alternative perspective is the realist perspective which views individuals as comprising open, nested systems in which each layer interacts with other layers and the environment in synergistic and unexpected ways (Bhaskar & Danermark, 2006; A. M. Clark, Lissel, & Davis, 2008; Westhorp, 2012). A realist perspective considers that regardless of the personal characteristics (e.g. biological or cognitive processes) or the circumstances related to the context (i.e. the physical

or social environment), it is the response of the individual which is most significant. In relation to walking specifically, a realist view focuses on how an individual responds to personal and environmental factors and how this response influences decisions to walk in the real-world (Pawson & Tilley, 1997; Yen, Flood, Thompson, Andersen, & Wong, 2014).

Different perspectives emphasise different facets of the problem of walking inactivity after stroke. During preparation of this review I read literature from various sources while always keeping my focus on the desired outcome: sustained change in walking behaviour. In presenting this literature review, I have opted to present the key factors that appeared most relevant from that reading to understanding this problem. In the final section, I discuss how each of these factors interacts using a complexity perspective to explain walking inactivity. (See section 2.1.1.6 ).

### 2.1.1.1 What is the likely impact of physical impairments on real-world walking after stroke?

One explanation for walking inactivity after stroke is it is directly related to the severity of motor impairments, meaning individuals with less impairments (and therefore greater physical ability) are more active than those individuals with more significant motor impairments (Carr & Shepherd, 2011; Robinson, Shumway-Cook, Matsuda, & Ciol, 2011). However, this assumption is challenged by research which compares levels of walking ability (measured by gait speed) with actual daily walking habits (measured with an activity monitor and/or self-report measures). Such research consistently shows stroke survivors who can walk at near normal speeds are as inactive as those with less ability (Danielsson, Meirelles, Willen, & Sunnerhagen, 2014; Fulk, Reynolds, Mondal, & Deutsch, 2010; Mudge & Stott, 2009; Rand et al., 2009). The consensus from these studies is, regardless of the level of motor impairments, stroke survivors are persistently inactive.

There is, however, a significant mismatch between the walking endurance of most stroke survivors and the demands of real-world settings. For example, sufficient walking endurance to manage distances around 400-1000m is necessary to complete essential activities like shopping in a supermarket and collecting

medication from a pharmacy (Brown et al., 2010; Mudge & Monacchio, 2013). One Canadian study (Mayo et al., 1999) followed up over 300 rehabilitation recipients at one year post-stroke. Of the 90 individuals who had not died or were not in institutional care, only 20 could walk continuously for six minutes. The average distance walked by those who could complete the walk test was 250m which suggests they had insufficient levels of walking endurance to meet the demands of the real world.

The degree of effort required to complete an activity depends on the physical capability of the person in relation to the demands of the activity; a concept called physiological reserve (Dishman et al., 2006; Owen, Humpel, Leslie, Bauman, & Sallis, 2004). When working at the limits of one's physiological reserve, people experience significant fatigue and discomfort, similar to what is experienced by healthy individuals during a long distance race (Ivey et al., 2005). Kramer et al. (2016) examined energy expenditure after stroke and found inside walking required high levels of energy expenditure. It is possible this additional effort was due to the loss of walking efficiency and adaptive biological changes evident following stroke (Billinger et al., 2012; Ivey et al., 2005). If strolling indoors requires a moderate level of intensity for people with stroke, walking longer distances or at a faster pace needed to walk effectively in community settings is likely to be even more strenuous and demanding. Further, the unpleasant symptoms experienced when working at the limits of physiological reserve may undermine motivation and may discourage future attempts at walking (Rand et al., 2009; Resnick et al., 2008). After stroke, walking outdoors is likely to be effortful and unpleasant because the challenges of real-world settings often exceed the physical resources survivors have available to them.

### 2.1.1.2 What is the likely impact of cognitive impairments on real-world walking after stroke?

Surveys of the prevalence of cognitive impairments after stroke estimate between 15-75% of survivors have some degree of difficulty with executive functioning which includes difficulties with information processing and attention (Cumming et al., 2013; Sun, Tan, & Yu, 2014). Real-world walking can be negatively impacted by cognitive impairments leading to poor evaluation of risks, lack of self-

awareness leading to careless walking and reduced drive to initiate activity; these factors can adversely affect decision making (Yogev-Seligmann, Hausdorff, & Giladi, 2008). The reciprocal and interacting relationship over time between executive functioning and levels of physical activity is now established with longitudinal research showing poor executive functioning predicts future reduction in physical activity for older adults (Daly et al., 2015; Sofi et al., 2011). Similar findings are still emerging in the stroke literature (Cumming et al., 2012). Reduced drive to initiate walking stemming from a loss of executive functioning may lead to a loss of opportunities to walk which, in turn, could compromise cognitive abilities even further.

In addition to the physical demands, the cognitive demands of walking outdoors may be significant (Lord & Rochester, 2007; Yogev-Seligmann et al., 2008). While walking several hundred metres to a shop, an individual is likely to encounter a number of obstacles such as curbs, slopes, foot or vehicular traffic and other environmental demands (Patla & Shumway-Cook, 1999; Yogev-Seligmann et al., 2008). Appropriate recognition of such obstacles requires continuous monitoring of visual input and the ability to selectively direct and divide attention (Lord & Rochester, 2007; Patla, 1997). Appropriately responding to obstacles requires the ability to flexibly adapt walking patterns such as lifting the foot to aid clearance, alternate foot placement, adjusting force propulsion or steering out of the way of anticipated obstacles (Patla & Shumway-Cook, 1999; Yogev-Seligmann et al., 2008). The cognitive ability to attend to at least two tasks simultaneously, such as scanning the environment for street signs while coping with obstacles, can be compromised with age and following neurological impairment (Beurskens & Bock, 2013; Smulders, van Swigchem, de Swart, Geurts, & Weerdesteyn, 2012). The cognitive challenges encountered walking in the real-world are likely to exceed the available cognitive capabilities of many stroke survivors; this is likely to create hesitancy when deciding whether to walk or not in the real-world and anxiety when doing so (D. J. Clark, 2015).

### 2.1.1.3  What is the likely impact of fatigue on real-world walking after stroke?

Limited energy provides a further explanation for walking inactivity after stroke. Post-stroke fatigue can contribute to additional unpleasant symptoms during

activity (Staub & Bogousslavsky, 2010). Post-stroke fatigue is a complex, disabling and poorly understood feature following-stroke (Choi-Kwon & Kim, 2011) and is likely to include both physical, cognitive and emotional factors. It is common with 1/4 to 3/4 of stroke survivors experiencing problems with fatigue (Choi-Kwon & Kim, 2011). There are various definitions of fatigue including "a feeling of early exhaustion developing during mental activity with a weariness, lack of energy and aversion to effort" (Staub & Bogousslavsky, 2010, p. 75). Coping with fatigue after stroke is difficult for stroke survivors and requires many to adjust their expectations of what they can achieve each day (Robison et al., 2009). Post-stroke fatigue may be a significant and unappreciated reason why even those with adequate physical ability choose to walk less often.

### 2.1.1.4   What is the likely impact of emotional and other psychosocial factors on real-world walking after stroke?

Experiencing a stroke produces a psychosocial crisis (Kirkevold, Bronken, Martinsen, & Kvigne, 2012). Qualitative studies examining adaptive processes following stroke talk of the uncertainly, challenges and tensions as people with stroke struggle to adapt and make sense of what has happened to them (Arntzen, Borg, & Hamran, 2014; Ellis-Hill et al., 2009; Horne et al., 2014; Kubina, Dubouloz, Davis, Kessler, & Egan, 2013; Robison et al., 2009; Satink et al., 2013). Regaining previously valued roles and activities is an ongoing struggle, which often continues for months and years after stroke (Pallesen, 2014). These experiences create considerable stress for the stroke survivor and their families which can be overwhelming, and these challenges are likely to add to the physical, cognitive and emotional burden experienced by stroke survivors.

One critical issue affecting real-world walking after stroke is a loss of confidence. Stroke survivors have identified a priority area for further research is helping people cope with a loss of confidence (Pollock, St George, Fenton, & Firkins, 2012). Barnsley (2012) interviewed stroke survivors who were seeking to improve outdoor mobility and found their levels of confidence varied and could be placed on a continuum between those described as confident explorers and those who were more hesitant. More confident participants tended to have higher expectations of their own recovery, a more relaxed disposition and several

meaningful destinations they wanted to reach (Barnsley et al., 2012). One possible explanation for the hesitancy experienced by less confident participants was they felt fearful. Common fears affecting walking in the real-world include fear of having a second stroke, fear of falling and fear of going outside (Barnsley et al., 2012; Horne et al., 2014; Logan, Dyas, & Gladman, 2004; Pound et al., 1998). This lack of confidence in relation to real-world walking may be an important contributor to decisions whether to walk outdoors and the emotions experienced when doing so.

A careful weighing up process is undertaken by older adults when deciding whether to go out or not (P. Gardner, 2014; H. M. Hanson et al., 2013). It may be the varying levels of confidence referred to above (Barnsley et al. 2012) result from what has been proposed as a subconscious risk appraisal process where an estimation of current capabilities is calculated in relation to the expected demands of the desired task(s) (Bandura, 1994; Lazarus & Folkman, 1987; Lewandowska et al., 2012). This estimation of personal capability is likely to contribute to decisions about whether to walk out and about in the real-world or not and how confident people with stroke feel when walking (Barclay, Ripat, et al., 2015; Barnsley et al., 2012; Horne et al., 2014).

Several theories of behaviour change contain overlapping constructs related to beliefs around capability (Ajzen, 1991; Bandura, 1994; Deci & Ryan, 2008a; Schwarzer, Lippke, & Luszczynska, 2011). Social Cognitive Theory (Bandura, 1986) explains *self-efficacy* as a perception of capability to perform a certain behaviour (Bandura, 1994, 1997). Although self-efficacy was initially proposed to be task specific (i.e. perceptions of capability to undertake a discrete task like walking); Bandura also introduced the concept of self-regulatory efficacy which he describes as perceived capability to perform a behaviour in various conditions or with impediments (Bandura 1997 cited D. M. Williams & Rhodes, 2014, p. 3). Williams, on reviewing the conceptual debate in psychology surrounding the nature of self-efficacy type constructs, (D. M. Williams, 2010; D. M. Williams & Rhodes, 2014), lists numerous self-efficacy subtypes including: task self-efficacy, self-regulatory efficacy, action self-efficacy, initiation self-efficacy, barrier self-efficacy, and coping self-efficacy. Behaviour self-regulation, as discussed later in

section 2.3.1, refers to psychological skills needed to initiate and sustain goal-directed behaviours in the face of obstacles. With the exception of task self-efficacy, the term self-regulatory efficacy arguably incorporates all other subtypes; it refers to perceptions of capability related to goal setting and goal striving in general (D. P. French, 2013; D. M. Williams, 2010).

Stroke survivors seem to experience hesitancy walking in specific real-world settings (Barnsley et al., 2012; Pound et al., 1998) as well as a broader loss of confidence following stroke (Ellis-Hill & Horn, 2000; Horne et al., 2014; Pollock et al., 2012). Ellis-Hill & Horn (2000) compared the self-concepts of stroke survivors with age and gender matched older adult controls, and found control participants had a stable self-concept but stroke survivors viewed themselves as less capable after their stroke. Qualitative data exploring the perspective of stroke survivors reveals confidence in specific situations is important but confidence relating to aspects of self-esteem and relationships to others is also relevant to overall levels of confidence to get out and about (Ellis-Hill & Horn, 2000; Horne et al., 2014). In this research the word *self-confidence* is used as an umbrella term to indicate both emotional and cognitive aspects of an evaluative judgement; and includes task-related self-efficacy (i.e. confidence during specific walking tasks), self-regulatory efficacy and overall perceptions of confidence.

### 2.1.1.5 How do environmental factors affect real-world walking after stroke?

Existing data strongly supports the influence of contextual factors on real-world walking behaviours (Barclay, Ripat, et al., 2015; Barnsley et al., 2012; Corrigan & McBurney, 2008b; Nanninga, Meijering, Postema, Schönherr, & Lettinga, 2017). The most well used theoretical framework in rehabilitation, the International Classification of Functioning Disability and Health (ICF), is based on a model which proposes behaviours emerge from an interaction between personal and environmental factors (Noreau & Boschen, 2010; World Health Organisation, 2002). Environmental factors have been described in various ways and are generally divided into physical and social domains (Heinemann et al., 2015; Jellema et al., 2016; Magasi et al., 2015; Sumathipala, Radcliffe, Sadler, Wolfe, & McKevitt, 2011). The physical domain includes features of the built and natural environment, while the social domain includes aspects of social support and the

attitudes of others (Garcia et al., 2015). While the ICF illustrates the contextual factors which shape functioning and disability, it does not provide any insight into *how* these contextual factors work to influence disablement or *which* contextual factors really matter (Magasi et al., 2015; Noreau & Boschen, 2010).

Early ecological theorists examined person-environment fit as a way of understanding how the demands of the environment (known as *'press'*) interacted with an individual's capabilities and their perceived control (Magasi et al., 2015; Nahemow, Lawton, & Center, 2016; Noreau & Boschen, 2010). In this view, the process of adaptation describes the way people change their behaviours to meet the demands of the environment (Magasi et al., 2015, p. 571) 'Press' can be positive or negative depending on how the individual responds (Noreau & Boschen, 2010, p. 275). These theorists argued there were two main types of behavioural responses. If the gap between demand and perceived competence was manageable, people stretch their capacities and adapt to the challenge. If, however, it was not possible or desirable to do so, then avoiding or excluding themselves from the situation was the more likely reaction (Magasi et al., 2015; Noreau & Boschen, 2010). Neuroscientific research broadly supports this idea, proposing that the ability to learn new skills and adapt is essential for effective functioning. There is a growing convergence of evidence from qualitative, theoretical and neuroscientific literature which suggests the process of adaptation or maladaptation is an essential feature of how people with stroke respond to environmental demands (Ellis-Hill et al., 2009; Kirkevold et al., 2012; Kubina et al., 2013; Lewandowska et al., 2012; Nanninga, Meijering, Schönherr, Postema, & Lettinga, 2014; Noreau & Boschen, 2010). In relation to real-world walking, the transition from the relative safety of home into more uncertain and challenging outdoor settings seems particularly problematic (Nanninga et al., 2014).

The role of social factors appears significant and can work to support or undermine these adaptive processes for stroke survivors (Barnsley et al., 2012; J. H. Morris, Oliver, Kroll, & MacGillivray, 2012; Nicholson et al., 2013; Sumathipala et al., 2011). Barnsley and colleagues (2012) found that even when the individual was quite capable of travelling outdoors alone, family members played a gate

keeping role based on their perception of advice given by physiotherapists and doctors. This affected the willingness of study participants to walk outdoors. Other qualitative data points to the advantages of social factors in providing motivation to be physically active after stroke (e.g. Nicholson et al., 2013) and the significance of social connections and social support to reengaging in personally valued activities (Barclay, Ripat, et al., 2015; Kubina et al., 2013). To sum up, factors relating to the social environment appear to enable or constrain the process of adaptation needed to reengage in real-world settings.

One of the key difficulties to advancing our knowledge of how environmental factors interact is knowing exactly which environmental factors matter and why. This issue is complicated by the large number of variables produced by rehabilitation research exploring environmental factors using socioecological models. For example, Heinemann et al. (2015) identified no less than 274 environmental factors requiring further exploration and Garcia et al. (2015) winnowed their list of social factors down to a pool of 82 different items. Knowing which of these is really important for stroke survivors is complicated by the significant measurement challenges involved in measuring "messy" contextual factors (Magasi et al., 2015, p. 570).

One solution could be to focus on the environmental factors that directly influence what a person *actually* does. For example, the role of the built environment influencing walking decisions for older adults was studied in a realist review by Yen et al. (2014). This review analysed data from 123 sources regarding the impact of distinctive features of the built environment such as aesthetics, land use and connectivity as well as personal factors related to the health of the older adult. Of note, no specific environmental features were found to directly affect walking, but environmental features did affect *perceptions* of safety. In other words, the significance of environment factors was determined by the interpretations held by the older adult and the meanings they ascribed to these features. This is supported by qualitative studies which have similarly found that features of the physical environment are less important than the evaluative judgements made by the person about their own capabilities when deciding

whether to walk outdoors (Gardner, 2014; Hanson et al., 2013; Yen, Flood, Thompson, Andersen, & Wong, 2014).

To summarise, people need to make a number of behavioural adaptations in response to the challenges they experience following stroke. Factors relating to the physical and social context can enable or constrain how they respond and may be particularly pertinent to understanding real-world walking behaviours. There appears to be a synergistic interaction between many of the factors which is difficult to gauge using biomedical, cognitive-behavioural or ecological frameworks in isolation, as is the predominant approach in rehabilitation. In the next section, I will explore how viewing problems of walking inactivity after stroke as a complex problem can provide additional insights to further our understanding of how personal and environmental factors interact to produce walking inactivity after stroke.

### 2.1.1.6   Walking inactivity as a complex adaptive behavioural response

Complexity perspectives suggest that by examining the way factors interact together rather than identifying a single causative factor provides a better way of understanding why a problem exists. Complexity theory can explain how physical, cognitive, emotional, social and environmental factors are related to each other and how changes emerge at multiple levels and magnify over time (Hawe, 2015; Noyes et al., 2013; Shiell et al., 2008; Westhorp, 2012).

Emergent outcome patterns describe the way components of the system interact to produce change and produce patterns of outcome not predictable or proportional to the input (Glouberman & Zimmerman, 2002). A scenario where outcomes are proportional to input size is a dose-response outcome pattern (e.g. Borde, Hortobágyi, & Granacher, 2015); but complex systems produce change that is large, moderate or negligible in response to the input and changes occur in either negative or positive directions (Kaisler & Madey, 2009). A series of feedback loops proceeding in a negative direction is called a vicious cycle, and a series proceeding in a positive direction is known as a virtuous cycle. In both situations, outcomes emerge and magnify in either direction.

A second type of outcome pattern where outcomes are not predictable or proportional is described as a phase shift. This term describes situations where there is an extended period where no change in outcomes occurs followed by a sudden increase in observable change. This pattern is commonly seen when a person learns a new skill (Westhorp, 2012). For example, during the acquisition or reacquisition of a motor skill a distinction can be made between learning and performance (Kantak & Winstein, 2012). During early learning, (particularly with complex tasks), considerable effort may need to be exerted with minimal gains in observable performance, particularly if motivation, memory or attention is impaired.  But as mastery develops, sudden gains in skilled performance can be observed (Kantak & Winstein, 2012). Emergent outcome patterns are typical of complex adaptive systems (Petticrew et al., 2013) and may help explain how contextual factors interact and magnify to produce walking inactivity after stroke.

Walking inactivity after stroke can be viewed as an adaptive behavioural response to multiple synergistic and interacting factors which negatively reinforce each other over time. This feedback loop leads to a vicious cycle of inactivity. Figure 2 provides an example of a vicious cycle of walking inactivity. A small change (such as a loss of physical fitness following enforced inactivity) can impair functional abilities which magnify over time leading to walking disablement and even social isolation (Cress & Meyer, 2003; Tak, Kuiper, Chorus, & Hopman-Rock, 2013). In contrast, improved physical fitness can be a catalyst for ongoing positive change in other areas (Dohle, Hartmann, & Keller, 2014; Mata et al., 2009; Prochaska, Spring, & Nigg, 2008; Schwandt, Skinner, Takruri, & Storey, 2015). There are no simple solutions to complex problems occurring in complex adaptive systems and interventions to address them will require careful consideration of how different factors interact together.

Avoids activity by
walking less often
and sitting more

ADAPTATION

Body adapts physically-
muscles become weaker
& fitness level reduces

Experiences walking
outdoors as demanding,
stressful & unpleasant

FEEDBACK

FEEDBACK

Loss confidence in
walking ability &
less inclined to try

Sees self as less
capable &
adjusts self-belief

FEEDBACK

FEEDBACK

Less likely to initiate
walking activity

Avoids activity by
walking less often
and sitting more

ADAPTATION

ADAPTATION

Figure 2. A possible 'vicious cycle' of walking inactivity

### 2.1.1.7  Section summary

After stroke, experiences of walking outdoors are likely to be fatiguing and
unpleasant because the demands of real-world settings often exceed the stroke
survivor's available physical and cognitive resources. Such unpleasant experiences
are likely to undermine confidence and lead to further avoidance of activity. By
avoiding activities, opportunities for successful experiences are minimised
reinforcing perceptions of reduced capability. A loss of cognitive capabilities
following stroke means a person is less likely to initiate physical activity which,
over time, is likely to have further detrimental effect on cognitive and physical
abilities. For those with a loss of physical or cognitive capability, a careful
weighing up process is undertaken when deciding whether to walk outdoors or
not. The responses of influential others can reinforce perceptions of lack of
capability and influence decision making. This vicious cycle of inactivity
continues to reinforce itself negatively through the processes of feedback and
adaptation. The next section will discuss the benefits of walking in preparation
for the final part of the chapter which will focus on possible ways to break this
vicious cycle.

## 2.2  Benefits of walking

Walking is the most popular type of physical activity, and it is particularly well
suited to those who are less able (De Moor, 2013; Lee & Buchner, 2008; Ministry

of Health, 2013; Tudor-Locke, 2012). A nationwide review of activity levels for older adults in New Zealand showed 73.3% of those who were physically active rated walking as their preferred activity (Ministry of Health, 2013). Walking at least one block a day (or around 10 minutes) can have a protective effect for even the most disabled people (Simonsick, Guralnik, & Fried, 1999; Simonsick, Guralnik, Volpato, Balfour, & Fried, 2005). For example, the Women's Health Study, a large longitudinal study of over 5000 woman, found, regardless of baseline physical ability, regular walkers were twice as likely as non-walkers to maintain their walking ability one year later (Simonsick et al., 2005). Recent public health reviews indicate that gains in health outcomes are proportionally greater for those who are less active and even a small increase in physical activity can produce significant benefits (see Powell, Paluch, & Blair, 2011; Tudor-Locke, 2012).

Walking regularly can also have a significant impact on physical, psychological and cognitive health (De Moor, 2013; J. N. Morris & Hardman, 1997; Murtagh et al., 2015; Tudor-Locke, 2012). With regard to physical health, commencing a regular walking routine can improve blood pressure and reduce body fat in those who have been previously inactive (Murtagh et al., 2015). One meta-analysis of the effects of walking found a 10% increase in aerobic capacity; which corresponds to a 15% reduction in population mortality (Murtagh et al., 2015). In relation to psychological health, walking programmes have been associated with significant reductions in depressive symptoms (effect size 0.86) (Robertson, Robertson, Jepson, & Maxwell, 2012). Finally, with regard to cognitive health, being physically active can reduce the risk of developing future cognitive problems by as much as 38% (Sofi et al., 2011). This protective effect is greatest for higher levels of physical activity, but low to moderate levels of activity can still provide considerable protection (-35%)(Sofi et al., 2011). Interestingly, evidence suggests a two-way relationship between physical activity and executive functioning (Daly et al., 2015). Due to its ability to achieve significant benefits on health and wellbeing with minimal financial outlay, walking for exercise has been described as the "perfect preventative medicine" (Tudor-Locke, 2012, p. 540).

### 2.2.1  Benefits of walking after stroke

Research on the benefits of walking for exercise after stroke is still emerging, but there is data to show being active for just 20-30 minutes a day after stroke reduces the relative risk of premature death by 41% (Towfighi et al., 2012). The research evidence for benefits of physical activity on cognition after stroke is less well studied. There is mounting evidence though, from both animal and human studies, for the neuroprotective benefits of exercise on several aspects of overall brain health including plastic changes in learning and memory (Cotman, Berchtold, & Christie, 2007; Daly et al., 2015; Sofi et al., 2011). There is limited research in stroke-specific populations, but positive findings from a systematic review on the effects of exercise on cognitive performance following stroke indicate similar processes are likely to be at work (Cumming et al., 2013, 2012). Walking regularly is likely to produce significant benefits for both body and brain health for stroke survivors.

The practice of being able to walk in the real-world is particularly valued by people with stroke ( Lord, McPherson, McNaughton, Rochester, & Weatherall, 2004; Robison et al., 2009). The majority of stroke survivors rate walking as important or very important (Lord et al., 2004). For people with stroke, walking is the preferred type of physical activity providing a way to ensure continuity with one's pre-stroke self and a way to reengage with previously desired activities (Morris et al., 2015).

In summary, if people with stroke walked more (i.e. further, faster or more often) then far reaching benefits for both stroke survivors and funders of their health care are likely. But despite the benefits and importance of real-world walking, there has been surprisingly little theoretical or empirical research satisfactorily exploring the topic in the rehabilitation literature. The next section will summarise what is currently known about the distinctive features of real-world behaviours and consider how new walking routines can develop.

### 2.2.2  Walking (more) in the real-world

Real-world walking usually serves three main purposes: walking for exercise or leisure, walking for transport and incidental walking during daily activities

(Darker, Larkin, & French, 2007; Lee & Buchner, 2008; Owen, Healy, Matthews, & Dunstan, 2010). National surveys using activity monitors in the US show the majority of non-sleeping time is spent in sitting (58%); followed by incidental activity (39%) and just 3% of time is spent in walking longer distances (Owen, Sparling, Healy, Dunstan, & Matthews, 2010). Walking during daily activities is the most common type of walking behaviour.

Walking is often an implicit or automatic type of behaviour initiated and executed below conscious awareness. As a consequence, memories of the act of walking may not be encoded, unless the walking is particularly intense or something unusual happens (Eves, Scott, Hoppé, & French, 2007). Eves and colleagues (2007) measured actual walking in military personnel on an air force base using a pedometer and compared this with self-report activity questionnaires. Walking while marching in groups was accurately recalled possibly due to its intensity but incidental activity was significantly under reported (Scott, Eves, French, & Hoppé, 2007).

Many walking activities are likely to be largely habitual behaviours embedded in daily activities and routines (F. A. Clark, 2000; Wood, Quinn, & Kashy, 2002). Researchers estimate that around 45% of most daily activities consist of habitual behaviours (Neal, Wood, & Quinn, 2006; Wood et al., 2002) and during habitual activities people are unlikely to be thinking directly about the performance of the activity. It is likely then, for most people there is limited awareness of daily walking habits and routines.

The phrase *walking habits and routines* refers to walking-related daily activities used to create order in one's day (F. A. Clark, 2000; F. A. Clark, Sanders, Carlson, Blanche, & Jackson, 2007). Such habits and routines have been developed to minimise the need for constant decision making and are an efficient way to manage the myriad of possible choices encountered in daily life (Bargh & Chartrand, 1999; Neal et al., 2006; Wood et al., 2002; Wood & Rünger, 2016). Our daily habits and routines carry the majority of the daily self-regulatory burden (Bargh & Chartrand, 1999, p. 462) and allow us to direct our limited executive control resources toward more important goal-directed activities.

Habituated behaviours develop when there is constant repetition of the behaviour in a stable context over long periods of time (B. Gardner, 2014; Neal et al., 2006; Wood & Rünger, 2016). Gradually, via an associative learning process, the behaviour becomes enacted automatically in response to contextual cues in the environment (Lally & Gardner, 2013; Lally, van Jaarsveld, Potts, & Wardle, 2010). Through the process of automaticity "behavioural control is outsourced to contextual cues" (Nilsen, Gardner, & Broström, 2013, p. 5) conserving cognitive resources for more challenging activities.

Rhodes and De Bruijn (2013b) reviewed research into the process of adoption and maintenance of physical activity behaviours and proposed successful adoption is reliant on reflective thinking (e.g. plans and evaluations) but successful maintenance is based on shifts into habituated behaviour through automaticity and motivation. Automatic processes include emotional responding and habitual behaviour (Michie, van Stralen, & West, 2011). Most research examining sustained change suggests a minimum timeframe of three months is needed to show long term change that is sustainable (Fjeldsoe, Neuhaus, Winkler, & Eakin, 2011). This figure is consistent with the automaticity research on the formation of new exercise habits- the average time to develop automaticity is around 6-10 weeks (Kaushal & Rhodes, 2015; Lally et al., 2010). Any sustained change in walking habits is likely to involve both reflective/conscious processes in the initial stages and habitual/automatic processes to maintain the change over the long term (Rhodes & de Bruijn, 2013b).

### 2.2.3 Section summary

Walking is often a largely habitual behaviour usually instigated by environmental cues. The most common type of walking behaviour is incidental walking during daily habits and routines. Walking more in the real-world is likely to involve changing daily walking habits. Developing any new habit is time consuming and requires repeated practice of the new activity over several weeks before sustained change is evident.

## 2.3  Interventions to change walking in the real-world

There are numerous theoretical frameworks which attempt to explain how interventions can produce change in health behaviours (Davis, Campbell, Hildon, Hobbs, & Michie, 2014). Attempts to synthesise health behaviour change theories have produced an elegant model known as COM-B which reduces the key features of the change process to only three core components: *C* for capability, *O* for opportunity, and *M* for motivation which together produce change in behaviour (*B*) (Michie, van Stralen, et al., 2011). In this model, both physical and psychological capabilities are viewed as internal to the individual; opportunities offered by the physical and social environment as external to the individual and together both aspects influence motivation to change behaviour. Figure 3 below shows the COM-B model.
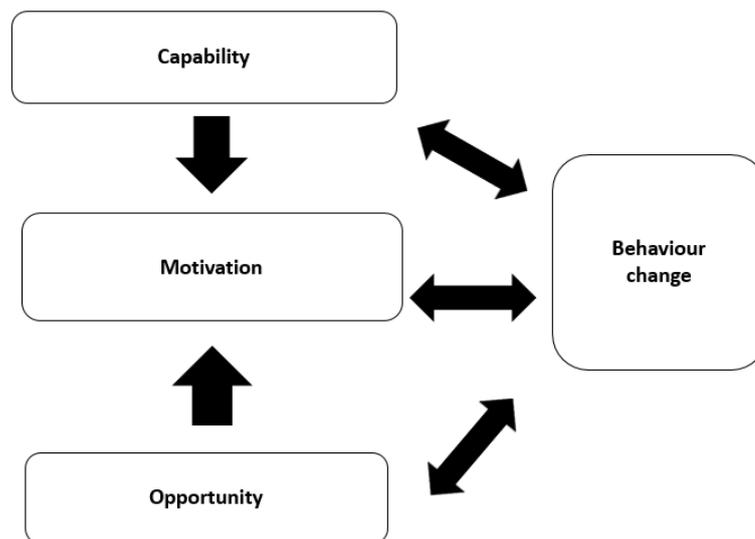


Figure 3. COM-B- A synthesised framework to explain behaviour change (Michie et al.2011)

According to the COM-B model, motivation is described in broad terms as "brain processes that energise and direct behaviour" (Michie, van Stralen, et al., 2011, p. 7). A distinction is made between reflective motivation that involves plans and evaluative judgements as part of conscious decision making and automatic processes that include habitual and emotional responses. A further key aspect of the model is the way it views the physical and social environment as influencing

motivation by providing opportunities. This extends the earlier discussion of environmental factors in section 2.1.6.

Sustained behavioural change is likely to require three stages: having a desire to change, turning that desire into action through the adoption of new behaviours, and then maintaining the new behaviours until they become habituated (Rhodes & de Bruijn, 2013b). The overall process is called behavioural self-regulation. Behavioural self-regulation involves learnt psychological skills that can enable an individual to exert control over themselves, to direct their energy and attention towards goal setting and striving (Baumeister & Vohs, 2004; De Ridder & De Wit, 2006; Mann, de Ridder, & Fujita, 2013). It requires intact executive functioning specifically prefrontal cortical activation (Alvarez & Emory, 2006; Buckley, Cohen, Kramer, McAuley, & Mullen, 2014; Wessel, Klein, Ott, & Ullsperger, 2014). Behavioural self-regulation is an essential part of human agency-the essence of how a person manages their own change processes (De Ridder & De Wit, 2006).

The gap between the desire to be more active (known as an *intention*) and the ability to turn this desire into actual behaviour (*the intention-behaviour gap*) has been examined in a meta-analysis (Rhodes & de Bruijn, 2013a). The review found that only 54% of those who intended to be active and 2% of those who did not had actually adopted new activity behaviours at follow-up (between 2 weeks and 6 months later). Although this review primarily included participants drawn from healthy undergraduate populations and did not distinguish between the adoption of new behaviours and the maintenance of behaviours, it does illustrate the challenge many people experience in changing activity behaviours and how difficult behavioural self-regulation can be even for healthy individuals.

The next section will review the research on intervention components which focus on planning to aid adoption of new activity behaviours. I will also review the more limited literature on interventions that seek to change beliefs about personal capability and influence habitual processes. I will conclude by highlighting what is known about the environmental factors which can influence sustained behavioural change in walking.

### 2.3.1 Intervention components that focus on planning

Intervention components that facilitate goal planning processes can enhance self-regulatory capabilities and energise motivation to overcome the intention-behaviour gap (Gollwitzer & Sheeran, 2006; Rhodes & de Bruijn, 2013b). There are many theories of change based on behavioural self-regulation including Control Theory (Carver & Scheier, 1982) and the Common Sense Model (Leventhal, Leventhal, & Breland, 2011). Self-regulatory theories propose reflective processes, such as goal planning and reflective monitoring can help change goal-directed health behaviours (De Ridder & De Wit, 2006). These reflective processes are the basis for interventions using change techniques that involve goal planning using implementation intentions (e.g. if-then planning) and self-monitoring using exercise diaries or other methods (e.g. Gollwitzer & Sheeran, 2006; Kersten, McPherson, Kayes, Theadom, & McCambridge, 2014).

A behaviour change technique is the smallest component or ingredient that is an observable and replicable part of a behavioural intervention (Michie & Johnston, 2012, p. 12). Michie, Abraham, Whittington, McAteer & Gupta(2009) completed an extensive systematic review which sought to determine which behaviour change techniques were effective in changing physical activity for healthy people. The meta-regression showed a modest overall effect size of 0.31 for behavioural interventions and this effect size increased to 0.42 for techniques associated with self-regulatory theories such as prompting intention formation, specific goal setting, feedback on performance, self-monitoring of behaviour and review of goals (Michie et al., 2009). Building on this research, a later review used walking more as the primary outcome rather than physical activity (Bird et al., 2013). Although the intervention components were not as well described in this second review, the conclusions broadly supported the Michie et al. (2009) review. Goal setting and self-monitoring were particularly effective behaviour change techniques to help people change walking behaviours (Bird et al., 2013; Ogilvie et al., 2007). Such change techniques are likely to improve walking by enhancing behavioural self-regulation.

The use of intervention components that focus on planning and self-monitoring have a strong evidence base in the physical activity literature (Fjeldsoe et al., 2011;

Gollwitzer & Sheeran, 2006; Michie et al., 2009; Rhodes & Pfaeffli, 2010), but these types of techniques may not suit everyone. Self-regulatory skills rely on the cognitive ability to think abstractly, to pay sustained attention and require information processing and memory skills which can deteriorate with age (Daly et al., 2015) and following neurological impairment (G. H. Taylor & Broomfield, 2013). In one systematic review, which examined the effectiveness of physical activity interventions in older adults, behaviour change techniques such as goal setting and self-monitoring actually led to lower levels of physical activity and confidence (D. P. French, 2013). Some clinical populations may need additional support and coaching to help with goal planning (Stretton, Mudge, Kayes, Taylor, & McPherson, 2013; G. H. Taylor & Broomfield, 2013).

### 2.3.2 Intervention components that focus on changing beliefs about personal capability to enhance motivation

Concepts like task self-efficacy, self-regulatory efficacy and perceived behavioural control have received considerable attention in the physical activity field (e.g. Ashford, Edmunds, & French, 2010). Self-regulatory efficacy is proposed to be particularly important to motivation because it is said to energise persistence in the face of barriers and setbacks (Bandura, 1997; D. M. Williams & Rhodes, 2014). There is increasing consensus that concepts like self-efficacy and perceived behavioural control are largely similar constructs reflecting judgements about personal capability (Cane, O'Connor, & Michie, 2012; Rhodes & Pfaeffli, 2010; D. M. Williams & Rhodes, 2014). Various capability beliefs appear in most behaviour change theories (e.g. Ajzen, 1991; Bandura, 1982; Cane, O'Connor, & Michie, 2012; Schwarzer, Lippke, & Luszczynska, 2011) but those theories do not make clear which intervention components can actually change beliefs about personal capability (Ashford et al., 2010; D. P. French, 2013; D. P. French, Olander, Chisholm, & Mc Sharry, 2014).

Self-efficacy and other capability beliefs may work best in conjunction with reflective self-regulatory processes when changing behaviour (Rhodes & de Bruijn, 2013b; D. M. Williams & Rhodes, 2014). The contention that these processes interact is supported by Darker and colleagues (2007) who developed an intervention particularly effective at producing change in walking habits. The

intervention had two parts; the first component was designed to improve motivation, the second aimed to help conscious decision-making processes through goal planning. The motivational component focused on identifying previous successful experiences and the planning component included developing action plans for walking. A health psychologist delivered the intervention using strategies drawn from motivational interviewing which encourages a collaborative interaction style (Ryan, Lynch, Vansteenkiste, & Deci, 2011). The intervention improved daily walking as measured with a pedometer one week later with the experimental group walking 87 minutes more per week (95% confidence interval (CI) 51.7-122 minutes) than the control group (Darker et al., 2010). Changes in the underlying mechanisms of perceived behavioural control (self-efficacy) and planning were demonstrated. Furthermore, a later replication study showed both the motivational component and the planning component together appeared to produce the largest increases in daily step counts with a large effect size ($d$= 1.06) for participants who received both components together compared to smaller effect size shown by participants who received components separately-one week apart (D. P. French, Stevenson, & Michie, 2012). One limitation of this study though was the very small number of participants (n= 10) in each of the intervention arms. On balance, this study does appear to indicate that intervention components enhancing motivation work best alongside planning components when seeking to change walking behaviours.

### 2.3.3 Intervention components that focus on automatic processes

What is missing though from research which examines the *action-control* framework of Rhodes & DeBruijn (e.g.2013a, 2013b) is any discussion about the motivation required to sustain the amount of repetitive practice that is necessary to develop automatic behaviour. Intrinsic motivation is a type of motivation where the desire to be active is derived from inherent satisfaction or enjoyment (Ryan, Williams, Patrick, & Deci, 2009). Interventions promoting intrinsic motivation can help maintain long-term change in physical activity behaviours in general (B. Gardner & Lally, 2013; Teixeira, Carraça, Markland, Silva, & Ryan, 2012).

In relation to walking, the development of intrinsic motivation might be particularly relevant for sustained change specifically (Kinnafick, Thøgersen-Ntoumani, & Duda, 2014). Internalisation describes a process where, over time, individuals come to consider an activity is consistent with their values and is the result of their own choice (Vansteenkiste, Williams, & Resnicow, 2012). Kinnafick and colleagues (2014) interviewed participants in a walking study and explored the process of adoption, relapse and maintenance of walking habits. They found the motivational process of internalisation was key to participants maintaining their new walking routines. However, this study was a qualitative study, so further research would be needed to ascertain whether this finding can be generalised to other situations.

The issue of which intervention components can best promote automaticity has been largely overlooked in the physical activity literature (B. Gardner, 2014; Rhodes & Nigg, 2011; Rhodes & Pfaeffli, 2010). Consequently, there is limited empirical data to guide intervention development. One small study examining how new gym attendees developed new exercise habits found habit formation occurred over an extended period (e.g. around six weeks). For an automatic habit to develop, the participant needed to exercise regularly and consistently; at least four times a week (Kaushal & Rhodes, 2015). A more recent study by the same authors successfully trained new gym attendees to use contextual cues to prompt regular gym attendance, for example leaving gym clothes out (Kaushal, Rhodes, Spence, & Meldrum, 2017). Positive environments encouraging regular and consistent practice which make exercising pleasurable, and interventions that strategically use contextual cues may be useful approaches to help support habit formation and promote automaticity (Kaushal & Rhodes, 2015; Kaushal et al., 2017; Lally et al., 2010) but this is yet to be studied in relation to walking.

### 2.3.4 Effects of the environment on opportunities to walk more in the real world

The significance of the social environment to engagement in walking programmes is likely to be sizeable (Carron, Hausenblas, & Mack, 1996; S. Hanson & Jones, 2015; Kassavou, Turner, & French, 2013). For example a meta-analysis of 80 studies with nearly 50,000 participants found the presence of

family support significantly improved adherence to exercise (Carron et al., 1996). The moderate-large effect size [0.62] is in contrast to the more modest effect sizes found in interventions focusing on individual level behavioural interventions to improve physical activity (e.g. 0.31 found by Michie et al., 2009).

Features of the social and attitudinal environment may be particularly influential on decisions to walk in the real-world. For example, in the previous section, the research by Darker and colleagues (2010) was cited as an example of a carefully developed and theoretically informed walking intervention delivered by a health psychologist that was effective at changing walking behaviours. However, when the intervention was extended across a number of sites and delivered by GP nurses, it was no longer effective (S. L. Williams, Michie, Dale, Stallard, & French, 2015). The authors questioned the suitability of practice nurses to deliver the intervention, questioning organisational issues influencing how the nurses interacted with their patients thus altering the social and attitudinal context in which the intervention was delivered. An alternative explanation for the lack of effectiveness could be the different number of weeks post-intervention when pedometer data was collected. In the original study (Darker et al. 2010), the number of steps was measured one week post intervention but in the follow-up study (D. P. French et al., 2011; S. L. Williams et al., 2015) data collection occurred six weeks post intervention. Neither study provides any evidence of the intervention leading to sustained change in walking behaviours.

One method of providing social support that does appear particularly relevant to sustained change in walking behaviours is the use of walking groups. Kassavou, Turner & French (2013) found group walking lead to significant changes in levels of physical activity [average effect size $d= 0.52$] but changes over the long term were actually greater [$d= 0.66$] than those occurring in the first six months [$d=0.45$]. In their review, older adults particularly preferred to walk in groups. Nineteen studies were included in the review and ten of these studies measured real-world walking using a pedometer. However, different self-report measures of physical activity were used in the remaining studies. As such, it was not possible to determine the relative contribution of walking over other types of physical activity. Despite this limitation, this review shows harnessing the power of social

connections may be a particularly effective approach to help people walk more often and keep on walking.

### 2.3.5   Section summary

In summary, interventions which use behaviour change techniques employing reflective processes (such as goal planning, feedback and self-monitoring); motivational techniques boosting self-confidence and encouraging intrinsic motivation; and regular and consistent practice appear to be important at promoting change in walking behaviours for health people. Contextual factors such as the interaction style of people delivering interventions, and different types of social support (such as group based walking) also appear to influence change.

## 2.4   Interventions to change walking in the real-world after stroke

There are usually numerous interacting components in rehabilitation interventions (Campbell et al., 2000; Wade, 2005). This means, in contrast to the interventions designed for healthy individuals, identifying key intervention components is less likely to be straightforward for multicomponent interventions in rehabilitation populations. Rehabilitation interventions are often tailored to meet individual needs which means, in practice, components can differ even further (Hawkins, Kreuter, Resnicow, Fishbein, & Dijkstra, 2008). Additionally, intervention components in healthcare are often poorly described (Möhler, Bartoszek, & Meyer, 2013). In this section, I provide a narrative review of interventions to change walking behaviour after stroke by grouping interventions according to the type of intervention. The purpose of this section is to start to identify intervention components or types most likely to be relevant to the next stage of intervention development.

The process of identifying effective intervention components can be difficult - the mysterious *black box* is a known conundrum for those dealing with complex problems and complex interventions (Astbury & Leeuw, 2010; Cieza & Bickenbach, 2014; DeJong, Horn, Conroy, Nichols, & Healton, 2005; Lipsey, 1993; Whyte & Hart, 2003). One way of countering this difficulty is to view interventions by the function they perform as a whole or the means with which

they hope to generate change (Michie et al., 2014). The Behaviour Change Wheel framework was developed to bring together the full range of intervention options in the field of behaviour change in a comprehensive and systematic way (Michie et al., 2014). Interventions most suitable for behaviour change in rehabilitation can be grouped by the following functions: training, education, persuasion, environmental restructuring and enablement. A three further functions (incentivisation, coercion and restriction) are less appropriate and even ethically questionable in health care contexts (Michie, van Stralen, et al., 2011). See Table 2 below.

Table 2. Intervention functions taken from 'The Behaviour Change Wheel"*

| Intervention Function | Definition |
| --- | --- |
| Training | Imparting physical or psychological skills |
| Education | Increasing knowledge or understanding |
| Persuasion | Using communication to induce positive or negative feelings to stimulate action |
| Environmental restructuring | Changing the physical or social context |
| Enablement | Increasing means or reducing barriers to increase capability (beyond education and training) or opportunity (beyond environmental restructuring) |

*Drawn from Michie et al. 2014

## 2.4.1 Interventions designed to provide physical skill training

Training interventions seek to enhance capability through developing skills (Michie et al., 2014). Task-oriented training refers to skill training regimes that focus on repeated practice of the task of walking or its component parts (Pollock et al., 2014; Shumway-Cook & Woollacott, 2012; States, Pappas, & Salem, 2009). The theory behind task-oriented training is based on explanations from use-dependent neural plasticity (Dobkin, 2004; Kleim & Jones, 2008). This treatment theory is based on neuroscientific evidence, usually drawn from laboratory settings and/or animal models (e.g. Kreisel et al., 2007), which show permanent changes in cortical maps, increases in the nutritive environment and increased number of synapses at the spinal cord can occur in response to repetitive and challenging physical training (Adkins et al., 2005). As a result, task-oriented physical training has increasingly become a prominent approach to improve walking after stroke for neurological physiotherapists (Dobkin, 2004; Dobkin &

Duncan, 2012; Pollock et al., 2014; Whyte, 2008). For a focused review exploring the clinical reasoning process used by neurological physiotherapists see section 5.2.2.

However, interventions which focus on physical training in clinic-based settings seem to show limited effectiveness at changing real-world walking. Data to support this conclusion comes from two high quality randomised trials. Mudge et al. (2009) delivered a task-oriented circuit-based exercise in a clinic to community-dwelling chronic stroke survivors over four weeks. The programme improved physical ability of the participants with the intervention group able to walk further than the control group using clinic-based measures. However Mudge measured real-world walking immediately following the intervention and three months later using the StepWatch™Activity monitor, a sensitive and valid measure of real-world walking after stroke (Berlin, 2006; Mudge & Stott, 2008; Strath, Pfeiffer, & Whitt-Glover, 2012). She found, at both time points, intervention participants did not walk any more in the real-world (Mudge et al., 2009). A second high quality trial known as LEAPS (Locomotor Experience Applied Post-Stroke) was designed to be the definitive study on the effect of eight weeks of treadmill training - a type of task-oriented physical training on walking recovery after stroke (Duncan et al., 2007, 2011; Nadeau et al., 2013). Participants who had a relatively acute stroke with moderate to severe walking difficulties were allocated to either early or late treadmill training in a physio clinic and the third group had low intensity exercises delivered at home (Duncan et al., 2007). Although both the task-oriented training and the home exercise group improved, there was no obvious benefit of one intervention over another in terms of real-world walking measured with the SAM (Duncan et al., 2011). Other research using clinic-based physical training for more chronic stroke survivors, although using less sensitive outcome measures to record real-world walking, show a similar lack of effectiveness (Ada et al., 2013; Pang et al., 2005).

Reflecting on the unexpected findings of the LEAPS study, the authors noted the similar degree of change between the two groups could not be fully explained by theories of use-dependent neural plasticity (Dobkin & Duncan, 2012; Nadeau et al., 2013). Both the treadmill training and home exercise groups received similar

time and attention from the therapists and both participated in goal setting (Duncan et al., 2007). This collaborative goal setting process may have enhanced the therapeutic connection and collaboration which potentially could have influenced outcomes in both groups (Kayes, Mudge, Bright, & McPherson, 2015). Such mechanisms of action are well recognised in psychotherapy (e.g. Mander et al., 2013; Norcross & Wampold, 2011). Alternatively, the task-oriented training could have worked as expected, but contextual features of the home setting may have produced unexpected benefits, meaning different mechanisms were at work in the two groups (e.g. Blanchard et al., 2011). In any case, the ability of physical training based in a clinic to produced change in real-world walking is questionable.

### 2.4.2 Interventions designed to educate and persuade

The provision of education and verbal persuasion also does not seem to be an effective way to change walking behaviours in the short or long term for people with mild stroke. Boysen et al. (2009) investigated the effect of education and persuasion on activity levels of people with stroke in a large trial (n= 314) that ran over two years. In this study, a physiotherapist developed an individualised physical activity plan and met five times with each participant over a two-year period. Michie et al. (2014) describe persuasion as communication efforts to stimulate action, and study reports describe the significant effort made by researchers to motivate participants and encourage them to do more (Boysen et al., 2009, p. 2). Walking behaviour was measured with a self-report measure –the Physical Activity Scale for the Elderly (PASE) at repeated time points up to 2 years and the incidence of mortality and recurrent strokes recorded. This scale includes work-related activities, but the majority of items meet the definition of real-world walking defined earlier in this thesis on page 3. No difference was found on any outcome for either the intervention or control group. Most participants, despite having only a mild stroke "did not seem responsive" to suggestions of changing activity levels (Boysen et al., 2009, p. 7). It appears components that focus solely on education and persuasion are also not sufficient to produce sustained change in walking behaviours.

### 2.4.3 Interventions designed to enable behavioural changes

Enablement based interventions aim to increase capability by increasing skills, to reduce barriers to participation and enhance environmental opportunities for behavioural change (Michie, van Stralen, et al., 2011). Lifestyle interventions seek to prevent secondary strokes and reduce mortality by targeting people with mild stroke using a combination of approaches to help change lifestyle behaviours (e.g. Boysen et al., 2009; Gillham & Endacott, 2010; Kono et al., 2013; Lawrence, Kerr, McVey, & Godwin, 2012). Gillham and Endacott (2010) provided 'enhanced secondary prevention' which included education and counselling using motivational interviewing and follow up phone support in a relatively small trial with 52 participants. Motivational interviewing seeks to promote a collaborative interaction style between the counsellor and participant and works to promote intrinsic motivation for change (Apodaca & Longabaugh, 2009; Rollnick, Kinnersley, & Stott, 1993; Ryan et al., 2011). Three months after the interview, participants who had received the intervention were more likely to spend 20 minutes in exercise 2-3 times a week than the control group (Gillham & Endacott, 2010). However, the outcome was not standardised and the person collecting the data over the phone was not blinded introducing the likelihood of response bias.

A Japanese study which used a different approach did show more significant lifestyle changes (Kono et al., 2013). In this study, 70 people with mild stroke were randomised to either a lifestyle intervention or control group. Both groups received lifestyle counselling about the importance of physical activity and reducing salt. In the intervention group, over a period of six months, the physiotherapist set progressive real-world walking goals and provided feedback to participants on how they were doing in relation to the goals. They also provided structured and progressive physical training in both the home setting and the clinic setting providing a type of environmental restructuring. Daily step counts were measured with an activity monitor at baseline and at the six month point immediately following the intervention. The daily step count of the control group did not change from baseline to six months, but the intervention group took 8422 steps/day which was a 35% increase in daily steps compared to their baseline. After the intervention had finished, there was no follow-up to see if this

change in walking was sustained. However, given the lengthy intervention (i.e. 24 weeks), it is likely that new walking habits were formed. In support of this conclusion, the incidence of vascular events was markedly less in the intervention group compared to the control group at the three year point. These findings suggest that firstly, a structured programme was needed to supplement activity counselling and that the programme could produce sustainable change given the long-term gains in cardiovascular health (Kono et al., 2013). The participants though had only a mild stroke, so it is not clear how applicable this intervention would be to more disabled participants.

Another example of an enablement intervention is the seminal study by Logan and colleagues (Logan, Gladman, et al., 2004; Logan, Dyas, et al., 2004; Logan, Walker, & Gladman, 2006). Logan, Gladman et al.,(2004) carefully developed and delivered an intervention that provided education and information about transport options and helped identify new possibilities to get out of the house for stroke survivors with varying degrees of walking disablement. Logan worked collaboratively with the stroke survivor to identify meaningful goals and assisted them to develop their capability to overcome barriers to getting out and about. She provided social support on outdoor outings to allay fears and promote greater confidence-a component called escorted community walking. This could be considered a type of environmental restructuring as this practice sought to change the social context of the experience (Logan et al., 2006). Using just seven sessions of home-based therapy over a three-month period, the intervention successfully increased outdoor walking after stroke with significant gains in self-reported walking at the four month point post randomisation. However these gains were no longer statistically significant six months later (Logan, Gladman, et al., 2004; Logan, Dyas, et al., 2004; Logan et al., 2006). As noted earlier in section 2.3.3, a minimum period of three months following the completion of an intervention is needed to show sustained behavioural change. Intervention participants did describe greater satisfaction with the amount of real-world walking they undertook and this satisfaction was sustained at the 10-month point (Logan, Gladman, et al., 2004). While this study does provide support for the beneficial effects of the intervention, it is not completely clear if the intervention led to sustained change in real world walking, which of the various intervention

components were most significant or if similar results are likely in different settings.

Unfortunately a lack of appreciation of the contribution of various intervention components probably led to a significant oversight when the Logan study intervention was rolled out across multiple sites in the UK in the "Getting out and about" study (Logan et al., 2014). In this large randomised controlled trial with 568 participants, both the control and the intervention groups were provided with a goal setting opportunity and encouraged to record outdoor journeys in a travel diary. The intervention group received up to 12 sessions delivered by a physiotherapist or occupational therapist and were offered multiple opportunities for escorted community walking. However, the trial found no difference in real-world walking or satisfaction with outdoor mobility between the two groups. One possible reason for the lack of difference between groups was the control group had inadvertently also received an active intervention through use of travel diaries (Logan et al., 2014).

Interventions which provide self-monitoring have been found to be particularly effective at improving physical activity for healthy people (Michie et al., 2009). One way of self-monitoring the amount of daily walking is to keep a daily record which may provide a form of informational feedback (e.g. Blamey, MacMillan, Fitzsimons, Shaw, & Mutrie, 2013). It is possible that the effect of self-monitoring via the travel diary coupled with the goal setting in a motivated group of control participants produced unexpected improvements in walking behaviour for both control and intervention participants although this was not identified or measured (Logan et al., 2014).

An alternate reason for the lack of difference between groups may be an active ingredient was no longer being delivered in the second trial but was inadvertently lost. Pawson (2005, p. S1:23), argues interventions can be "leaky" they can evolve and change over time. This may complicate implementation of novel interventions into new contexts. To illustrate: intervention guidelines for community dwelling stroke survivors in Australia (National Stroke Foundation., 2012) and related implementation research (McCluskey & Middleton, 2010; McCluskey et al., 2013) recommend the practice of escorted community walking,

but do not explicitly link it to the collaborative goal setting and barrier identification in the original study (Logan, Gladman, et al., 2004). Similarly the training for the "Getting out and about" study focused primarily on strategies to enhance escorted community walking (Logan et al., 2014). Secondary analysis of the study suggested some therapist/patient combinations were more successful than others at improving the amount of outdoor outings. This finding, though unexpected, is strikingly similar to research with healthy participants discussed previously in section 2.3.4 (e.g. S. L. Williams et al., 2015). It seems, it is not just what is done in an intervention to change walking behaviour but the interaction style of the person who delivers it which is relevant and warrants further study. Understanding which ingredients have the capacity to generate change in walking behaviours could help guide both researchers and clinicians to optimise their selection of treatment components.

### 2.4.4  Section summary

Based on the evidence so far, neither providing physical training in a clinic nor advice and persuasion to be more active after stroke are effective approaches to produce sustained change in real-world walking after stroke. Effective interventions seem to: include multiple components to enhance motivation, provide support for change, encourage goal setting and provide progressive physical training with feedback in both clinic and real-world settings. In addition, research reviewed in this section highlights helping clinicians to select the correct intervention activities for the right reason is complicated by lack of insight into which intervention components really matter and why.

### 2.5  Chapter summary

This review has explored the complex and synergistic reasons behind walking inactivity after stroke. A case has been made for the potential benefits of walking on physical and mental health and wellbeing for stroke survivors. Intervention components which use goal planning, boost confidence and motivation and engage social support can effectively improve real-world walking for healthy people. Historically, physiotherapy researchers and clinicians drawing on theoretical models focusing on use-dependent plasticity have prioritised improving physical ability via physical training. Such theories neither recognise

the complexity of the problem of walking inactivity nor provide a coherent explanation of how physiotherapy interventions can enable people to walk more after stroke. In the next chapter a research philosophy called realism will be outlined. This philosophy has the potential to overcome the limitations of current approaches and better explain the causal processes needed for sustained change. The treatment theory developed in this research will aim to explain how to help people with stroke adopt new walking routines that can be sustained long term.

# Chapter 3   Designing a methodological framework

The main purpose of this chapter is to set up the methodological foundations needed for this doctoral research. The starting point for the project was the real-world clinical issue of the lack of transfer of gains from physical training into sustained change in real-world walking behaviours. This situated the project as problem-based and practice-oriented. In this chapter, I explain the research philosophy, theoretical perspectives and methodologies used in each of the three research phases. Specific details about the *methods* used for each of the three phases are described. Section 3.2 on page 42 describes the values (or axiology); namely the applied nature of both the research question and the products of the research, the ethical imperative to promote client-centred interventions and my commitment to a theoretically informed development process. Section 3.3 on page 45, explains how the MRC guidelines influenced the development of the research questions. I then move on to explain why the research philosophy of realism was selected to provide an overarching framework for this study and how each of the three phases (despite the different theoretical perspectives) fit together. The final sections outline the use of mixed methods in this project and introduce the background concepts needed to understand the theory building tools employed in phase 3. This chapter describes a coherent programme of inquiry to address the clinical problem at the heart of this project.

## 3.1 Overview of three phases of research in this thesis.

| | Phase 1: Systematic Review | Phase 2: Qualitative Enquiry | Phase 3: Treatment Theory Development |
|---|---|---|---|
| **Research Philosophy** | Positivism | Realism | Realism |
| **Theoretical Perspective** | Biomechanical + Behavioural | Constructivist | Scientific Realism |
| **Methodology** | Systematic Review | Interpretive Descriptive | Realist Evaluation |
| **Methods for Data Collection & Analysis** | Meta-analysis of randomised controlled trials | Thematic analysis of interviews | Treatment theory building & impact evaluation using a case study |

Figure 4. Overview of theoretical positioning of the three research phases

Figure 4 provides an overview of the theoretical positioning of each of the three phases of research contained in this thesis. The overview was used as a reference point during the project to check for methodological coherence, both within each of the phases and between the phases. It was developed iteratively throughout the design process

## 3.2 Axiological contributions to research design

Three core values directly influenced the methodological design and development of this project as a whole; the applied nature, the client-centred focus and the systematic approach taken to build theory. The explicit consideration of key values (i.e. axiology) was a particularly important reference point throughout this project because the values of researchers themselves can influence how they view problems and the design decisions they make (Anderson & Funnell, 2005; Maxwell, 2013). Due to the iterative nature of the project, these

values helped to provide a constant source of reference to guide design decisions. The values were identified early in the project and were used as guiding principles. Being explicit about such values provided a consistent reference point and gives useful information to those who may wish to read or use research because such values can help explain the context in which the research is positioned (Collins & O'Cathain, 2009; Shannon-Baker, 2015).

The first guiding value of the project was the importance of its *practical* or *applied* nature. The starting point was a clinical problem needing to be addressed (Mudge et al., 2009). When making research design decisions, I constantly referred back to the desired outcome of sustained change in real-world walking in people with stroke. This value guided me to select literature and methodologies that focused on understanding how change can occur, to seek out perspectives of stroke survivors on difficulties with real-world walking and to additionally include the perspectives of expert clinicians during consultation processes. This principle extended to making decisions around intervention design. I made concerted efforts to ensure any interventions developed would be practically feasible and effective for both people with stroke and those delivering the interventions. Issues of clinical relevance, ecological fit and the delivery capability of those involved were therefore important considerations during research design and intervention development (Hawe, 2015).

The second value was my personal commitment to *client-centred practice* (Cott, 2004; Leplege et al., 2007; McPherson & Siegert, 2007). Client-centred (or person-centred) practice involves an approach to rehabilitation where the therapist does not assume what the client needs but instead works to ensure the expressed needs of the client are kept at the forefront of client-therapist interactions (Cott, 2004). Client-centred practice can promote client engagement in rehabilitation processes (Bright, Boland, Rutherford, Kayes, & McPherson, 2012; Bright, Kayes, Worrall, & McPherson, 2014), values a collaborative approach to decision making (Rosewilliam, Roskell, & Pandyan, 2011) and works to support the autonomy of those receiving rehabilitation, thus providing a strong ethical foundation (Leplege et al., 2007).

An important barrier to person-centred practice can be the tendency for health professionals to prioritise their own perspectives over the perspectives of their clients and to subconsciously direct interactions with rehabilitation recipients (Anderson & Funnell, 2005; Jones, Livingstone, & Hawkes, 2012; J. H. Morris et al., 2014; Mudge, Kayes, & McPherson, 2015; Mudge, Stretton, & Kayes, 2013). Before starting this project, my colleagues and I undertook focused self-reflection on our personal perspectives as physiotherapy clinicians and academics toward client-centred care which led to the publication of an autoethnographic account (Mudge et al., 2013). This account highlighted our inherent tendency to focus on a biomechanical view of walking and an interaction style that saw ourselves as the primary source of expertise. To counter this tendency, I intentionally sought to design a project that provided ample opportunities to engage with the perspectives of stroke survivors and continued to reflect carefully on how my professional background as a physiotherapist influenced my understanding of walking. Further information about how my commitment to client-centred practice intersected with my professional perspectives in relation to this research is discussed in section 5.2.2 on page 81.

The third value is the importance of *systematically applying relevant theory* to guide intervention development. This project has been directly informed by the MRC guidelines for the development of complex interventions (Medical Research Council, 2006). These guidelines recommend any new intervention undertakes a careful and phased development process that is likely to involve mixed methods. The guidelines recommend starting with an intervention development phase which seeks to develop or clarify a theoretical understanding of likely causal change processes that the intervention produces. A better understanding of the mechanisms of change needed to produce sustained change in walking behaviour is likely to lead to more robust theoretical development that in turn can advance knowledge and optimise rehabilitation interventions. My commitment to valuing theory-informed interventions prompted me to select the MRC framework over other possible frameworks because of the focus on theoretical development, it's high level of uptake internationally and its relevance to the NZ context because of the way the framework encourages intervention development to be tailored to local contexts (Craig & Petticrew, 2013; Griffiths & Norman, 2013).

## 3.3 MRC guidance on intervention development

During the intervention development phase, the MRC guidelines on the development of complex interventions recommend three key goals to be achieved in order to develop an understanding of how an intervention might work (Medical Research Council, 2006). These goals are: 1) to identify the evidence base; 2) to identify and develop theory; and 3) to model processes and outcomes. Table 3 shows how each of the research questions of this thesis map onto the MRC guidelines.

Table 3. Overview of MRC goals and research questions for each phase

| MRC Goals | Research questions | Research phase |
|---|---|---|
| 1) to identify the evidence base | How effective are current intervention on real-world walking and can benefits be sustained? | Phase 1 - Systematic review |
| 2a) to identify theory | What does real-world walking mean to people with stroke and how do they think it can be better? | Phase 2 - Qualitative enquiry |
| 2b) to develop theory | How can physiotherapists intervene to support sustained change in real-world walking behaviours? | Phase 3a - Treatment theory building |
| 3) to model processes and outcomes/impact | What was the potential impact of the intervention and if it worked, how and why did it work?<br>1. Did the expected mechanisms of action operate?<br>2. Were there any unexpected mechanisms of action?<br>3. What features of context prevented anticipated mechanisms of action from being activated? | Phase 3b - Evaluation using case study |

The MRC guidelines have been influential (Craig & Petticrew, 2013; Griffiths & Norman, 2013) and although they provide useful recommendations for intervention development; they provide little methodological guidance on how to understand causal change processes (Moore et al., 2014) or navigate the philosophical and theoretical complexities inherent in mixing research methodologies and methods (e.g. Giddings & Grant, 2007). As a consequence the guidelines intentionally leave the selection of specific methodological approaches to the discretion of the researcher (Moore et al., 2014).

Informed by these MRC guidelines, I designed a multi-phase project. The first phase aimed to summarise the existing evidence base for interventions to improve real-world walking after stroke and is described in Chapter Four. The second phase aimed to examine insider perspectives on real-world walking and involved a qualitative enquiry with people with stroke exploring what real-world walking meant to them. The findings of this study are described in Chapter Five. The first two phases were designed as sequential independent studies each with its own research questions, data collection, analysis and interpretation; but both phases were designed to contribute to the wider programme of inquiry. The third phase aimed to build a theoretical model of how change could occur and to explain the underlying causal processes (or mechanisms of action) responsible for the change. It was designed as an iterative and fully integrated mixed methods study with integration occurring during data collection, analysis and interpretation. Chapters Six and Seven describe this third phase. An overarching realist research paradigm was selected for the project because it was felt to provide the best fit for the project (Pawson & Tilley, 1997; Pawson, 2006; Maxwell, 2013; Sayer, 2000). The process for selection of a realist philosophy is outlined below.

## 3.4   Realist philosophy

There were at least three major contenders for an overarching research philosophy; transformative, pragmatist and realist approaches. All three were broadly consistent with the values and goals of the project and compatible with mixed methods research (Maxwell, 2011; Shannon-Baker, 2015; Tashakkori & Teddlie, 2010). In the early stages of this project, each of these approaches were carefully considered. A pragmatist philosophy (e.g. Morgan, 2007) lent itself to the applied nature of the project but I felt that realism provided a more robust philosophical basis (Maxwell & Mittapalli, 2010). Throughout the project, I intentionally sought to understand the perspectives of stroke survivors and work collaboratively; so a transformative approach intuitively had appeal. However, this type of approach did not explicitly support the theory building needed. As the project developed though, I gradually recognised a realist philosophy provided the best fit for the project for the following reasons. First, realism holds

to a stratified view of reality and this ontological depth emphasises the significance of underlying causal mechanisms contributing to change. As the primary goal of the project was to understand how sustained change could occur, this view was likely to help produce new insights into causation. Second, a realist perspective explicitly explores how contextual factors can influence change processes. Given the emphasis on walking in real-world settings, understanding how the context influenced walking was likely to be important. Third, a realist perspective offers a distinctive view of interventions as programmes that work by providing resources that influence the reasoning of recipients (Pawson & Tilley, 1997; Pawson, 2006, 2013).

As a novice mixed-method researcher, there were also pragmatic reasons for selecting a realist approach. The existence of formal guidelines (Wong, Greenhalgh, Westhorp, Buckingham, & Pawson, 2013; Wong et al., 2016), training material (Wong, Westhorp, Pawson, & Greenhalgh, 2013) and ongoing support through the RAMSES listserv forum (RAMESES@JISCMAIL.AC.UK) provided helpful methodological guidance. I concluded a realist perspective would be the optimal approach to provide insights on how sustained change can occur.

Realism is a research philosophy that acknowledges the existence of an external, independent and stratified reality (Bhaskar, 2008; Sayer, 2000; Pawson & Tilley, 1997; Maxwell, 2012). Realism contends there is a real-world that exists "independently of perceptions, theories and constructions" (e.g. has a realist ontology) but it can only be understood through a person's senses and perspective (i.e. has a constructivist epistemology) (Maxwell & Mittapalli, 2010, p. 146). Stratification refers to a layered view of reality that includes what can be seen and measured but also recognises the existence of underlying entities known as mechanisms which cannot be seen nor measured (Bhaskar, 2008; Pawson & Tilley, 1997).

Realism initially developed from the field of sociology (e.g. Bhaskar, 2008; Sayer, 2000) and there are two variants or brands of realism commonly used in health-related research. *Critical realism* (e.g. Bhaskar, 2008; Bhaskar & Danermark, 2006; P. McEvoy & Richards, 2006) and *scientific realism* (e.g. Pawson & Tilley, 1997; Westhorp, 2014; Wong, Weshorp, Pawson, & Greenhalgh, 2013b) share similar

ontological and epistemological understandings and differ mainly on the level at which they conceptualise mechanisms and the values and purpose of the research (Dalkin, Greenhalgh, Jones, Cunningham, & Lhussier, 2015; Porter, 2015). In critical realism, mechanisms are often viewed in sociological terms and the purpose of a realist lens is to critique the way structural forces affect human actions (Dalkin et al., 2015). Scientific realism has a particularly applied focus and evaluators Ray Pawson and Nick Tilley pioneered the application of realist ideas to understand evaluation related problems (Pawson & Tilley, 1997; Pawson, 2006, 2013). This approach is gaining favour in many health related fields to help understand complex problems (Astbury & Leeuw, 2010; Blamey & Mackenzie, 2007; Marchal, van Belle, van Olmen, Hoeree, & Kegels, 2012). Throughout this thesis and particularly in the third phase, I draw on the work of Pawson & Tilley to explain the likely processes of change needed to improve real-world walking. For example, in this thesis, the term *mechanisms of action* most often describe how an individual changes their reasoning in response to resources provided by the intervention (Pawson, 2006; Pawson & Tilley, 1997).

Mechanisms have been identified for both physical and social worlds and both types of mechanisms embody a central tenet of realism - generative causation. An example of a causal mechanism from the physical world that has a real effect is the force of gravity which influences how objects move (Dalkin et al., 2015). In the social world, a commonly examined psychosocial mechanism is *trust* which has real effects and changes what people do because it changes how people think, reason and feel and therefore interact with others (e.g. Jagosh et al., 2015). Both physical and social mechanisms share key features; they generate or produce outcomes; they are not visible but must be inferred from the observable data; their capacity or generative potential may be unrealised and they are sensitive to changes in context (Astbury & Leeuw, 2010; Bhaskar, 2008).

Social mechanisms have been variously defined as entities (e.g. norms or belief systems), processes (sequences where later events depend on earlier ones), social structures (such as gender, class or cultural patterns of relationships) and, at an individual level, as changes in human reasoning (Astbury & Leeuw, 2010; Hedström & Ylikoski, 2010; Pawson & Tilley, 1997). This change in human

reasoning can occur in response to the resources and opportunities provided by an intervention (Pawson, 2013). For example, creating a plan to walk around the block after breakfast provides a new resource (i.e. the plan) which links an intention to act to an environmental cue that changes reasoning ("breakfast has finished so I will go for that walk now") and leads to a greater likelihood of performing the new behaviour.

Human beings have the capacity to make choices and act in certain ways (Hedström & Ylikoski, 2010). It is likely different types of mechanisms that control action can co-exist at multiple levels of reality such as the biological, psychological, psychosocial and cultural levels (Bhaskar & Danermark, 2006; Bhaskar, Frank, Hoyer, Naess, & Park, 2010). Discussions around human agency are common in sociological writings and human agency can be viewed at an individual or collective level (e.g. Sayer, 2000). There is an increasing body of neuroscientific research which supports the existence of agentic mechanisms at a neurobiological level (Inzlicht, Bartholow, & Hirsh, 2015; Inzlicht, Legault, & Teper, 2014; Legault & Inzlicht, 2013). This laminated view of reality expounded by Bhaskhar & Danermark (2006) recognises explanations for how mechanisms of action that produce change are likely to involve these multiple levels of reality.

Realists hold to a contingent view of causation which argues the presence of certain contextual features can influence whether mechanisms are activated or not (Dalkin et al., 2015; Pawson & Tilley, 1997). The example of gunpowder from the physical world, can illustrate the significance of contextual factors enabling or constraining the activation of mechanisms (Pawson & Tilley, 1997, p. 58). Several essential ingredients are required to make gunpowder. Charcoal, potassium nitrate and sulphur are all essential ingredients but are not sufficient on their own to release the latent explosive potential inherent in gunpowder. The flame is a key active ingredient which works with the other ingredients to activate the as yet unrealised capacity. However, certain contextual features (wet weather, for example) can constrain the flame from triggering the change process. Whether such activation occurs is dependent on specific conditions or contexts that can constrain or enable mechanisms from firing (Astbury & Leeuw, 2010; Pawson & Tilley, 1997). Two earlier examples of mechanisms used were gravity and trust.

Gravity and trust are also examples of mechanisms that can be constrained or enabled by contextual factors. The force of gravity is constrained when an object is under water. Collaborative interaction styles can enable trust and synergy to develop (Bright et al., 2014). A distinctive feature of a realist perspective is carefully considering how the context surrounding an implementation effort can influence the activation of mechanisms.

The literature reviewed in Chapter Two illustrates the relevance of a contingent view of causation to understanding how context can influence walking. Certain contextual features, such as the presence or absence of outdoor seating or attitudes of others, may work either as a constraint (e.g. Barnsley et al., 2012) or an enabler (Nicholson et al., 2013) due to the way an individual responds. Such reasoning may work to limit walking opportunities (e.g. "I am not feeling strong today and there is nowhere to stop and rest so I won't go") or optimise opportunities (e.g. "my wife wants to come too so it will be good to do it together"). This contingent view can generate new insights into how interventions produce change and the way the context surrounding interventions can contribute to these effects (Blamey & Mackenzie, 2007).

Intervention effectiveness can be determined by identifying what it is about an intervention that generates change (Westhorp, 2014). For example, a group based intervention seeking to promote physical activity would be considered successful if the recipient decides to respond to the opportunities offered by the programme. Such resources may be new information about the value of being active, new relationships with other group recipients, new experiences that produce greater trust in their body, and new opportunities to experience success in being active (A. M. Clark, Whelan, Barbour, & MacIntyre, 2005). In response to these resources, group members may become more receptive to the idea of being active and fully participate in the programme activities. As a consequence, the circumstances and characteristics of the individual change which, in turn, change the context (Pfadenhauer et al., 2015). The new context then triggers new mechanisms which contribute to the increasing effectiveness of the intervention.

Pawson and Tilley's emphasis on understanding different outcome patterns following interventions using the Context-Mechanism-Outcome configuration

(commonly referred to as a CMO configuration) was especially useful to this project (Pawson & Tilley, 1997). I argue any intervention aiming to produce sustained change in real-world walking (i.e. outcome = 'O') needs to consider the influence of the real-world setting (i.e. the contextual factors represented by 'C') and how the resources provided by an intervention leads to the activation of intervention mechanisms (known as 'M'). These CMO configurations encapsulate a realist view of active ingredients as they explain how the context activates a mechanism and what kind of outcome occurs as a result.

Although scientific realism emerged from the field of evaluation, this theoretical framework is now increasingly used in health settings to increase understanding of how complex health interventions work. This is primarily because this approach explicitly links the context, mechanisms and outcomes in CMO configurations and in doing so unpacks the black box (A. M. Clark, MacIntyre, & Cruickshank, 2007; Marchal et al., 2012; Abhyankar, Cheyne, Maxwell, Harris, & McCourt, 2013). While the distinction between intervention components, contextual factors and mechanisms of action can provide useful insights for intervention developers, in practice distinguishing between each element can be challenging (Dalkin et al., 2015; Marchal et al., 2012). This means applying a realist perspective is often demanding and requires a shift in thinking around core concepts.

### 3.4.1 Comparison of core concepts

Although realism is the overarching philosophy, this mixed-methods thesis draws, at times, on different theoretical perspectives when appropriate. In the first phase the majority of studies in the systematic review tended to be drawn from a biomechanical or behavioural perspective. In the second phase, where qualitative and constructivist perspectives were dominant, a different theoretical framework was used. Finally, in the third phase, a stronger realist perspective emerged. There are several core concepts in this thesis such as causation, context, mechanisms, outcomes, treatment theories, interventions and active ingredients. To help understand the distinct perspectives of each of the theoretical perspectives in relation to a realist view I developed a table which compares these concepts (See Table 4).

Table 4. Comparison of realist view with alternate perspectives on core concepts

| Dominant theoretical framework(s) | Realism | Biomedical/ Biomechanical | Behavioural | Constructivist |
|---|---|---|---|---|
| Related disciplinary fields | (Realist) Evaluation | Physiotherapy and Rehabilitation | Health Psychology | Varied |
| Causation (how interventions cause change) | Focuses on generative causation through (hidden) mechanisms which led to semi-regular patterns of outcomes, dependent on context for them to fire/activate (Pawson & Tilley, 1997) | Causation often not explicitly discussed but likely implicitly informed by biomedical account that works to remove cause of problem or minimise effects (Wade, 2015)<br><br>This view usually holds a secessionist view of causation that states if X happens then Y will happen (Pawson & Tilley, 1997; Dobkin, 2009b) | Understanding of causation dominated by social cognitive theories that focus on intrapersonal constructs which provide insights into motivation but not how to promote action (Brug et al., 2005; Rhodes & Nigg, 2011) | Constructivist researchers focus on a socially constructed understanding of human thought and action which is not compatible with a secessionist view of causation (Maxwell, 2012b, p. 656) |
| Context | A set of characteristics and circumstances that surround the implementation effort (Pfadenhauer et al., 2015)<br><br>Context interacts, influences, modifies, facilitates or constrains the activation of mechanisms | Contextual features do contribute to functioning but topic is conceptually underdeveloped and largely ignored (e.g. Hart et al., 2014a) | Often views contextual factors as a variables that need to be controlled for in order to avoid contamination with outcomes (e.g.Bishop, Fenge-Davies, Kirby, & Geraghty, 2015)<br><br>May be viewed as a moderator (e.g. Chase, 2015) or alternatively as a barrier or facilitator (e.g.Nicholson et al., 2013) | Provide in-depth understanding of meaning and context for each unique individual (Maxwell, 2012a) |

| Dominant theoretical framework(s) | Realism | Biomedical/ Biomechanical | Behavioural | Constructivist |
|---|---|---|---|---|
| Related disciplinary fields | (Realist) Evaluation | Physiotherapy and Rehabilitation | Health Psychology | Varied |
| Mechanisms | Refer to underlying entities processes or structures which operate in particular contexts to generate outcomes of interest (Astbury & Leeuw, 2010)<br><br>At individual level can be described as change in reasoning in response to the resources provided (Pawson & Tilley, 1997) | Processes by which the treatment's essential ingredients induce change in the target of treatment (Hart, Tsaousides, et al., 2014) | Refers to hypothesised mediators of desired outcomes<br><br>Usually taken from various mid-range theories (e.g. self-efficacy, autonomous motivation, self-regulation etc.)<br><br>Usually identified using statistical tests<br><br>Often considered a type of variable (e.g. Teixeira et al., 2012) | Not explicitly discussed but constructivist studies likely provide rich source of data on underlying processes (Maxwell, 2012b; Nicholls, 2009b) |
| Outcomes | Are considered in terms of immediate, intermediate and long term outcomes as well as unanticipated outcomes (Westhorp, 2014) | Described as a treatment target, which is a specific and measurable aspect of functioning selected for change in the patient(or other recipient of treatment, e.g., a caregiver)(Hart, Tsaousides, et al., 2014) | Refers to change in specific observable behaviour- often measured with self-report measures (e.g. Michie et al., 2009) | Are not the focus as constructivist research avoids causal claims (Maxwell, 2012b) |

| Dominant theoretical framework(s) | Realism | Biomedical/ Biomechanical | Behavioural | Constructivist |
|---|---|---|---|---|
| Related disciplinary fields | (Realist) Evaluation | Physiotherapy and Rehabilitation | Health Psychology | Varied |
| Treatment theory | Provides an explanatory account of how programme (intervention) works, with whom and under what circumstances (Blamey & Mackenzie, 2007)<br><br>Best articulated with explicit theory of change and theory of action linking key components (Funnell & Rogers, 2011) | Conceptual system that predicts the effects of specific forms of treatment on their targets, specifying the law(s) that expresses the relations between essential ingredients and treatment target changes (Whyte, 2014) | Treatment theories usually based on specific mid-range theory e.g. self-regulatory theory – but mechanisms of action under debate partly because current theories have limited predictive power (D. P. French, 2013; Rhodes & Nigg, 2011; Sniehotta, Presseau, & Araújo-Soares, 2014) | Some methodologies can provide useful insights to building theory (e.g. Barnsley et al., 2012; Ellis-Hill, Payne, & Ward, 2008) |
| Active ingredients | Components of the treatment bundle that were responsible for the effect (Lipsey, 1993) or mechanisms which are "necessary for the intervention to have its effects" (A. M. Clark, Thirsk, Wiens, Ski, & Thompson, 2015, p. 458). | Attributes of a treatment, selected or delivered by the clinician, that play a role in the treatment's effects on the target of treatment (Whyte, 2014). | "Intervention components that can be specifically linked to effects on outcomes such that, were they omitted, the intervention would be ineffective... distinct from mechanisms of action" (McCleary, Duncan, Stewart, & Francis, 2013, p. 2) | Not discussed |

Differentiating between these theoretical perspectives clarified my understanding about what was distinctive about a realist view and helped generate complementary insights. This process of differentiation is a particular strength of mixed methods research and is discussed further in the next section. This process of exploring how concepts differed helped to make sense of the literature I was reviewing and the language that I was using to explain concepts. This was particularly helpful during integration of quantitative and qualitative data during the final phase.

## 3.5  Mixed methods

Mixed methods are particularly suitable for understanding the complex nature of rehabilitation interventions and can provide new insights by drawing on the complementary perspectives provided by range of quantitative and qualitative methods (Cresswell, 2009; Farquhar, Ewing, & Booth, 2011; Shaw & DeForge, 2012). Maxwell & Mittapalli (2010) proposed a realist view is particularly congruent with mixed methods research in part because it has a realist ontology and a constructivist epistemology. This means using an overarching realist philosophy in mixed methods can be particularly productive, because it validates and supports key aspects of both quantitative and qualitative approaches and provides a way to overcome the limitations of each. To illustrate: one way of understanding real-world walking is to consider it as something that can be objectively measured and recorded quantitatively using an activity monitor (e.g. Dobkin & Dorsch, 2011; Fulk et al., 2010). This approach is consistent with a positivist or realist ontological view, and can be thought of as an external or *outsider's* perspective (Nicholls, 2009a). An alternative understanding of real-world walking values the perspective of the person who has suffered the stroke (i.e. an *insider's* perspective). From this perspective, real-world walking may be a significant and meaningful activity with important symbolic value (e.g. Gibson & Teachman, 2012; Jordan, Berkowitz, Hannold, Velozo, & Behrman, 2013). An interpretivist or constructivist approach focuses on understanding meaning from the perspective of the person experiencing the phenomenon (Nicholls, 2009a; Van Manen, 1997), and this is consistent with the epistemology of realism. From a realist point of view, both quantitative and qualitative approaches are valid, can

provide complementary perspectives and can justifiably be incorporated into a mixed methods thesis (Maxwell & Mittapalli, 2010).

The design of mixed methods studies requires careful consideration of several aspects. Collins & O'Cathain (2009) have usefully summarised these key issues into ten points and each of these points will now be explored further in relation to this research project. *First*, at various times the term *mixed methods* has been used to describe methods of data collection, methodologies of research or a distinctive research philosophy ( Johnson, Onwuegbuzie, & Turner, 2007). In this project, which used an overarching realist research philosophy, the term was used primarily to refer to methods of data collection. The phrase mixed methods can also describe the process of collecting, analysing and integrating both quantitative and qualitative data in a single study or in multiple studies as part of a coherent programme of inquiry ( Johnson et al., 2007). Although there were three phases (one qualitative, one quantitative and one integrated), the programme as a whole can be considered a mixed methods study because all three phases contributed to a single programme of inquiry.

*Second,* Collins & O'Cathain  (2009) state the importance of *recognising the mental models* used by researchers during the design process. The mental models of researchers contain their experiences, values and beliefs and can significantly influence design, analysis and interpretation of mixed methods studies (e.g. Hunt, 2009; Shaw, Connelly, & Zecevic, 2010). Reflective practices can help to recognise the influence of these mental models (Anderson & Funnell, 2005). Throughout this project, I completed several reflective activities designed to reveal how my mental models or paradigms could influence the research. An interactive design map combining goals, research questions, analysis strategies and conceptual frameworks was constructed  in the early days of the research and is included in Appendix B (Maxwell, 2013). In addition to keeping a reflective journal, I completed guided interviews with experienced qualitative researchers, and held regular discussions with my supervisory team. Topics for specific critical reflection included personal and professional goals, professional models of practice and person-centred practice.

*Third, utilising typologies* to assist with research design is recommended, particularly for novice researchers (Creswell & Plano Clark, 2011). Typologies in this context refer to well established combinations of quantitative and qualitative strands to provide some structure to the design process. A three phase project was used for this project and the design is broadly in keeping with the recommendations of the MRC guidelines which recommend a quantitative systematic review followed by theory building with interviews and then a phase which focuses on examining causal change processes (Medical Research Council, 2006).

*Fourth,* Collins & O'Cathain (2009) remind mixed method researchers to be explicit about both the *purpose* and the *reasons* for mixing methods. The first purpose for the use of mixed methods in this research was to provide a type of conceptual triangulation. Greene, Caracelli and Graham (1989) describe triangulation as a way of providing convergence using different methods. A further reason for mixing methods was to provide complementary insights to assist with intervention development (Campbell et al., 2000). Complementariness refers to greater illumination of findings through "elaboration, enhancement, illustration or clarification" (Greene et al., 1989, p. 259). The process of complementarity provided insights into how intervention components elicited processes behind sustained change.

*Fifth,* careful attention to the development of appropriate research questions for the different strands is recommended. The overall objective of this programme of research is to develop a treatment theory to inform the future development of interventions to promote sustained change in real-world walking after stroke. Each of the three phases has its own research question which was carefully constructed based on the goal of each phase, the theoretical frameworks and methodologies being used. Table 3 on page 45 lists these questions.

*Sixth,* Collins & O'Cathain (2009) alerts researchers to the need to be explicit about which strand is the priority when mixing methods. For the first phase of this project, quantitative data was dominant. In the second phase, qualitative data was prominent. In the third phase, a blended approach was taken with both

types of data having equal emphasis. Outcome data was primarily quantitative and data about mechanisms of action was primarily qualitative in the third phase.

*Seventh,* in relation to *sample design,* Collins & O'Cathain (2009) argue sample size should be influenced by the unit of analysis being used. For example, a case study may aim for 3-5 participants (Yin, 2014), where as a grounded theory study would require larger numbers (Onwuegbuzie & Collins, 2007). Qualitative and quantitative data in the third phase were collected concurrently because the goal of this phase was triangulation and complementarity (Onwuegbuzie & Collins, 2007). This study used a parallel approach to sampling (Onwuegbuzie & Collins, 2007) where different individuals participated in the qualitative and mixed methods phase but both samples were drawn from the same population (i.e. people with stroke living in the Greater Auckland area who have a desire to improve walking). In this research, depending on the type of methodology being utilised, there was careful consideration of issues around sample size for each phase.

The *eighth* point refers to the need for careful selection of different types of data collection to ensure different approaches produce data with "complementary strengths and non-overlapping weaknesses" (Johnson & Turner, 2003, p. 299). Deductive reasoning starts with a hypothesis which is testable and often produces quantitative outcome data. For example, the systematic review in the first phase collected quantitative outcome data that could be compared across different studies. However, the review did not indicate how or why change occurred. The interview data in the second phase collected qualitative data about contextual elements and insights into the reasoning of participants that explained how they thought change could occur but the findings cannot be compared to other contexts (Nicholls, 2009b). The third phase used both quantitative measures and qualitative data to overcome the limitations of both data sources by providing information on whether change had occurred and insights into what had caused the change.

The *ninth* point relates to issues around *data analysis* in mixed methods relating to how the quantitative and qualitative data strands are analysed and integrated. Wooley argues two strands can only be truly integrated when:

> components are explicitly related to each other within a single
> study and in such a way as to be mutually illuminating, thereby
> producing findings that are greater than the sum of the parts
> (Woolley, 2009, p. 7).

In this programme of inquiry the first two phases were analysed separately. During the third phase, two techniques for data integration were used (O'Cathain, Murphy, & Nicholl, 2010). More details about these data integration techniques are provided in section 7.2.5 on page 174.

Finally, the *tenth* point refers to the ability of the mixed methods researcher to make inferences or generalisations from the findings which realists address through the development of mid-range theories. Mechanisms are considered to be the building blocks for mid-range theories, and it is these theories that can then be transferred to different contexts (Astbury & Leeuw, 2010, p. 374). The development of mid-range theories produces knowledge that is useful in other contexts (Angus & Clark, 2012; Astbury & Leeuw, 2010; Blamey & Mackenzie, 2007; P. McEvoy & Richards, 2006; Pawson & Tilley, 1997). To sum up, a mixed methods design was used in this project to generate complementary insights to assist with theory building.

## 3.6   Building treatment theories

Small theories (also called programme theories or treatment theories) was a term coined by Lipsey as a way of explaining the so called *black box* (Lipsey, 1993). He described their purpose as:

> A treatment theory is a set of propositions regarding what goes
> into the black box...that is how a bad situation is transformed into
> a better one through treatment inputs (Lipsey, 1993, p. 11).

A treatment theory is a specific type of theory with three elements; it is abstract in nature, it describes what the intervention comprises and how it is expected to work (Davidoff et al., 2015; Hart, Tsaousides, et al., 2014; Lipsey, 1993; Siegert et al., 2005). In a treatment theory, the desired outcome (e.g. sustained change in walking behaviour) and the reasons why or how change occurs are linked with what the therapist needs to do. This final category includes treatment activities which can be known as intervention components or ingredients of therapy. Understanding each of these elements helps to *unpack the black box.*

*Small* theories of treatments can be distinguished from *mid-range* or *grand* theories due to the differences in levels of abstraction (Davidoff et al., 2015). The principles provided by grand theories can be used across several broad domains (Whyte, 2008). The theory of relativity from physics or conflict theory from sociology are two examples of grand theories (Davidoff et al., 2015; Whyte, 2008). Rehabilitation academics have concluded it is unlikely a single grand theory will provide a unifying framework for rehabilitation but a "myriad of theories" are more likely to be relevant (Whyte, 2008, p. 208). Mid-range theories are a broad grouping of theories positioned between grand theories and small theories and have direct relevance to understanding problems and can guide intervention development. For example, self-regulatory theory from health psychology (De Ridder & De Wit, 2006) describes the way individuals direct and control their actions to achieve their desired goals and has been successfully used as framework to guide goal setting in rehabilitation (e.g. McPherson, Kayes, Weatherall, & on behalf of all members of the Goals-SR Research Group, 2009). Given the nature of clinical practice, it is likely mid-range theories from a number of disciplines outside rehabilitation will be important (Hart, Tsaousides, et al., 2014; Hart, Ferraro, Myers, & Ellis, 2014; Higgs & Titchen, 1998). As well as building a specific small (treatment) theory, this thesis will seek to identify mid-range theories likely to be of relevance.

One particularly useful contribution to this thesis, drawn from the discipline of evaluation, was the practice of developing an explicit treatment theory (Blamey et al., 2013; Funnell & Rogers, 2011; Lipsey, 1993; Weiss, 1997). There are a variety of recommended methods including logic models, pipeline models and outcome chains amongst others (Blamey & Mackenzie, 2007; Funnell & Rogers, 2011). Funnel and Rogers (2011) provide insightful and practical advice in their book "Purposeful Programme Theory". They propose that ideally every treatment theory should have two components: a theory of change and a theory of action. A theory of change provides an explicit theoretical description of how it is proposed the programme will produce change and a theory of action describes activities specifically selected to promote the desired change processes. An outcomes chain links immediate, intermediate and long-term outcome and is pivotal because it combines both theories together. This thesis will focus on building a treatment

theory that includes a theory of change and a theory of action which together explain how an intervention can lead to sustained change in walking behaviours after stroke.

## 3.7 Methodological foundations of specific phases

In this section, I will outline the theoretical framework and the methodology used for each of the three phases. As noted already, more specific information about the methods for each phase is contained in the relevant chapter. Figure 5 provides an overview of how the different phases relate to each other.
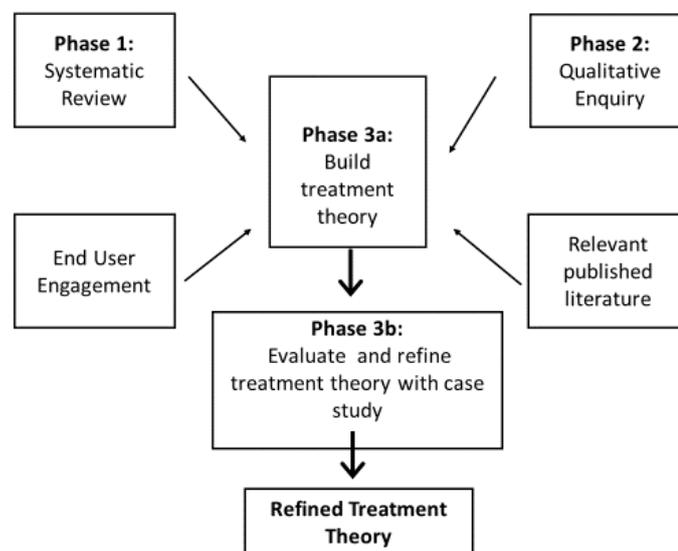


Figure 5. Relationships between different phases of project

### 3.7.1 Phase 1

The first task undertaken in this project was the synthesis of information with a systematic review. Systematic review methodologies seek to answer questions about effectiveness, have a number of strengths including specific methodological guidelines and are a commonly used methodology in rehabilitation and health (Higgins & Green, 2009). Systematic review methodologies draw on a view of causation commonly found in positivist research philosophies (Nicholls, 2009a) and seek to determine causation through experimental methods (Pawson & Tilley, 1997; Petticrew et al., 2013b). Both positivist and realist perspectives value empirical ways of viewing a real-world (Maxwell & Mittapalli, 2010). The purpose of this kind of research is to try to

understand if something is effective, or not, on average, rather than how or why it is effective (Noyes et al., 2013; Petticrew et al., 2013). The specific research question was, "How effective are current interventions at improving real-world walking and can they be sustained?" Chapter Four describes the methods and findings of Phase 1 in detail.

### 3.7.2  Phase 2

The purpose of Phase 2 was to provide insight into the perspectives of people with stroke to inform the theory building for the final phase. This second phase used a qualitative approach to aid understanding of an insider perspective about what real-world walking meant to people after stroke and how they thought it could be better. Interpretive Descriptive methodology was used for this phase (Thorne, 2008). Interpretive descriptive is a qualitative methodology designed for research to address clinical problems (Thorne, 2008; Thorne, Kirkham, & MacDonald-Emes, 1997). This methodology was particularly appropriate for the topic because it recognises the messiness and complexity of clinical practice and brings an applied and constructivist qualitative lens to understanding the problem (Thorne, 2008). The methods and findings of Phase 2 are discussed in more detail in Chapter Five.

A realist research philosophy has a constructivist epistemology which considers knowledge is constructed through a person's senses and perspective (Maxwell & Mittapalli, 2010, p. 146). This is similar to the constructivist roots of interpretive descriptive methodology (Thorne, 2008). Some researchers argue realist and relativist approaches are not compatible (e.g. Denzin, 2012). In contrast, Maxwell (2010) contends realism is compatible with qualitative research and can overcome some of the limitations of qualitative approaches informed by a relativist paradigm such as the difficulty generalising findings to other contexts. This is because a realist perspective (as discussed in section 3.5) seeks to identify mid-range theories which are theoretically portable between contexts (Astbury & Leeuw, 2010). Rather than ignoring or minimising philosophical assumptions, they propose a realist research philosophy can work with different theoretical perspectives by viewing them as a type of mental model or tool (Maxwell, 2011, 2013). By viewing differing theoretical perspectives as tools, complementary

insights can provide the flexibility needed to generate new understanding and help refine ideas thus enhancing theory building (Greene et al., 1989; Maxwell & Mittapalli, 2010; Shaw & DeForge, 2012).

### 3.7.3 Phase 3

The purpose of the third phase was to build, evaluate and refine a treatment theory using tools drawn from the field of evaluation. Chapter Six describes the theory building work which led to the development of a theory of change and a theory of action. The development of these theories drew on data integrated from the first phase, second phase and the end user consultation processes (Bazeley, 2009). The first group of end users in this phase consisted of neurological physiotherapists (which included clinicians, clinical educators and lecturers) who contributed to theory building by attempting to explicitly articulate their understanding of the concept of carryover in neurological physiotherapy as a starting point for theory building. The second group that I consulted with included rehabilitation academics who of end users employed their content knowledge in the field of behaviour change to provide additional detail of explanatory core concepts that influenced carryover. More information about this process is provided in section 6.4.3

Chapter Seven describes how the treatment theory was operationalised into an intervention, delivered to people with stroke and the potential impact of the intervention evaluated. To assist with intervention development a third end-user consultation group comprising people with stroke and their families was used. Feedback from this group was used to develop the intervention. For example, the development of the walking group was directly informed through discussion with this group. The group also provided feedback regarding the types of outcome measures they felt were likely to be appropriate and manageable for the evaluation. A case-study approach (Yin, 2014) was used to evaluate the intervention (Wong et al., 2016). Outcome data was compared to outcomes predicted by the initial treatment theory. This process of comparing theoretical and empirical data enabled further refinement of the initial treatment theory. Further information about the methods and findings used in the third phase are provided in Chapters Six and Seven.

## 3.8 Chapter summary

Chapter Three has charted the development process undertaken to provide the project with its methodological foundation. The chapter provided an overview of the three phases of research, a discussion of the significance of three core values to the development of this project and an explanation of the importance of the MRC guidelines. The key characteristics of a realist research philosophy were outlined and the way this philosophy views the core concepts of this thesis explained. Such concepts include generative causation, context-dependent mechanisms of action, the significance of mid-range theories and the importance of CMO configurations to explain patterns of outcomes. Mixed method data collection approaches were used in this project to provide complementary information to inform theory building and careful attention was given to how the qualitative and quantitative strands were integrated. More specific details about the research methods used is covered in each of the relevant chapters. The relationship between theoretical frameworks, methodologies and methods has been detailed in an effort to ensure there is a sense of logical consistency and coherence between all of the phases.

# Chapter 4  Phase 1- Reviewing what is currently known

## 4.1  Introduction

This chapter provides a systematic review of what is currently known about the effectiveness of interventions to improve real-world walking after stroke and seeks to clarify whether any benefits can be sustained. As described in the introduction to this thesis, real-world walking describes actual walking in usual settings as opposed to the walking that occurs in a clinic or standardised environment characteristic of rehabilitation settings (World Health Organisation, 2002). Real-world walking behaviours can be measured with an activity monitor or by retrospective self-reports of actual walking (Tudor-Locke & Myers, 2001). The review was published in 2017 (Stretton, Mudge, Kayes, & McPherson, 2017).

Several randomised controlled trials have investigated the use of physical training to improve walking for people with stroke (Ada et al., 2013; Duncan et al., 2011; Mudge et al., 2009; Pang et al., 2005; Van De Port, Wevers, Lindeman, & Kwakkel, 2012). Most studies report similar findings with gains in the ability to walk further and/or faster in the indoor clinic setting (Ada et al., 2013; Mudge et al., 2009; Pang et al., 2005; Van De Port et al., 2012). The size of the treatment effect in these studies is modest (e.g. 20-50m increase in the six-minute walk test - a measure of walking ability) and gains in ability following skill training are seldom sustained once the intervention has ceased (Wade, Collen, Robb, & Warlow, 1992; J. Green, Young, Forster, Collen, & Wade, 2004; Ada et al., 2013; Mudge et al., 2009).

Intervention components informed by Control Theory (Carver & Scheier, 1982) such as goal setting and self-monitoring appear particularly effective at changing levels of physical activity for healthy people presumably by improving behavioural self-regulation (Michie et al., 2009). However it is not clear whether such behaviour change techniques which require self-regulatory skills are effective at promoting sustained change in real-world walking following stroke (D. P. French et al., 2014). The overall research question for the review was firstly: how effective are current interventions at improving walking in the real-world

compared to usual care or no intervention for people with stroke? Secondly, can any benefits be sustained?

## 4.2   Methods

This systematic review was informed by guidelines produced by the Cochrane collaboration (Higgins & Green, 2009) and drew on a positivist research philosophy that prioritises empirical evidence from randomised controlled trials (Noyes et al., 2013; Petticrew et al., 2013). The majority of research identified in this review had a biomedical or behavioural theoretical perspective and a systematic approach was useful to help summarise this body of research. As discussed in section 3.7.1 and summarised in Figure 4, both positivist and realist perspectives value empirical data, although a realist perspective also values the hidden generative mechanisms that produce the outcomes that empirical observations record (Angus & Clark, 2012; A. M. Clark et al., 2015; P. McEvoy & Richards, 2006). I began this research process by undertaking a systematic review of the literature.  In later stages, I applied the insights gained to inform the later phases of research where the focus shifted to seeking greater understanding of how interventions work and in what contexts. For more information about how the data in this review contributed to theory building using a realist perspective see section 6.3.1.

In this systematic review, the first step was to include all published randomised controlled trials or quasi randomised controlled trials exploring the effectiveness of either a single intervention or combined interventions on real-world walking following stroke. The primary outcome was a change in real-world walking (as measured by an activity monitor such as an accelerometer or pedometer and/or measured with self-report questionnaire). The definition of real-world walking behaviour was developed through an iterative process that involved reviewing existing definitions of related concepts (e.g. community ambulation, performance, capacity and capability) and debate and consultation with the review team to reach a consensus on a definition. The primary outcome focus of this review is walking activity a person actually *does do* in real-world settings (e.g. performance) as opposed to what they *can do* (e.g. capacity or capability)

(Holsbeeke et al., 2009). The full definition of real-world walking was provided in Chapter One on page 3.

Studies were included if they included participants ≥16 years of age with a stroke of any type, a randomised or quasi-randomised study design was used and if there was a control group that provided usual care, no intervention or attention control. When screening for inclusion, I looked carefully at the outcome measures in each study to ascertain whether it reflected real-world walking behaviour as described in our definition. For a self-report measure to be included, the majority of items (i.e. >50%) needed to be consistent with our definition. If I was not able to obtain a copy of the outcome measure then it was not included. Interventions were considered as long as an outcome measure that quantified real-world walking was used. Interventions were included whether delivered by a health professional or a lay person and irrespective of whether the mode of delivery was one on one, to a group or via computer or phone. Only studies published in English were included due to funding and resource limitations.

### 4.2.1  Search strategy

The following databases were searched; EBSCO Megafile (which includes Medline, CINAHL, Sports Discus), AMED, Scopus and the Cochrane Database of Systematic Reviews. A second search using key words of; 'walking and stroke', 'gait and stroke' and 'activity and stroke' was undertaken in PEDRO, OT Seeker and Psychbite. The reference lists of three Cochrane systematic reviews (Barclay, Stevenson, et al., 2015; Pollock et al., 2014; States et al., 2009) which included interventions to improve walking after stroke were hand searched for relevant studies that met our inclusion criteria. Databases were searched from the date of their inception; the initial searching took place in February 2013 and was updated in November 2015. See Appendix A for the full search strategy.

### 4.2.2  Screening for inclusion

The initial screening process involved reviewing titles and abstracts to identify those papers possibly or probably meeting the inclusion criteria. The full text of each paper was retrieved and reviewed by two independent reviewers (myself and my primary supervisor) to determine eligibility for inclusion. If there was any

uncertainty, a copy of the outcome measure was obtained and closely scrutinised. Disagreements were initially resolved by discussion and consensus and, if necessary, a third reviewer (my secondary supervisor). acted as an adjudicator

Some of the studies published a protocol or further information about the intervention (Duncan et al., 2007; Galvin, Cusack, & Stokes, 2008; Logan et al., 2006; Mansfield et al., 2013). These papers were excluded from the meta-analysis but referred to during the data extraction process for additional information as needed.

The mobility subscale of the Nottingham Extended Activities of Daily Living, was identified as potentially containing items of relevance. Authors of each study (n=2) using this outcome were contacted to request the raw data to enable a more thorough analysis. Both sets of authors contacted were able to provide this data (Galvin, Cusack, O'Grady, Murphy, & Stokes, 2011; Logan, Gladman, et al., 2004) and these two studies were then included following reanalysis of the data supplied. Reanalysis involved dichotomising the raw data in Excel 2010 (into '0' for did not do and '1' for did do) and the scores summed for each item with means and standard deviations calculated. For example, the first item on the mobility subscale is "In the last few weeks did you walk around outside?" There were four preselected answers and each response was given an '0' if the answer was 'Not at all' but an '1' if it was either 'with help', 'on your own with difficulty' or 'on your own'. This was necessary to ensure the outcome truly reflected what someone actually did do, regardless of whether they required assistance to do it.

### 4.2.3 Data extraction and analysis

Data were extracted and level of bias assessed independently by two reviewers (myself and my primary supervisor) using the Cochrane Risk of Bias Form which evaluates each study for different sources of potential bias (Higgins & Green, 2009). Extraction of information from each study included: a) study aims, b) design, c) description of participants including inclusion and exclusion criteria, d) study setting, e) description of intervention and control including duration, timing and who delivered it, f) outcomes that reflected the domain of interest

and g) potential for bias issues, including the presence of a blinded assessor and how missing data was handled.

Data were entered in Review Manager (RevMan)5 and individual effect sizes, using post-intervention outcomes calculated. Given the heterogeneity of the outcome measures, a standardised mean difference (SMD) was used to calculate the overall effect size and measures of consistency using the $I^2$ statistic were calculated (Higgins & Green, 2009). A random effects analysis was undertaken (Higgins & Green, 2009). Two of the studies (Duncan et al., 2011; Mudge et al., 2009) used the same outcome measure- StepWatch$^{TM}$ Activity monitor, so an additional analysis for these studies using a mean difference  was completed. Three studies (Galvin, Stokes, & Cusack, 2014; Mudge et al., 2009; Van De Port et al., 2012) did a follow-up assessment at three  months post intervention and two studies (Logan, Gladman, et al., 2004; Pohl et al., 2007) at six months and so follow-up results were included for five studies.

In line with the review protocol, interventions were grouped as either a) primarily consisting of progressive exercise or b) explicitly including at least one or more of the 40 behaviour change techniques as outlined by the CALO-RE taxonomy for use in interventions to improve physical activity (Michie, Ashford, et al., 2011). The presence of a specific behaviour change technique in included studies was identified either by using the taxonomy or by identifying an explicit intent (documented in either the published paper or manual of procedures) to support behaviour change. Preplanned subgroup analysis was undertaken to compare progressive exercise alone to interventions including at least one behaviour change technique in conjunction with either exercise or escorted community walking. Overall standardised mean differences were calculated for these two subgroups using the final assessment point.

## 4.3  Results

Figure 6 shows the flow of information through the study. Seven separate trials met all of the inclusion criteria (Dean et al., 2012; Duncan et al., 2011; Mansfield et al., 2013; Mudge et al., 2009; Pang et al., 2005; Pohl et al., 2007; Van De Port et al., 2012). One of these trials (Duncan et al., 2011) had more than one treatment arm

and so both arms were included in our review: a) the early Locomotor Training Programme (LTP) on a treadmill ('Duncan 2011a LTP') and b) the Home Exercise Programme ('Duncan 2011b HEP') using the data from Nadeau et al. (2013). For this study the size of the control group was adjusted accordingly (i.e. the total number of the control group was divided by two). Following reanalysis of the raw outcome data, two more studies (Galvin et al., 2014; Logan, Gladman, et al., 2004) met our inclusion criteria. This meant that the review included nine separate studies with 10 treatment arms.

The trials included a variety of different interventions with four using primarily progressive task-oriented exercises either individually (Pohl et al., 2007) or group based (Dean et al., 2012; Mudge et al., 2009; Pang et al., 2005; Van De Port et al., 2012). The five remaining trials (Dean et al., 2012; Mansfield et al., 2015; Galvin et al., 2011; Logan, Gladman, et al., 2004; Nadeau et al., 2013) included at least one behaviour change technique as defined by the CALO-RE taxonomy (Michie, Ashford, et al., 2011). Appendix C provides an overview of the studies included in the review. Each study is identified by the first author and date. Appendix D on page 307 contains a list of studies excluded with reasons why.
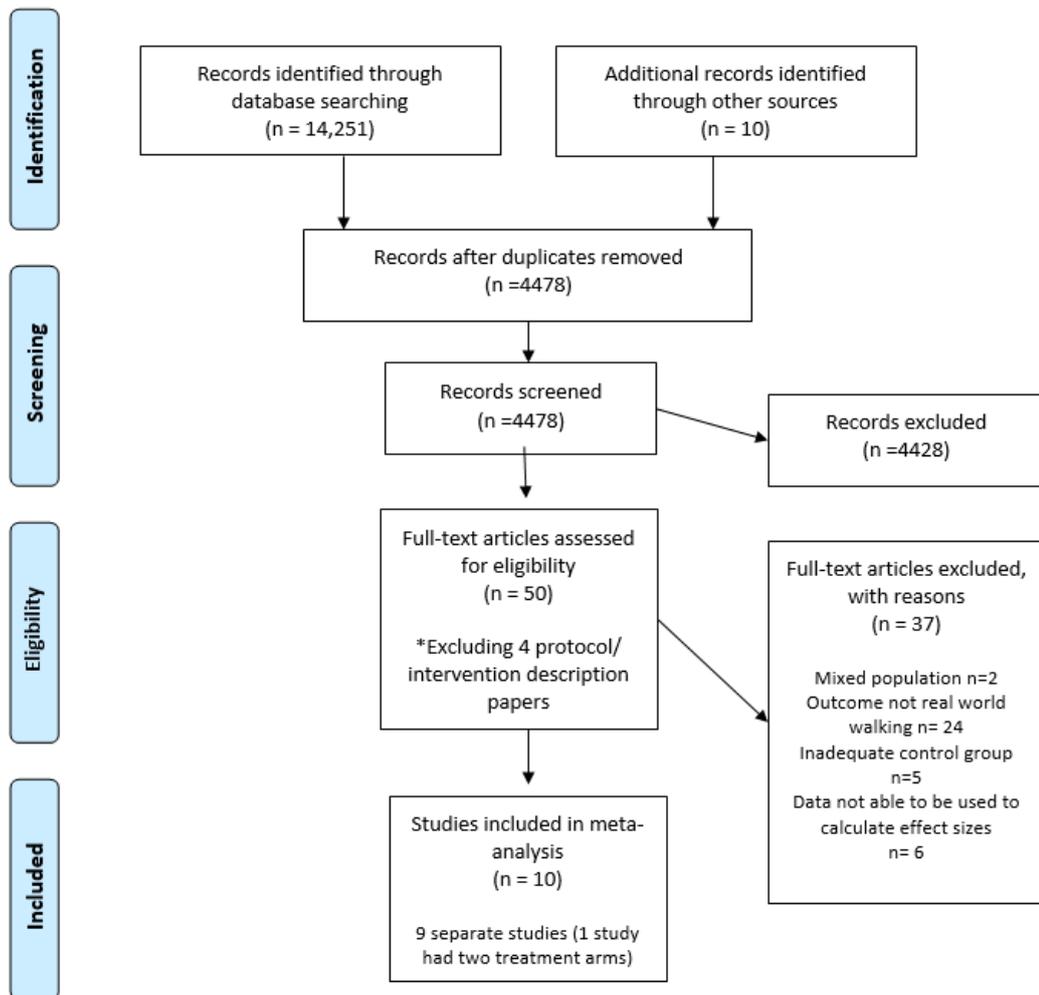
Figure 6. Flow of information through the study

### 4.3.1 Risk of bias in included studies

In this review, the majority of studies had appropriate processes for randomisation and blinded outcome assessment. Blinding of participants and delivery personnel is particularly difficult in rehabilitation interventions studies where activity components are observable. Two of the studies in this review included an adequate attention control such as arm exercises or social/educational interventions to counter this source of bias (Mudge et al., 2009; Pang et al., 2005). Table 5 below shows that overall there appeared a very low risk of bias influencing the findings of this review.

Table 5. Risk of bias table for each included study using Cochrane Risk of Bias Tool*

| Study | Random Sequence Generation | Allocation Concealment | Blinding Participants and Personnel | Blinding of Outcome Assessment | Incomplete Data | Selective Reporting | Other Bias and Notes |
|---|---|---|---|---|---|---|---|
| Dean 2012 | Low | Low | High | Low | Low | Low | Outcome measure (pedometer) not valid for this population |
| Duncan 2011 | Low | Low | Low | Low | Low | Low | High quality study |
| Galvin 2011 | Low | Unclear | High | Low | Low | Low | |
| Logan 2004 | Low | Unclear | High | Low | Low | Unclear | |
| Mansfield 2015 | Low | Low | High | Low | Low | Low | |
| Mudge 2009 | Low | Low | Low | Low | Low | Low | High quality study |
| Pang 2005 | Low | Unclear | Unclear | Low | Low | Unclear | |
| Pohl 2007 | High | High | High | Unclear | Low | Low | |
| Van de Port 2012 | Low | Low | High | Low | Low | Low | |

Drawn from Higgins & Green, (2009)

## 4.3.2 Measures of treatment effect

The standardised mean difference in favour of the intervention was small (SMD 0.29; 95% confidence interval 0.17- 0.41) indicating the interventions had a small but positive effect on improving real-world walking (see Figure 7).

| Study or Subgroup | Experimental Mean | SD | Total | Control Mean | SD | Total | Weight | Std. Mean Difference IV, Random, 95% CI |
|---|---|---|---|---|---|---|---|---|
| Dean 2012 | 4,365 | 3,350 | 64 | 3,357 | 3,256 | 62 | 10.6% | 0.30 [-0.05, 0.65] |
| Duncan 2011a LTP (1) | 3,926 | 2,913 | 120 | 3,360 | 2,857 | 68 | 13.9% | 0.19 [-0.10, 0.49] |
| Duncan 2011b HEP (2) | 4,343 | 3,501 | 120 | 3,360 | 2,857 | 68 | 13.8% | 0.30 [-0.00, 0.60] |
| Galvin 2011 | 3.7 | 1.69 | 18 | 3.55 | 2.16 | 19 | 3.5% | 0.08 [-0.57, 0.72] |
| Logan 2004 | 4.02 | 2 | 84 | 3.21 | 2.32 | 74 | 12.7% | 0.37 [0.06, 0.69] |
| Mansfield 2015 | 6,195 | 2,918 | 29 | 5,604 | 2,524 | 28 | 5.3% | 0.21 [-0.31, 0.73] |
| Mudge 2009 | 5,804 | 2,019 | 31 | 5,359 | 2,027 | 27 | 5.3% | 0.22 [-0.30, 0.73] |
| Pang 2005 | 13.7 | 10.9 | 30 | 18.6 | 16.8 | 30 | 5.5% | -0.34 [-0.85, 0.17] |
| Pohl 2007 | 8.5 | 3.9 | 72 | 6.3 | 3.7 | 72 | 11.6% | 0.58 [0.24, 0.91] |
| Van de Port 2012 | 13.47 | 1.44 | 125 | 12.82 | 1.9 | 117 | 17.8% | 0.39 [0.13, 0.64] |
| | | | | | | | | |
| Total (95% CI) | | | 693 | | | 565 | 100.0% | 0.29 [0.17, 0.41] |

Heterogeneity: Tau² = 0.01; Chi² = 10.50, df = 9 (P = 0.31); I² = 14%
Test for overall effect: Z = 4.58 (P < 0.00001)

Footnotes
(1) Duncan 2011 has two treatment arms so 'n' of control group is divided by 2
(2) Duncan 2011 has two treatment arms so 'n' of control group is divided by 2

Figure 7. Effect of current interventions on real-world walking at post-intervention assessment

Five studies included follow-up data at a second assessment point (Galvin et al., 2008; Logan, Gladman, et al., 2004; Mudge et al., 2009; Pohl et al., 2007; Van de Port et al., 2012). The overall SMD of the effectiveness of the interventions at the follow-up assessment was 0.32 [0.16-0.48]. This indicates that changes in real-world walking following interventions can potentially be sustained once the intervention has finished (see Figure 8).

| Study or Subgroup | Experimental Mean | SD | Total | Control Mean | SD | Total | Weight | Std. Mean Difference IV, Random, 95% CI |
|---|---|---|---|---|---|---|---|---|
| Pohl 2007 | 10 | 4.1 | 64 | 7.8 | 4.8 | 64 | 20.7% | 0.49 [0.14, 0.84] |
| Galvin 2011 | 4.95 | 1.79 | 18 | 4.05 | 2.16 | 17 | 5.7% | 0.44 [-0.23, 1.12] |
| Van de Port 2012 | 13.5 | 1.42 | 125 | 13.03 | 1.82 | 117 | 40.0% | 0.29 [0.03, 0.54] |
| Logan 2004 | 3.55 | 2.18 | 76 | 2.98 | 2.3 | 69 | 24.0% | 0.25 [-0.07, 0.58] |
| Mudge 2009 | 5,559 | 1,517.2 | 31 | 5,360 | 1,521.9 | 27 | 9.6% | 0.13 [-0.39, 0.65] |
| | | | | | | | | |
| Total (95% CI) | | | 314 | | | 294 | 100.0% | 0.32 [0.16, 0.48] |

Heterogeneity: Tau² = 0.00; Chi² = 1.77, df = 4 (P = 0.78); I² = 0%
Test for overall effect: Z = 3.86 (P = 0.0001)

Figure 8. Effect of current interventions on real-world walking at follow-up assessment

A variety of self-report measures were used for analysis: Rivermead Mobility Index (Pohl 2007; Van De Port 2012); dichotomised mobility subscale of the Nottingham Extended Activities of Daily Living, (Galvin 2008; Logan 2004); and the Physical Activity Scale for Individuals with Disabilities (Pang 2005). One study used a pedometer (Dean 2012) but two studies used the StepWatch $^{TM}$ Activity Monitor (Mudge et al., 2009; Nadeau et al., 2013). A mean difference was calculated for the studies which provided specific information about the size of the treatment effect. The overall mean difference for the StepWatch$^{TM}$ was 675 average steps per day [CI 137, 1213]. The study which had the highest change in average number of steps per day (983 mean step/day [CI 59, 1906]) was the home exercise arm of the LEAPS study (Duncan 2011b HEP). By contrast, the early treadmill training arm (Duncan 2011a LTP) and Mudge 2009 had 566 (CI -290 to 1422.01) and 445 (CI -599 to1489) change in average daily steps respectively. StepWatch $^{TM}$ outputs in people with stroke demonstrate considerable variability (English et al., 2013); however the mean increase of 983 steps/day for the Home Exercise group (Duncan 2011b HEP) in the LEAPS study (Nadeau et al., 2013) represents a proportional increase in daily step counts of between 4-70% compared to normative values for people with stroke who have not received any intervention (English et al., 2013).

### 4.3.3 Subgroup Analysis

Subgroup analysis of exercise interventions alone versus interventions that used at least one behaviour change technique showed there was a difference in effect sizes with an SMD of 0.19 [-0.11, 0.49] for exercise and 0.27 [0.12, 0.43] for those using behaviour change techniques indicating the likely effectiveness of techniques. For this analysis, the final assessment point was used to represent a sustained change in real-world walking (see Figure 9).
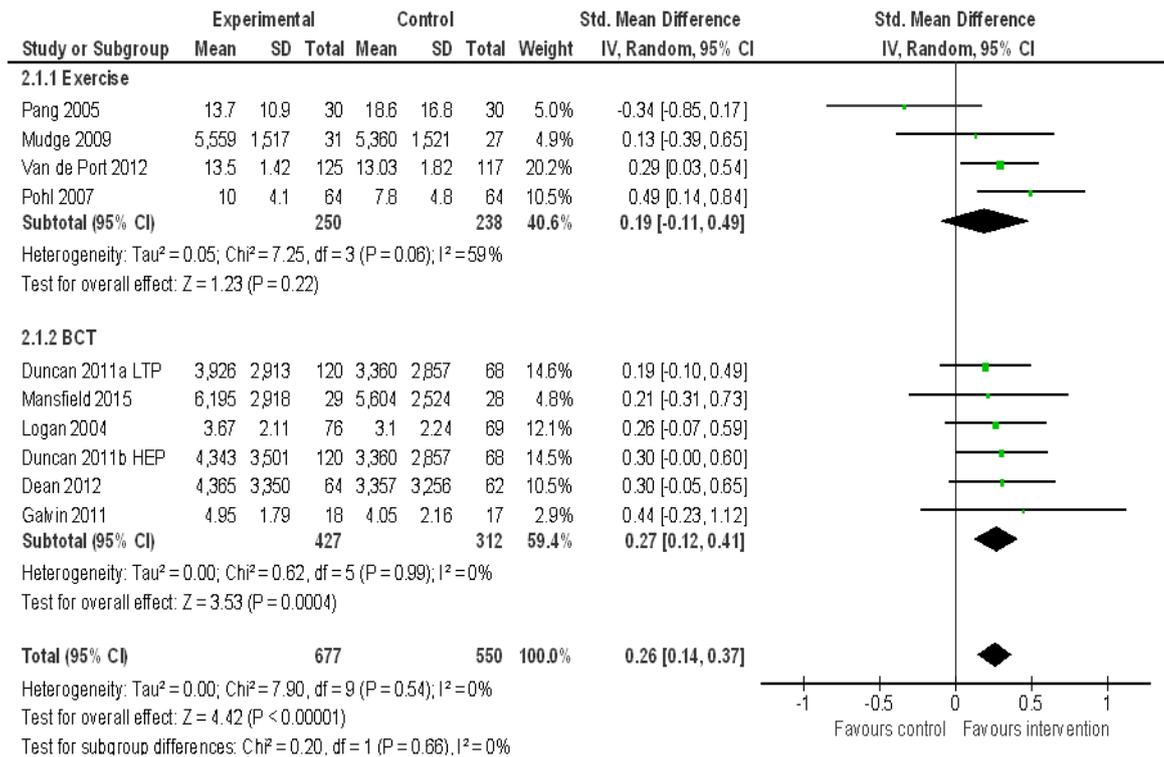
Figure 9. Subgroup analysis of exercise vs. behaviour change techniques + exercise on improving real-world walking at final assessment

## 4.4 Discussion

The main findings of this systematic review were that current interventions to improve real-world walking after stroke are effective and do lead to sustained change but some interventions appear to be more effective than others. For example, interventions which include at least one behaviour change techniques- with exercise or real-world practice were usually more effective than those that used exercise alone. Behaviour change techniques utilised in the studies with the largest and most robust effect sizes included goal setting and barrier identification (e.g. Duncan et al., 2007; Logan et al., 2006). However specific details regarding the optimum approach, the ideal combination of techniques, the influence of social or environmental contextual factors and the mechanisms underlying these findings remains unclear. Further research is needed to answer these questions.

The review did reveal some examples of ways to operationalise behaviour change techniques for people with stroke, which draw on a strong theoretical basis from

health psychology. For example, in the Home Exercise Programme arm of the LEAPS (Duncan et al., 2007) study, participants were encouraged to walk in the real-world and a plan was developed with the therapist to make the most of any gains. Specifically, a barrier identification change technique was employed where each participant was asked, '*What is limiting you from achieving your goal relative to walking?*' and a plan to address the barriers included as part of the treatment.

This review has some weaknesses reflective of research in the field. Both subjective and objective measures of real-world walking were included in the review. The theoretical concept of real-world walking has been variably defined in the literature and lacks conceptual development. As a consequence, electronic searching was challenging. Determining whether an outcome measure accurately reflected the construct of real-world walking was also difficult and led to considerable debate at times between team members before eventual consensus. Only a reasonably small number of studies used the same self-reported measures of physical activity which meant overall mean differences could not be calculated. We also acknowledge that walking is often a subconscious activity which may lead to under reporting of activity levels by self-report measures (Scott et al., 2007; Tudor-Locke & Myers, 2001). However, several of the included studies were of very high quality and well powered. In addition the $I^2$ value of 14% indicates that there were low levels of heterogeneity in the outcomes reported among studies included in the review. Several processes including careful development of the search strategy, contacting authors and the methodical process consistent with the best-practice guidelines were undertaken suggesting our review is likely to have identified the majority of studies meeting the inclusion criteria and the findings are likely to be robust.

A number of systematic reviews exploring the effectiveness of interventions to improve walking competency after stroke have been published (e.g. Pollock et al., 2014; States et al., 2009). In general, the conclusions are that repetitive exercise programmes are effective at improving walking ability as measured by clinic-based tests such as walking speed or endurance. However, this review shows that clinic-based exercise programmes alone are usually not sufficient to produce sustained change in real-world walking behaviour. The finding that the Home

Exercise Programme group of the LEAPS study walked more often than the treadmill training group also suggests that physical training in the home setting has a stronger mode of action than repetitive practice in a clinic setting. These results, along with the results of Logan, Gladman et al. (2004), support the value of integrating personally meaningful goal setting and context-specific training into programmes designed to improve the amount of walking in the real-world following stroke rehabilitation

## 4.5 Chapter summary

This review demonstrated that current interventions can improve real world walking to a small degree and that benefits can be sustained. Results indicated that those interventions employing behaviour change techniques such as goal planning in addition to progressive exercise/real-world practice were likely to be more effective than physical training alone at improving real-world walking behaviour after stroke.

# Chapter 5  Phase 2 - Exploring the perspective of people with stroke toward real-world walking

## 5.1  Introduction

This qualitative study sought an insider's perspective of the value of walking in the real-world for people after stroke and an understanding of what can help or hinder walking. Interventions that are individually tailored are more likely to help people without health conditions to walk more (Ogilvie et al., 2007). More needs to be understood about the perspectives of people after stroke before interventions can be appropriately customised for them. This second phase aimed to generate insights on how contextual factors can influence these perspectives. The specific research question was, "What does real-world walking mean to people after stroke and how do they think it can be better?" Using qualitative data and a constructivist lens, this study contributed data to enhance theory building processes in later stages of this thesis.

Tailoring an intervention involves matching intervention components to the preferences and needs of individuals (Hawkins et al., 2008). Physiotherapists appear the ideal partner to support stroke survivors to walk more with their expertise in walking difficulties following stroke (J. H. Morris & Williams, 2009). Studies show that the perspectives toward rehabilitation interventions that promote physical activity by those with stroke and physiotherapists differ (Stretton et al., 2013; J. H. Morris et al., 2014). For example, one study interviewed 38 stroke survivors on the value of physical activity and their beliefs about what could help them be more active; groups of family members and physiotherapists were also interviewed and asked similar questions. Both people with stroke and family members considered that through being engaged in physical activity they experienced greater continuity with life they had lived before stroke and they experienced greater ability to reengage with meaningful activities. However physiotherapists focused more on the physical and functional aspects of physical activity and tended to interact with patients using a directive rather than collaborative style (J. H. Morris et al., 2014). Further research is needed to clarify

the perspectives of people with stroke toward real-world walking so that interventions can be tailored to better meet their needs.

The dynamic interaction that exists between a person and their environment is both complex and individualised (Noreau & Boschen, 2010). One contextual feature can enable functioning for one person but constrain functioning for another. For example, walking aids for some stroke survivors are perceived favourably because the aid can enable greater independence when walking. On the other hand, some stroke survivors might walk less with the aid due to a sense of embarrassment (Pettersson, 2007). It is likely a person's thinking and reasoning is influenced by the meaning they place on the contextual feature rather than the feature itself (Pape, Kim, & Weiner, 2002). Learning how people with stroke perceive different contextual features could help us to understand the motivational factors that influence their decision making processes around real-world walking.

Understanding the meaning and significance of real-world walking to people with stroke could also help clinicians interact more effectively (Hall, Ferreira, Maher, Latimer, & Ferreira, 2010). Patient centred goal setting is a key feature in most rehabilitation interventions and involves a collaborative process of negotiating goals between the patient, family and clinicians that relate to patients' expressed needs, values and expectations (Rosewilliam et al., 2011). An understanding of what the act of walking represents, the value it holds and whether it meets any needs of the person with stroke is invaluable in this process. To illustrate: the process of goal setting could be guided better by knowing if walking is valued as simply a means of getting from one place to another following stroke or whether it has a deeper meaning that contributes to someone's sense of who they are or enjoyment (e.g. Nanninga et al., 2017). However, there is evidence that clinicians face an "interactional dilemma" in practice ( Levack, Dean, Siegert, & McPherson, 2011, p. 122), in no small part because their perspectives on what should be the focus differ from priorities held by patients and their families ( Levack et al., 2011; J. H. Morris et al., 2014; Rosewilliam et al., 2011).

## 5.2 Methods

### 5.2.1 Design

In this study, a qualitative methodology known as interpretive description was used to explore perspectives of community dwelling stroke survivors toward real-world walking (Thorne et al., 1997; Thorne, Kirkham, & O'Flynn-Magee, 2004). Interpretive Description draws on a constructivist theoretical perspective which considers that knowledge is constructed from multiple realities, is complex, contextual and subjective, the researcher and the person being researched interact and influence each other and theory must emerge or be grounded in the data using inductive reasoning (Thorne et al., 2004; Thorne, 2008; Hunt, 2009). This epistemological view is shared by a realist philosophy of research (Maxwell, 2012a; Maxwell & Mittapalli, 2010; Wong, Westhorp, et al., 2013).

A distinctive feature of interpretive descriptive, in contrast with other types of qualitative methodologies, such as phenomenology or ethnography, is its applied nature. Theory is viewed, not as the ultimate purpose, but as a tool to address clinical issues and problems (Thorne, 2008; Hunt, 2009; St George, 2010). Interpretive Description is a generic qualitative approach (Kahlke, 2014) that is especially flexible and is therefore well suited to projects that will integrate data from both qualitative and quantitative sources (Greene, Kreider, & Mayer, 2005; Maxwell & Mittapalli, 2010). Unlike grounded theory methodology which is primarily concerned with theory building from the research process, this phase only sought to develop greater understanding of the perspectives of stroke survivors. However, it was anticipated that the findings could then be used to inform later theory building efforts in the third phase. A range of strategies were used to enhance the methodological rigour of this enquiry such as careful design, strategies to ensure sampling sufficiency, researcher reflexivity, keeping an audit trail, negative case analysis, data immersion and member checking amongst others. Further details about the strategies used are contained in Appendix E on page 308.

### 5.2.2 Theoretical forestructuring

In this section I describe the processes that I undertook as a researcher to develop an understanding of how my personal and professional background influenced the way I approached this research process. Thorne (2008, 2016) recommends that researchers (and particularly those with a clinical background) explicitly identify what has influenced the way they view the research topic and the way this could affect how the research process develops. In particular she recommends: a) locating the theoretical allegiances (e.g. paradigms or methodologies); b) locating the discipline (i.e. physiotherapy and neurological rehabilitation); and c) positioning the researcher within these ideas.

Such a process of theoretical forestructuring involves both review and critical appraisal of existing literatures and personal critical reflection. Appendix E outlines the practices I used - primarily reading, personal critical reflection and reflective interactions with colleagues. To further illustrate this: Appendix F provides an example from my research journal of a reflection I wrote in preparation for a pre-understanding interview with an experienced qualitative researcher. The next two paragraphs provide a targeted review of the literature which summarises the likely clinical reasoning processes of neurological physiotherapists when seeking to improve real-world walking.

There is a broad consensus that the impact of injury or disease on human movement is the central area of concern for physiotherapy (Cott et al., 1995; Gibson, Nixon, & Nicholls, 2010; Wikström-Grotell & Eriksson, 2012). The sub-discipline of neurological physiotherapy is concerned with how neurological damage affects human movement (e.g. Carr & Shepherd, 2011; Shumway-Cook & Woollacott, 2012). In dealing with clinical problems, physiotherapists often employ a clinical reasoning process known as hypothetico-deductive or diagnostic reasoning (Barnitt & Partridge, 1997; Edwards, Jones, Higgs, Trede, & Jensen, 2004; Edwards & Richardson, 2008). This diagnostic reasoning is based on a biomechanical (or body-as-a-machine) view of human functioning (Nicholls & Gibson, 2010) that compares relevant tissue structures, such as deficits in strength or joint range, to a normal reference point. The goal of a deficit reduction model (Barnitt & Partridge, 1997; Edwards & Richardson, 2008) is to

connect such deficits to movement problems and develop a plan to reduce or minimise the deficits (Nicholls & Gibson, 2010; Wikström-Grotell & Eriksson, 2012). A deficit reduction model may be particularly useful when the aim is to 'fix' a problem, but for clients living with a long term chronic condition that cannot be 'fixed', relying solely on this approach can be problematic (Edwards & Richardson, 2008; Larsson, Liljedahl, & Gard, 2010; Mudge et al., 2015).

However, some academics suggest expert physiotherapists are able to draw on other clinical reasoning processes such as narrative reasoning (Barnitt & Partridge, 1997). This type of reasoning recognises the different lived experiences of patients, the influence of contextual factors and the way that knowledge is socially constructed (Edwards et al., 2004; Jensen, Gwyer, Shepard, & Hack, 2000; Shaw & DeForge, 2012). As discussed in Chapter Two, the way that an individual responds to various contextual factors (such as personal fears or the built environment) seems to be more significant than the contextual factor itself when deciding whether to walk outdoors (e.g. Yen et al., 2014). As noted in the introduction for this chapter, a factor that is enabling for one person, may constrain another (e.g. Pape et al., 2002; Pettersson, 2007). These learnings reinforced for me the importance of exploring perspectives of a stroke survivors toward real-world walking to better understand what matters to them. The process of explicitly articulating the disciplinary perspectives of neurological physiotherapists helps locate this research in its wider disciplinary context. It also may help explain a possible source of the contrasting perspectives noted earlier where physiotherapists tend focus on the physical and functional aspects of walking, whereas people with stroke and their family members consider walking as a way to reengage with meaningful activities (Kubina et al., 2013; J. H. Morris et al., 2014).

### 5.2.3   Participants and Sampling

Participants were eligible for inclusion if they had experienced a stroke and reported difficulty walking in the real-world after stroke. Purposive sampling was used to select a diversity of participants based on characteristics hypothesised to potentially affect their perspectives (Thorne, 2008). Specific sampling characteristics included: age (under 65 or over 65), length of time since stroke

(less than 6 months, 6-12 months, >12 months), gender, ethnicity (Māori, Pacifica, Asian or NZ European) and physical limitations affecting walking abilities (<0.8m/s or >0.8m/s of average walking speed on a timed test). The value of 0.8m/s was used to distinguish between people with different levels of physical ability because there is evidence that those who have walking speeds over 0.8m/s are more physically able to walk in real-world settings (D. Taylor, Stretton, Mudge, & Garrett, 2006). Participants were recruited primarily thorough a community based stroke programme run by a charitable organisation, as well as through personal and professional networks. Potential participants were given a verbal invitation and a flyer outlining the purpose of the study and invited to contact me. I visited each person who initiated contact with me to explain the study in more detail. Ethical approval was provided by the AUT Ethics Committee. Appendix G on page 316 contains the information sheet for participants. I aimed for 8-10 participants because my professional experience indicated that difficulty with walking is common following stroke and so I considered I could achieve adequate diversity in perspectives with a relatively small sample (Sandelowski, 1995). As described by Thorne (2008), the criteria used to determine when to stop sampling was when we considered that any additional data collected would be unlikely to add to further understanding of the phenomenon.

### 5.2.4 Data Collection

Each participant took part in a semi-structured interview. Most interviews took around 50-60 minutes. Questions sought to understand the perspective of participants toward real-world walking. Examples of questions include: "what does real-world walking mean to you? "Tell me about a time when getting out and about was a positive experience for you?" Some questions focused on the actions and/or attitudes of family and health professionals. Such questions aimed to help understand how elements of social context could influence perspectives of participants. Other questions sought to focus on strategies that worked well for participants (e.g. "In relation to your walking, if life could be better for you how would it be?") These questions were included in an attempt to counter the disciplinary tendency of physiotherapists, noted earlier, to focus primarily on

deficit reduction (Barnitt & Partridge, 1997; Edwards & Richardson, 2008). At the start of the interview participants were asked to select a pseudonym that was used throughout transcription, analysis and presentation. Interviews were audio recorded and transcribed verbatim. Following each interview, I wrote a brief synopsis to provide a summary of the story as a whole and made notes about any contextual features that might be relevant.

### 5.2.5  Data Analysis

Interpretive Descriptive methodology can best be viewed as a coherent organising framework (Thorne, 2016, p. 68) which means that various analytic methods can be used as long as they are consistent with the direction and theoretical positioning of the study as a whole. For the majority of the analysis, I used thematic analysis to analyse the qualitative data as described by Braun & Clarke (2006). Thematic analysis is a method which helps identify patterns or themes in the data using a six-stage process of data analysis (Braun & Clarke, 2006, 2013). During the first stage of thematic analysis transcripts were read several times to provide initial familiarisation with the data and any ideas were noted (Braun & Clarke, 2006). During the second stage I completed two readings of the transcripts to generate the initial codes. The first focused on, 'What does real-world walking mean to this person?' and the second reading focused on, 'What helps or hinders real-world walking?' During this stage, I used manual data driven coding and developed a codebook as a reference which explained what each code meant and aided consistency during coding. For the fifth and sixth transcripts, the codebook and codes were used with a mixture of deductive and inductive coding and the codebook revised. Deductive coding was used for the final two transcripts because no new codes were generated through the coding of the final two transcripts. Appendix H contains an excerpt from the codebook. Data was entered into a computer software for further analysis (*NVivo 10*, 2012). For the third stage, codes were categorised into clusters to search for themes. Throughout the project, memos as described by Charmaz (2014) were used. Appendix I contains an excerpt from my research diary of the audit trail I kept regarding the process of analysis. Early stage memos related to my assumptions of the project, whereas later memos focused on analytic decisions and provided a

way to park reflections for later consideration. Appendix J contains two examples of memo writing. Mind mapping was also used for grouping codes together.

Once the data were coded, I reviewed the emerging themes by checking for similarity and overlap by returning to the coded data. During this process, I revisited transcripts that did not include any mention of the themes to try to understand whether certain themes occurred more or less frequently (Thorne, 2008). I presented preliminary themes, code and evidence to the supervisory team to discuss interpretation.

I created a thematic map as part of the process of reviewing, defining and naming themes (Braun & Clarke, 2006, 2013). During the development of the thematic map, it became clear that several of the emerging themes were directly linked, appearing to represent two different points on a continuum. For example, forced to be dependent vs freedom; hope of recovery vs feeling helpless and hopeless.

To develop greater understanding of the connection between these points, I used some additional analytic strategies (Maxwell & Miller, 2008) more commonly associated with grounded theory (Strauss & Corbin, 1998; Charmaz, 2014; . Grounded theory draws on a constructivist theoretical framework and seeks to develop explanatory theories of basic social processes (Charmaz, 2014) such as axial coding and narrative strategies. Analytic strategies, which examine relationships or interactions between codes can be called connecting strategies (Maxwell & Miller, 2008). Such interactions may involve individual or cognitive processes as well as inter-individual processes (i.e. social processes). The contiguous nature of data refers to data which are in close contact to each other or interact with each other. The purpose of these additional analytic strategies was to develop greater understanding into the contiguity of the data.

Two examples of recommended connecting strategies are axial coding and narrative strategies (Maxwell & Miller, 2008; Strauss & Corbin, 1998). Both were included to add additional explanatory insights. Axial coding is an analytic strategy which aims to explore the relationships or connections between categories (Strauss & Corbin cited in Charmaz, 2014). Appendix E on page 308 provides examples of how the axial coding strategies were used. Narrative

strategies can help retain the contextual features that can be lost during categorising strategies like thematic analysis (Maxwell & Miller, 2008). This required me to return to the uncoded transcripts and write a detailed narrative summary of each of the participants' stories. See Appendix K for an example of this strategy. Final analysis involved moving between the categorising data with the NVivo nodes and the narrative summaries to provide a richer understanding of the data and its contextual features. A final thematic model was developed following this process (See Figure 10. Thematic map on page 87).

I undertook a range of strategies to enhance confidence in the study findings (Tracy, 2010; Crotty, 1998; Nicholls, 2009a, 2009b; Maxwell, 2012b). The purpose of these strategies was to ensure that data collected was credible, sufficient, abundant and reflected the complexity of the phenomenon being explored (Tracy, 2010, p. 840). Examples of such strategies included extensive immersion in the data, returning to interview participants to review study findings, analytic memos, negative case analysis and discussion with my supervisory team around coding decisions. Appendix E contains additional information about the categorising and connecting analytic strategies used as well as additional information about other strategies for rigour associated with this phase.

## 5.3   Findings

Eight participants were interviewed and included in the data set. A diverse sample was achieved and a range of different participant characteristics was evident. Table 6 summarises the participant characteristics. Findings are presented as key themes relevant to the first key question about what real-world walking means to people followed by key findings that explore how walking can be better by clarifying what helps or hinders real-world walking for participants.

The overall finding was that walking can promote wellbeing for people after stroke because it meets basic emotional and psychological needs and provides hope for future recovery. It can provide a sense of freedom from being constrained; an opportunity to manage negative emotions through a change in environment; and can be seen as an indicator of progress which builds confidence. The first macro-theme related to the meaning of real-world walking

included two sub-themes: *Freedom from dependence* and *Hope of getting better step by step*. The second macro-theme related to how participants thought their real-world walking could be improved and two sub-themes were evident in the data. They were *Motivating self to overcome* and *Make it social*. Each of these themes appeared to sit on a continuum, with participants moving from one end of the continuum to the other depending on different events that occurred and how they responded. Figure 10. Thematic map summarises the four themes and their relationship to each other. The thematic map was designed to depict two key aspects. First, the way the themes interact together to support forward momentum, propelled by the final two themes. Second, the map depicts the difficulties participants faced which often hindered their walking progress - much like pushing a boulder uphill.
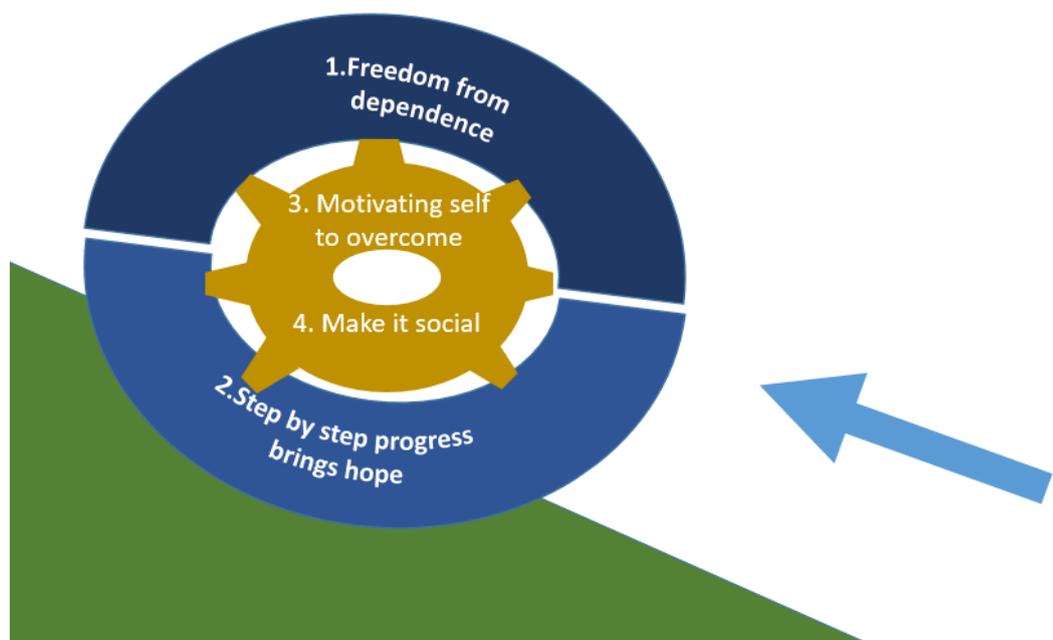


Figure 10. Thematic map

Table 6. Participant characteristics

| Self-selected Pseudonym | Lottie | John | Brownie | Jia Wai | Kay | Mary | Maria | Steve |
|---|---|---|---|---|---|---|---|---|
| Demographic characteristics | | | | | | | | |
| Age | 70 | 61 | 45 | 67 | 69 | 84 | 36 | 85 |
| Ethnicity | NZ European | NZ European | Māori | NZ European | Indian | Scottish | Tongan | NZ European |
| Sex | Female | Male | Male | Male | Female | Female | Female | Male |
| Time since last stroke | >12 months | <6 months | >12 months | <6 months | Between 6-12 months | <6 months | >12 months | >12 months |
| Physical ability: Gait speed | > 0.8m/s; | >0.8m/s | < 0.8m/s | >0.8m/s | < 0.8m/s | < 0.8m/s | < 0.8m/s | >0.8m/s |
| Aid for walking | Frame | No aid | No aid | Stick | Frame | Frame | No aid | No aid |
| Living situation | Rest home | Own home with wife | Board with caregiver | Rest home | Own home with husband | Own home | Own home with family | Own home with wife |

### 5.3.1 What does real-world walking mean to people?

Walking in the real-world was a concept readily understood by participants and deeply valued as something *basic* to being human. It seemed to provide opportunities for freedom by allowing participants to choose when and where they went. Being able to change location could help reduce the negative emotions connected with feeling stuck in one place. Experiencing progress in walking appeared to lead to greater hope of progress in other areas of their recovery journey. Conversely, difficulties with walking were linked to frustration and a sense of helplessness.

### 5.3.1.1 Opportunity for freedom from dependence

Walking in the real-world was associated with independence and freedom by many participants. They described what appeared to be a psychological freedom related to the ability to choose when and where to walk. John summarised this freedom to choose clearly.

> *...the walking gives me freedom...I can choose and do my own thing...it has been a means to set me free (John, 61 years)*

This concept of freedom was a common finding in the data. As well as the freedom to choose, real-world walking meant freedom from the need to constantly pay attention when walking particularly outdoors. In response to the question, "What does real-world walking mean to you?" some participants described their desire to be free from the need to pay conscious attention to how they walked in real-world settings.

> *I think just doing it automatically and not having to concentrate. (Lottie, 70 years)*

> *I understand that clear as. I wish I could be one of those people. You have got to look around you. Especially for kids that don't know...a kid might bump into your crutch or your walking stick or something and you have a fall; you scare that kid. (Brownie, 45 years)*

This need to pay attention to what was happening around them when out and about restricted them mentally and emotionally. For some, the need to concentrate on the act of walking was so demanding they had to force themselves to walk, step by step.

> *I am not feeling the best and you have to walk, you have to have*
> *an effort, make an effort to walk. (Kay, 69 years)*

For some of the younger participants, freedom in real-world walking meant freedom from unwanted attention from others.

> *[Real-world walking means] I can walk without thinking that*
> *someone is laughing at me, without thinking [about] using my*
> *splint or my stick... Walking for free. (Maria, 36 years)*

Few of the study participants were able to drive at the time of the interview. Most expressed frustration at having to depend on others to drive them to appointments or help to manage various activities. For some people, the significance of being able to get out and about through walking was particularly important due to their personal circumstances. This is illustrated poignantly in a story shared by Lottie. She explained how she used to walk each day around the block without having to cross the road and on her own. Her husband who had a history of being abusive provided her with no help to get out and about. One day coming home on the bus she discovered that the pavement was being repaired by the council and she could no longer use it. Soon after this event Lottie left her home and her husband and moved into a rest home.

> *The thing that frightened me when I came home, was that when I*
> *got off the bus I still had to walk right around the block to get*
> *home...because one side of my footpath had gone and the road was*
> *too dangerous for someone like me to walk on... I did feel*
> *trapped...I did feel trapped then. (Lottie, 70 years)*

For Lottie, being able to get out and walk gave her an opportunity to exert control over her world. The loss of an accessible route during road works meant

she no longer had this opportunity and as a result she felt trapped which put a significant strain on her emotionally.

A number of participants described how they often felt *stuck in one place.* Walking enabled them to change their geographical location and this could positively influence their mind-set as well. Change in their geographical setting sometimes seemed to bring a fresh perspective.

> *If you are stuck in a room or a space and you are just sitting there,*
> *well your mind is going to go to the wrong places. But if you can*
> *move about even for five minutes or even out the door to a seat;*
> *you are in another space and you feel more confident and the more*
> *confident you feel, the better you feel. (Lottie, 70 years)*

The experience of feeling *stuck in the same place* seemed related to a sense of lacking control and lacking variety-both appeared detrimental emotionally.

> *You know right now I haven't got much of a choice cause I am only*
> *doing half a block so I don't get far so I am seeing the same things.*
> *(John, 61 years)*

Participants voiced a need for variety, for *different* things. Brownie enjoyed listening to *different* stories told by his local dairy owner; Jia Wai treated himself to a beach view as a reward after his daily walk; John enjoyed seeing different houses due to his background in building; Lottie enjoyed the different flowers. Walking outdoors seemed to provide opportunities for variety which could have a positive effect on emotional wellbeing.

### 5.3.1.2 Hope of getting better step by step

Many participants described the way that progress in walking generated confidence that they linked to hope for further recovery. The ultimate hope expressed by many participants was to one day feel *normal* again, including walking normally. Certain types of experiences were identified as particularly important in promoting confidence and motivation. For example, successful walking experiences appeared to contribute to a sense of achievement and mastery. This generated positive emotions which seemed to improve confidence.

> *.. So every step, you take the further I can walk, the more confident*
> *I am getting. (Lottie, 70 years)*

This process of incremental progress leading to improved confidence and hope was evident in several stories. Participants described different experiences such as trying to surf, walking during rehabilitation, walking in the mall, supermarket or beachfront. Often they described being uncertain how they would go, but successful attempts led to positive emotional experiences and the desire to do more. For example, Steve's physiotherapist took him down to the letterbox and he describes his thinking in response to the experience:

> *I felt it was a step in the right direction and if I have done it down*
> *there once I am sure I will be able to do it again and maybe the*
> *next time I could do it without [name of physio]. I would have to*
> *go down with my stick myself. Now I go the letterbox and I don't*
> *take a stick. (Steve, 85 years)*

However, if progress was lost or not attained to a desirable level, it led to discouragement and frustration, impacting the person's mood. For example, one of the participants experienced a second stroke after an operation which caused emotional barriers when trying to return to his daily walking routines:

> *So I've got to build up my knee again...after the op so that was*
> *mentally challenging too because I had done all that bloody work*
> *and lost it. (John, 61 years)*

### 5.3.2 How can walking be better?

#### 5.3.2.1 Motivating self to overcome

In this section I discuss the different strategies used by participants to *overcome* the difficulties they experienced with their walking. Nearly all participants considered they were very motivated but felt their recovery journey was a struggle. Participants used a number of proactive strategies to overcome the difficulties they were experiencing with their walking. These included *giving things a go:*

*Well....shucks I can go on forever about overcoming...umm. Really it is a frustration...it is like anything I suppose you learn by making mistakes, I must have made heaps of mistakes...but life wise if you don't do it for yourself then who will? (Brownie, 45 years)*

Many participants described regular routines of *going for a walk*. Focusing thinking by *having a goal or a plan* could help focus walking efforts. For example, John had a walking event he was working toward. *Taking note* of different features outdoors, such as gardens, helped to provide interest. Lottie described the careful planning that went into her outdoor walking trips including knowing where the closest park bench was so that she could rest when out walking, and taking a mobile phone with her.

*I am going to go up with one of the ladies from here one day so we both know where the seat is before we cross to go to the mall. So that is all we need. And I will always have my phone on me so that if I collapse or anything, someone can feel my pockets for a phone. (Lottie, 70 years)*

The word motivation was used by several of the participants when they described strategies to help themselves overcome the struggles they experienced living with the consequences of stroke. Participants worked hard to find ways to motivate themselves in spite of the difficulties they experienced. For example, Jia Wai was particularly pleased with the strategy he had developed to motivate himself. During his daily walk, he 'rewarded' himself when walking by adding an extra house to his route to give him a sense of progress.

*The method of managing or self-motivating myself on a long walk was very important because that made it successful or not. (Jia Wai, 67 years)*

Unfortunately, like John, Jia Wai went on to experience a further stroke, and found getting back into his daily routines more challenging and he had less confidence after this setback.

The other way that participants described improving their walking was experiencing success when walking which built their confidence and motivated them to do more. Such experiences when successful were associated with a sense of elation. They could involve the support of another person. Steve reflected on his experience of walking to the letterbox with the physiotherapist and the glee he experienced:

> *So we walked down to the letterbox. I remember it well because I waved my stick at [name of neighbour] and said 'hey look at me, I'm walking!' And that was great - really. (Steve, 85 years)*

### 5.3.2.2 Making it social

Woven throughout the stories told by participants was the significance of social connections, which seemed to meet a variety of needs. Some stories described the social support provided by others: spouses, friends, physiotherapists, neighbours, dairy owners. The practical support of others provided important assistance to manage daily activities but could leave the person feeling like a burden, particularly if they longed to return to lost roles but could not due to the stroke.

Walking was at times used to increase opportunities for social connections - walking in the real-world could create the chance to meet others when out and about.

> *...my walks can be rather elongated because I get talking to people around the street and the dogs and things over the way so I make it a social event as well as a physical event. (John 61 years)*

The emotional support provided by others when walking appeared to reduce anxiety and promote confidence. This kind of emotional support was particularly valued.

> *...so I did it [the walking] with family members to begin with and the more confidence I got I actually did it on my own. So confidence you know does ...create better health. (Lottie, 70 years)*

Each of the themes existed on a continuum and participants moved between seeing walking as an opportunity for freedom and viewing difficulties in walking as a sign of being forced into a position they did not want to be in. By the same token, seeing progress in walking gave hope for continual improvement, but difficulty walking and lack of progress led to discouragement and even despair for some.

> *Walking I ...go walking with the hope that I'll be better... and it is frustrating,  it is hard,  not easy to walk, sometimes I dread going out and everything because I get so tired. (Kay, 69 years)*

As noted earlier in section 5.2.5, strategies to enhance validity are discussed in detail in Appendix E. One of these strategies included discussing the findings with the end-user group who included many of the phase 2 participants. All group members supported the findings overall, although one man (Jia Wai) disputed the value of walking itself as providing a sense of autonomy. For him, moving into a rest home was the key to giving him autonomy over his life rather than the act of walking. This lead to modification of the theme to acknowledge walking could be one way of providing autonomy and for different people and different times had greater or less significance.

## 5.4  Discussion

The main finding of this study was that people with stroke considered the practice of walking in the real-world to be a profoundly important activity that could enhance their wellbeing. Positive wellbeing involves functioning well and feeling good (Dodge, Daly, Huyton, & Sanders, 2012; Huppert, 2009). Effective psychological functioning includes feeling in control of one's life, being able to pursue valued goals and having positive social connections (Huppert, 2009). Choosing when and where to walk provided the opportunity to exercise control, and progress in walking-related goals boosted confidence by providing an opportunity to experience a sense of success. Being able to get out and about led to increased opportunities for social interactions. However, difficulty walking led to frustration and other negative emotions including a sense of hopelessness and helplessness. Participants used personal resources such as planning skills, daily

routines, concentrating carefully and confidence building experiences to motivate themselves to overcome the significant challenges they faced in walking in the real-world. They drew on social resources to help themselves. Walking can improve psychological functioning and enhance wellbeing by providing positive emotional experiences that can help people with stroke feel better (Dodge et al., 2012; Huppert, 2009). Rather than merely providing a means to get from one point to another, walking in the real-world was deeply important to stroke survivors and inherently motivating. In the rest of this section I will discuss some of the key findings from this study in relation to the loss of automaticity, the significance of confidence to walking and explore possible explanations for the amount of negative emotion expressed by participants.

### 5.4.1  Automaticity in walking

In varying degrees, participants described needing to pay careful attention when walking in the real-world. Real-world settings were felt to be unpredictable and demanding which meant that cognitive and emotional effort was needed to walk safely and successfully. This need to consciously focus on walking, an activity that is usually undertaken with automatic subconscious control, was a burden to many participants. The need for effortful attention when walking outdoors is a relatively novel finding in the physiotherapy literature, but one that has support from other qualitative research in stroke (Ellis-Hill, Payne, & Ward, 2000) and other neurological populations such as spinal cord injured patients (e.g. Jordan et al., 2013). Ellis-Hill et al. (2000) eloquently describes the experience of a *self-body split* in her narrative study of stroke survivors at multiple time points over the first year following stroke. Her participants reported a precarious relationship with their body; finding it unreliable and untrustworthy, needing conscious management.

Research into the neural control of walking reveals that there are two processes available to control walking in challenging settings and at any one time depending on the capabilities of the individual and the demands of the task, the balance point between the two systems can shift (D. J. Clark, 2015; Yogev-Seligmann et al., 2008). When walking occurs automatically without conscious thought, it is driven by lower level neurones that include central pattern

generators in the spinal cord and specialised areas in the brainstem. A variety of factors may influence perceptions of capability such as pain, or musculo-skeletal, visual or sensory impairments. If the walking task is particularly challenging or the individual perceives their capability to walk is impaired in some way, then the alternate route to control is used. This alternate route known as executive control utilises the prefrontal cortex to drive the activation of lower level neurons needed for walking (D. J. Clark, 2015), and this is experienced as needing to concentrate or pay attention while walking.

However, the need to use executive control strategies during walking outdoors creates a significant cognitive burden because having to concentrate on the act of walking is fatiguing and leaves few attentional resources for other cognitive tasks like route navigation or conversing with travel partners (Lord & Rochester, 2007; Yogev-Seligmann et al., 2008). The degree of concentration may depend on the degree of physical ability with more physically disabled participants describing the need for greater concentration more often. The need to use executive control strategies when walking outdoors may explain why participants found having to pay attention to the act of walking burdensome and why they longed to be free from this constraint.

### 5.4.2  Confidence

Participants used the word *confidence* to describe their perceived capability to walk in different outdoor settings. They actively sought ways to rebuild confidence in their ability. Progress in walking occurred in small steps, both literally and figuratively, leading to increases in confidence. The issue of confidence after stroke has been explored in more detail by Horne et al. (2014). Participants in Horne's study described how a loss of confidence was related to a sense of decreased competence, loss of skills and inability to engage in desired activities. They described a process of learning to master skills again by gradually and progressively increasing skills in both social interactions and physical tasks. The similarity in findings between the current study and Horne's (2014) suggests a process of progressive mastery may be central to building self-confidence in real-world walking skills as well. This sense of progressive mastery is similar to the concept of enactive task mastery introduced by Bandura (Bandura, 1982,

1997) which suggests that building self-confidence in walking is worth exploring further.

### 5.4.3 Negative emotions

A wide range of negative emotions was demonstrated in the data from frustration, to lack of confidence and a sense by participants that their emotional needs were not understood by those close to them. Notably, similar patterns of emotional responses have been described for both inpatient (McGrath & Adams, 1999) and community dwelling stroke survivors (White et al., 2008). For example, White et al. (2008) explored mood changes in a qualitative study of community dwelling stroke survivors using a modified form of grounded theory and found feelings of frustration, reduced self-confidence, dependency and loss. The exact cause of these emotional responses has received limited attention in the stroke literature. Research on emotions after stroke often focuses on the presence or absence of depressive symptoms (e.g. Hackett & Pickles, 2014) and largely neglects other emotional experiences.

One possible explanation for some of the negative emotions experienced is that they may stem from an inability to achieve desired goals (McGrath & Adams, 1999; Siegert, McPherson, & Taylor, 2004). Self-regulation is the capability to set, pursue and attain desired goals (Mann et al., 2013; Inzlicht et al., 2014). Drawing on Control Theory, Carver and Scheir (1982) propose that negative emotional responses occur when there is a discrepancy between a desired goal and perceptions of current reality. Based on cybernetic theories of control, this theory provides a basis for understanding the control of human behaviour using the characteristics of feedback loops (Inzlicht et al., 2014). If progress toward a desired goal is slower than expected, a neurochemical signal known as an Error Related Negativity signal is activated which leads to change in firing of dopamine and results in negative emotions (Inzlicht et al., 2015, 2014). This signal has been described as "a distress signal of self-regulation failure" (Legault & Inzlicht, 2013, p. 125). This sense of failure leads to frustration and anxiety, and if the situation is not resolved, the person may *withdraw* from opportunities leading to disengagement from the desired activity. A sense of lack of control over their ability to achieve desirable activities may explain in part the emotional struggle

voiced by all participants. However, this explanation will require further clinical investigation in people with stroke.

### 5.4.4 Self-Determination Theory

In addition to the sense of being free from needing to pay constant attention, the use of the word *free* was used by participants to refer to the ability to choose where or when they wanted to walk. Neuroscientific research suggests human beings are "born to choose" (Leotti, Iyengar, & Ochsner, 2010, p. 461) and therefore pre-programmed biologically to find choice and control rewarding. Having this restricted is aversive (Leotti et al., 2010; Inzlicht et al., 2014). Deci & Ryan ( 2000, 2008a) propose that the subjective experience of feeling free to choose reflects the need for human autonomy.

According to Self-Determination Theory, autonomy is one of the three innate, universal basic psychological needs that are essential for wellbeing (Deci & Flaste, 1995; Deci & Ryan, 2008a, 2000). These are the need for autonomy (freedom of choice), competence (being able to control the outcome and experience mastery) and social connectedness (the universal desire to interact and be connected to others). Proponents of Self-Determination Theory argue that these needs must be met in order for people to function and grow optimally and to experience wellbeing and that if any of these needs is thwarted then wellbeing is adversely affected (Deci & Flaste, 1995; Deci & Ryan, 2000, 2008a; Fortier, Duda, Guerin, & Teixeira, 2012). There is a compelling body of literature supporting the use of Self-Determination Theory in a number of health related contexts including physical activity (Fortier et al., 2012; Ng et al., 2012; Teixeira et al., 2012). Comparing the themes developed inductively in this study with the core constructs of Self-Determination Theory reveals several parallels. Table 7 illustrates how the study themes relate to key theoretical constructs from Self-Determination Theory. These findings indicate this theory is likely to inform the development of interventions to improve real-world walking after stroke.

Table 7. Comparison between findings and constructs from Self-Determination Theory

| Themes from Qualitative Enquiry | Constructs from Self-Determination Theory |
| --- | --- |
| Freedom from forced dependence | Needs satisfaction: Autonomy |
| Step by step progress brings hope | Needs satisfaction: Competence |
| Motivating self to overcome | Participation motives (autonomous vs. controlled) |
| Make it social | Needs satisfaction: Social connectedness |

The physical benefits of walking have been well reported in health literature (Lee & Buchner, 2008; Tudor-Locke, 2012). Walking related research on psychological aspects of walking has tended to focus on its value in treating mental health problems such as depression (e.g. Robertson et al., 2012). This study points to potential benefits of walking more often as a positive way to meet psychological needs to promote wellbeing and support motivation. This suggests that Self-Determination Theory may provide a useful theoretical framework to understand how walking can meet these needs.

### 5.4.5 Improving walking in the real-world

Participants used different types of planning strategies to help improve their walking. These included having a goal or something to aim for, having a plan to minimise the risk to themselves when out and about, scheduling a regular walk and identifying motivational strategies that were particularly helpful. Having a specific plan for action that links a specific contextual cue, such as location or time with a predetermined action (known as implementation intentions) has been found to be feasible and acceptable following stroke (Kersten, McCambridge, M. Kayes, Theadom, & McPherson, 2015; Kersten et al., 2014). Using if-then structure to support planning may help with the implementation of plans to improve walking.

Despite the high levels of sedentary behaviour after stroke (English et al., 2013), most participants did have a regular walking routine that was personally important. None of the participants mentioned aiming for a specific amount of time walking (i.e. at least 30 minutes on most days) as recommended in physical activity guidelines post stroke (Billinger et al., 2014). Little is known about

walking habits and routines following stroke but existing evidence indicates sedentary habits are established quite early on following stroke (Tieges et al., 2015). For example, one observational study showed sitting habits measured at one month post stroke were unchanged at 12 months, despite any recovery in physical ability that may or may not have occurred (Tieges et al., 2015). A qualitative study seeking to understand daily habits and routines following stroke found survivors described a sense of waiting, they felt reluctant to give up old pre-stroke habits, but were uncertain which new ones to start (Wallenbert & Jonsson, 2005). This dilemma seemed to lead to a sense of inertia and lack of direction. Helping people to walk more often has been suggested by some to be one of the easiest habits to integrate into existing lifestyles (Tudor-Locke, 2012) since it requires less cognitive effort to form a new habit in a familiar context (Nilsen et al., 2013). Extending existing walking habits may be one way to help increase the amount of walking, but this would need to be further explored to determine if it is practical given the difficulties experienced by participants.

Participants looked for opportunities to build confidence in their walking skills by practising the desired activity and working to overcome their fears and sense of vulnerability in real-world settings. The participants voiced some common fears including fear of falling, fear of being watched by others and fear of unexpected events such as children or animals suddenly coming upon them. The fear of having a second stroke was not mentioned in this cohort but is an additional fear expressed by others in related studies (Ellis-Hill et al., 2000; Horne et al., 2014; Nicholson et al., 2013). Noticing features of the built environment such as available seating helped to allay some fears and increase confidence in walking outdoors (Ottoni, Sims-Gould, Winters, Heijnen, & McKay, 2016).

Participants drew on their social connections to help them improve their walking, but walking itself can provide an avenue to create opportunities to build more social connections. These findings match those of Gardner (2014) who used an ethnographic study to understand the insider perspectives of disabled older adults toward community mobility. Similar to the current study, Gardner found the strong desire to connect with others was a powerful force that drew people to

overcome the challenges they faced in walking outdoors. For participants in this study walking regularly was one way to enhance both physical and social integration.

### 5.4.6  Study Limitations

There are several limitations to this study. First, there was a relatively small number of participants. However, the data collected from these participants provided rich insights into the complexity of meaning behind real world walking and the analytic process involved extensive immersion in the data. In addition no new concepts were identified in the data from the transcripts of the last two participants indicating that, despite the small number of participants, sufficient data were collected to understanding the meaning of real world walking and therefore meet the aims of the study. The majority of participants were recruited from a community-based exercise programme in central Auckland, so it is possible these participants were more focused on physical activity than most stroke survivors. However, data from the two participants recruited through other avenues and living in different geographical parts of Auckland did not indicate this was the case. Finally, this research was designed to generate inductive data driven findings but it is possible analysis and interpretation of the findings were influenced by other factors. For example the application of theoretical frameworks like Self-Determination Theory (Deci & Ryan, 2008a)  and Control Theory (Carver & Scheier, 1982) though consistent with the realist philosophy could arguably have influenced later stages of analysis. More information about the range of strategies taken to ensure sufficient rigour for this study is detailed further in Appendix E.

### 5.4.7  Clinical Implications

One interesting finding was the level of planning that people engaged in to ensure they could pre-empt problems. Advance knowledge of whether there was a place to sit down significantly influenced walking decisions for some. Other contextual factors relating to the physical environment include the presence of outdoor landmarks that can provide indicators of progress and the value of establishing walking routes that are safe and accessible. For example, walking around the block, even multiple times may be a helpful option. The person can

be encouraged to progress walking by adding on more minutes, more houses or more blocks as able. Factors relating to the social environment can help improve real-world walking. Escorted community walking may be a simple but potentially powerful strategy to support confidence building (Logan, Gladman, et al., 2004; Logan et al., 2006). Organising a person (e.g. a family member, assistant or therapist) to escort the person with stroke when walking outdoors, may help reduce anxiety and provide emotional support, when encountering challenging situations.

Further research examining ways to enhance social connections such as walking buddies or walking groups may be a worthwhile avenue to explore for this group as the impact of social factors on real-world walking after stroke is largely unexplored. The next stage of this research is to turn these findings into an intervention that aims to help people change their walking habits and maintain their habits despite setbacks. The intervention will aim to: develop planning skills, build confidence through progressive mastery, create supportive social connections and extend existing walking habits and routines.

## 5.5   Conclusions

Being able to walk out and about in the real-world can provide valuable psychological resources to people with stroke. The experience of walking in the real-world was highly valued by study participants. Walking in the real-world however is a demanding activity that requires careful attention. This meant participants often felt very vulnerable when walking outdoors. Participants' negative emotions significant hindered their walking in the real-world. Contextual features of the built and attitudinal environment, such as the presence of seating and the support of others when walking were helpful. People with stroke use planning skills, confidence building experiences, changes to their thinking, everyday routines and draw on social resources to motivate themselves to overcome the significant challenges they face walking in the real-world.

# Chapter 6   Phase 3a- Building the treatment theory

## 6.1   Introduction to Phase 3

The purpose of the final phase of this PhD research was to iteratively build, evaluate and refine a treatment theory informed by an explicit theoretical explanation of how physiotherapists can enable stroke survivors to walk more in the real-world. The design of this phase is based on two sets of best practice recommendations: guidelines from the MRC on intervention development for complex interventions (Medical Research Council, 2006) and guidance produced by the RAMSES project on how to conduct realist research (Wong et al., 2016; Wong, Greenhalgh, et al., 2013; Wong, Westhorp, et al., 2013). This third phase directly builds on the findings of Phases 1 and 2 and consists of two parts. First, Phase 3a describes the process of initial treatment theory building (described in this chapter). Second, (Phase 3b) contains the operationalisation of this theory into an intervention, the rationale for the selection of intervention components, the impact evaluation of the intervention and revision of the treatment theory (see Chapter Seven). Figure 11 illustrates the process of theory building over the whole phase, from the *initial rough theory* proposed in this chapter, through to refinement of the treatment theory in light of the evaluation findings. The remainder of this chapter will justify the selection of methodological frameworks and other design decisions used across Phase 3 by explaining how realist logic was applied and outlining the process of developing the theory of change, the theory of action and the outcome chain for the initial rough theory.
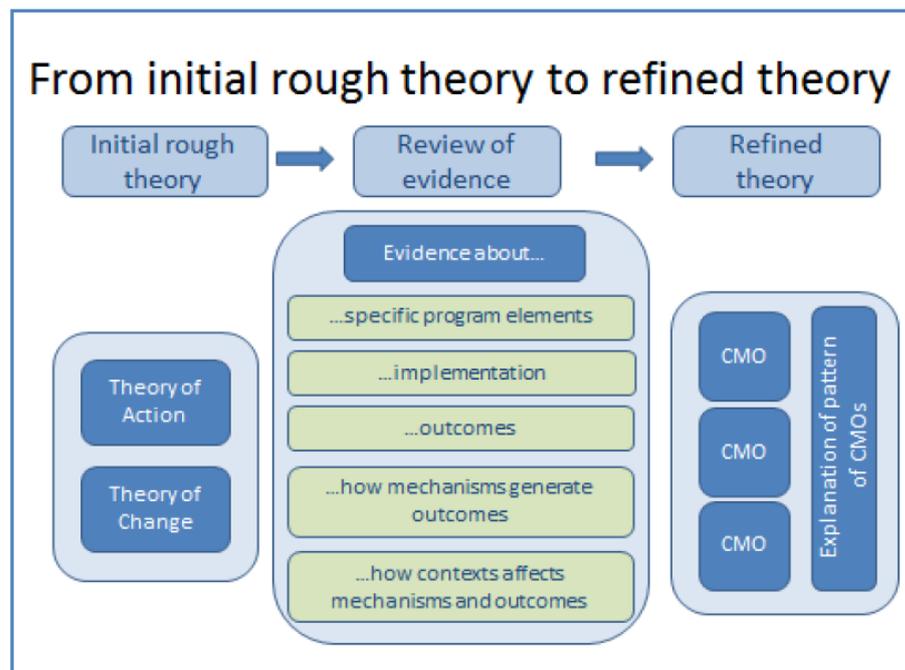
Figure 11. Process and sources of evidence to build theoretical understanding of change
(Taken from Wong, Westhorp, Pawson & Greenshalgh, 2013)

## 6.2  Key design issues for Phase 3

The MRC framework for the development of complex interventions offers limited
guidance on constructing a theoretical explanation of how an intervention is
expected to work (Campbell et al., 2000; Moore et al.2014, 2015). Consequently,
intervention developers may approach theory building, design and evaluation of
complex interventions based on the MRC guidelines in an "ad hoc" fashion
(Moore et al., 2014, p. 102) which could limit the veracity and applicability of any
insights gained.  To counter these limitations, I paid particular attention to
design issues during this phase to ensure I used a systematic, transparent and
methodologically robust approach.

Several alternate methodological frameworks were considered to aid theory
building. Each approach was evaluated against predetermined criteria to
determine the best fit for Phase 3. These criteria included relevance to the topic, a
robust methodology and one likely to be reasonably practicable within the
constraints of a PhD project (See Table 8). As discussed in Chapter Two, (see
section 2.1.1.6), walking inactivity after stroke represents a particularly complex
problem (Aarts et al., 1997; Glouberman & Zimmerman, 2002) and interventions
designed to adequately address such complexity necessarily require a

multidimensional approach (Clark, 2013; Connelly, 2007; Hawe, 2015). The cognitive and individualistic traditions inherent in behaviourism have been noted by several scholars (e.g. B. Gardner, 2014; Glanz & Bishop, 2010; Rhodes & Nigg, 2011) and this emphasis appeared to influence the theoretical breadth of one alternate approach, the Theoretical Domains Framework (Cane et al., 2012). To illustrate, a single category named "environmental context and resources" covers all person-environment interactions and a single category labelled "social influences" is used to describe numerous interpersonal factors influencing behaviour change in the Theoretical Domains Framework (Cane et al., 2012). Consequently, this framework alone had insufficient theoretical scope to support exploration of the contextual factors both emerging in the data and highlighted in the literature reviewed (e.g. collaborative social interactions and context specific practice). Other approaches like intervention mapping recommend a comprehensive development process which focuses primarily on behavioural and environmental factors but not on motivational or social factors (Bartholomew, Parcel, Kok, Gottlieb, & Fernandez, 2011). Intervention mapping appeared difficult to complete within the time constraints of a mixed-methods thesis. Table 8 below outlines these different approaches and their fit against the criteria. This comparison shows Realist Evaluation (a type of theory-driven enquiry) was selected as the optimal choice for the third phase.

Table 8. Selection of methodology for treatment theory development

| Criteria | Causal modelling (Hardeman, 2005) | Intervention mapping (Brug et al., 2005) | Theoretical Domains Framework (**S.D.** French et al., 2012) | Participatory Action Research (Seekins & White, 2012) | Realist evaluation (Pawson & Tilley, 1997) |
|---|---|---|---|---|---|
| Key characteristics | Builds theory with mathematical modelling | Builds theory using 5 stage process for intervention development; focus determinants | Developed through synthesis behaviour change frameworks | Builds theory by seeking involvement co-researchers in theory development | Builds theory using CMO configurations and refines it with evaluative data |
| **Relevant to topic** Recognises complexity of the intervention, significance of context and mechanisms Fits with project design, goals, aims and philosophy | × | × | × | √ | √ |
| **Reasonable to achieve within time frames** Clear guidelines Manage intellectual property adequately Easy to organise from a logistical perspective | √ | × | √ | × | √ |
| **Robust** Defensible methodology Philosophically consistent with rehabilitation physiotherapy Consistent with MRC framework | √ | √ | √ | √ | √ |

### 6.2.1 Theory-driven research enquiry in health

Theory-driven research approaches represent alternate methodologies to theory building in health which have emerged over the last 15 years in response to the limitations of more traditional experimental research methodologies (Astbury & Leeuw, 2010; Blamey & Mackenzie, 2007; Davidoff et al., 2015; Lipsey, 1993; Marchal et al., 2012; Moore et al., 2015; Pawson, 2013; Pawson & Tilley, 1997; Petticrew et al., 2013; Weiss, 1997; Wong et al., 2016). These limitations include difficulties explaining inconsistencies in outcomes across apparently similar studies, the presence of outcome patterns showing a non-linear response pattern and the influence of context on outcomes (Marchal et al., 2012; Weiss, 1997). In contrast to experimental designs that use analytic techniques like randomisation to "isolate the effect of each variable on the outcome" (Marchal et al., 2012, p. 193), theory-driven approaches aim to understand how change occurs and what contextual features can enable or constrain change. In other words to understand how variables interact to produce outcomes (Pawson & Tilley, 1997; Weiss, 1997). See Marchal et al. (2012) for a comparison of the three different types of theory driven research: Theory-driven Evaluation, Theory of Change and Realist Evaluation.

The role of researchers in theory-driven enquiry is three fold: a) to 'surface' implicit assumptions about how the intervention is supposed to work for closer examination; b) to link the activities of the intervention to desired outcomes and c) to expose the mechanisms of action activated by each intervention component (Marchal et al., 2012). The purpose of a theory-driven enquiry is primarily theory building; it aims to strengthen the existing knowledge base and to produce transferable findings that can be applied to settings which share similar features (Astbury & Leeuw, 2010; Marchal et al., 2012;. Pawson & Tilley, 1997). A treatment theory does this by linking treatment activities (or components), intervention mechanisms (i.e. how the intervention works) and desired outcomes together (Hart, Tsaousides, et al., 2014; Lipsey, 1993).

One branch of theory-driven enquiry that is gaining prominence is Realist Evaluation (Pawson & Tilley, 1997; Pawson & Tilley, 2009; Wong et al., 2013).

Realist Evaluation met all the criteria needed for the theory building phase of this project and was selected for use because of the way it explicitly recognised the complexity of the problem and likely intervention, the significance of the context, the availability of methodological guidance, the robust philosophical basis on which it is based and its coherence with the overarching realist research philosophy of the project as discussed in Chapter Three in section 3.4.

The iterative nature of this project has already been noted. In practice, this meant at times research findings shaped later design decisions. An example is the decision to use tools from outside realist evaluation to assist with theory building and intervention development. In a later section (see section 6.4.3), a process of end-user consultation with physiotherapists and a focused mini-literature review are described. The outcome of this process was the recognition that a core construct examined in this thesis; *carryover,* is conceptually under-developed and largely unarticulated. Consequently, existing literature in physiotherapy and rehabilitation provided minimal guidance on how to develop an intervention to improve carryover. In the context of realist evaluation, however, it is argued that drawing on a broader literature base (i.e. outside of physiotherapy and rehabilitation) to identify relevant programmes with a more established theoretical basis can inform theory building. The Behaviour Change Wheel which was developed by health psychologists provides a practical, accessible and evidence-informed approach to intervention development (Michie et al., 2014). To support the development of a treatment theory, I drew on theory building tools such as the Behaviour Change Wheel (which incorporates the Theoretical Domains Framework) as well as more conventional approaches to theory building such as logic models which include theories of change and theories of action (Funnell & Rogers, 2011). The next section explains how these tools were adapted using realist logic to fit the purpose of the research and maintain methodological coherence.

### 6.2.2 Application of realist logic to the design decisions in Phase 3

A realist philosophy was applied throughout the third phase to ensure theoretical coherence during theory building efforts (Pawson & Tilley, 1997; Pawson, 2002).

Realist logic is a logic of analysis that involves several key characteristics such as the focus on explanatory theory building via development of CMO configurations and the use of mid-range theories (as described in Chapter Three in section 3.5 on page 55). A further feature of realist logic is the emphasis on abductive reasoning to aid theory building and help identify (hidden) mechanisms of action. Abductive logic starts with a specific outcome and works backwards and outwards from this point (P. McEvoy & Richards, 2006). It involves a process of forming ideas and speculating about possible causes and connections (akin to a detective seeking clues) but continuing to seek data to confirm such speculations (Maxwell & Mittapalli, 2010; P. McEvoy & Richards, 2006; Wong, Westhorp, et al., 2013). Such an approach could be open to a charge of bias but realist scholars who use mixed methods argue the integration of findings produced through the use of deductive, inductive and abductive logic can provide complementary insights and provide a balancing effect (Maxwell & Mittapalli, 2010; P. McEvoy & Richards, 2006). Astbury & Leeuw (2010, p. 375) caution that theory building based on abductive reasoning involves "constant shuttling back and forth between empirical data and theory". This characterised the approach taken throughout Phase 3. This application of realist logic for each of the three tools selected for Phase 3 is expanded on in Table 9.

Table 9. Application of realist logic to each tool

| | Description | Application of realist logic |
|---|---|---|
| **Phase 3a-Tool 1: Theory of change (and outcome chain)** (Funnell & Rogers, 2011) | • Outcome chain is a type of logic model that links a theory of change and a theory of action<br>• Description of how change is expected to occur including immediate, intermediate and ultimate outcomes<br>• Developed through 1) Situation analysis, 2) Focusing and Scoping and 3) Outcome chain | Outcomes linked to 'If-then' statements to explain how context, mechanisms and outcomes are linked for each of the identified outcomes via preliminary CMO configurations (See Table 13) |
| **Phase 3a-Tool 2: Theory of Action** (Michie et al., 2014) | • Provides systematic approach; understanding the problem in behavioural terms, selecting and specifying target behaviours, identifying what needs to change, identifying intervention options.<br>• Based on systematic method for understanding behaviour, the 'Behaviour Change Wheel' and the Theoretical Domains Framework which links intervention components to behaviour change techniques | Works backwards from desired behavioural outcome to select key behaviour change goals most likely to support this outcome<br>Links behaviour change techniques and other activities (what therapist can do) with how change occurs (mechanisms of action) and desired outcomes<br>Uses mid-range theories (Control Theory and Self-Determination Theory) to inform selection of intervention components and links components to key mechanisms of action<br>Explicitly considers social and environmental contextual factors to overcome limitations of the Theoretical Domains Framework |
| **Phase 3b-Tool 3: Realist impact evaluation using a case study** (Westhorp, 2014; Yin, 2014) | • Evaluates impact of intervention on expected and unexpected outcomes and clarifies whether mechanisms of actions were activated as expected | Measures activation of mechanisms and outcomes using mixed methods to evaluate support for theory of change<br>Seeks to identify what contextual factors constrain or enable activation of mechanisms<br>Identifies any unexpected outcomes |

## 6.3 Theory building

Data to inform theory building came from a variety of sources, namely quantitative data from Phase 1, qualitative data from Phase 2 and data from end user consultative processes. Combining data that has been developed through deductive processes such as quantitatively driven research, data developed through inductive processes like interviews, as well as data produced by the explicit articulation of mental models is likely to produce more robust insights to aid theory building than any single approach (Funnell & Rogers, 2011). Figure 12 was first presented in Chapter Three and is reproduced below to provide an overview of how I used the different sources of data to inform theory building.

In addition, I selected and used two theories; Control Theory (Carver & Scheier, 1982) and Self-Determination Theory (Deci & Ryan, 2008b) to inform theory building. I used these theories to predict which components of the intervention were likely to be most influential and why, and to help identify possible mechanisms of action and specify the types of outcomes expected. The rationale for the selection of these two substantive theories is explained in more detail in section 6.3.1.1 and section 6.3.2.1.
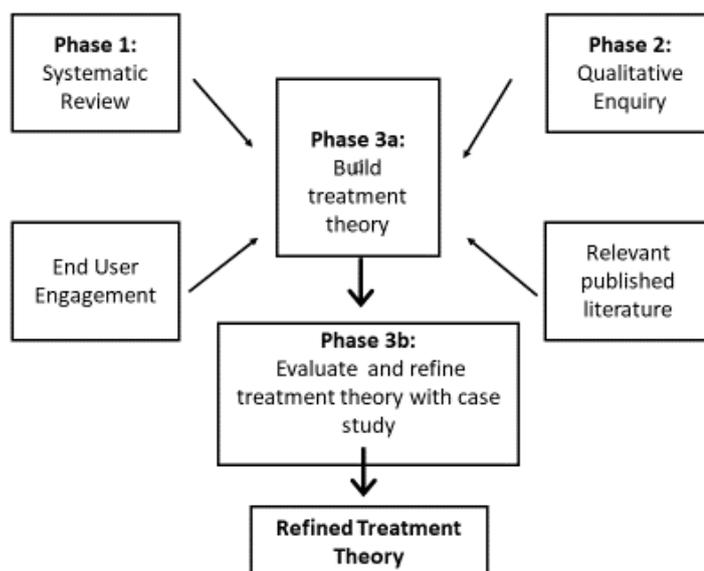
Figure 12. Relationships between different phases of project

Informed by Funnell & Rogers (2011), I constructed a series of tasks to develop the theory of change. The process involved a situation analysis of the problem, focusing and scoping to identify desired outcomes and priorities and articulating the mental models held by expert clinicians and academics. The theory of action connects the activities of an intervention with the theory of change. In developing this treatment theory, I was guided by the Behaviour Change Wheel and the Theoretical Domains Framework (Michie et al., 2014).

Figure 13 provides an overview of each of the tasks I undertook to build the treatment theory. As noted in the previous section (e.g. 6.2.1), theory building was iterative and at times involved *'shuttling back and forth'* between data and relevant literature across different tasks (Astbury & Leeuw, 2010, p. 375) to develop a more nuanced understanding of how change could occur.

**Theory of change**

1. Situation Analysis
2. Focusing & Scoping
   Identify desired outcomes
   Identifying priorities
3. Articulating mental models of end users
   Concept evaluation (carryover)
   Articulating mental models of end users
   Consultation with physiotherapy academics
   Focused Literature Review
   Consultation with academics outside physiotherapy
4. Development initial rough theory
   Discussion group with content experts
   Grouping of mechanisms
5. Data integration (tracing the thread)

**Development of Outcome Chain**

**Theory of action**

6. Identification of important success criteria
7. Identification of types of features likely to affect pattern of outcomes and/or implementation
8. Specification of programme activities using Behaviour Change Wheel
   Define the problem in behavioural terms
   Select and specify target behaviours
   Identify what needs to change using Theoretical Domains Framework
   Identify intervention options
   Identify content and implementation options including behaviour change techniques and mode delivery

Figure 13. Steps taken to build treatment theory
(Adapted from Funnell & Rogers 2011 & Michie et al. 2014)

I synthesised and integrated data from all sources leading to the development of a theory of change, a theory of action and an outcome chain which is displayed pictorially as a pyramid in Figure 18 on page 139and explained in Table 13. I then operationalised the treatment theory into an intervention called *Walking for Wellbeing after Stroke* which is described in Chapter Seven. The next section reviews how the findings of the systematic review in Phase 1 and the qualitative enquiry in Phase 2, relevant published literature and the neuroscientific literature on feedback loops informed the theory building process.

### 6.3.1 Findings from Systematic Review Data in Phase 1

The main sources of deductive data were the systematic review findings (phase 1, Chapter Four). However, the findings required further exploration before they could be included (O'Cathain et al., 2010). A recognised limitation of systematic

review methodology is that while it is effective at answering questions of effectiveness, it is not designed to provide information about *how* such change occurs; or why different interventions work the way they do (Connelly, 2007; Möhler, Köpke, & Meyer, 2015; Noyes et al., 2013). At face value, the two studies in the review which had the most robust effect sizes look very different (Nadeau et al., 2013; Logan, Gladman, et al., 2004). One was delivered by physiotherapists, based on supervised repetitive exercise and was relatively intensive with 36 sessions over 12 weeks (Duncan et al., 2007; Nadeau et al., 2013). The second was delivered by an occupational therapist, provided escorted walking in the real-world, and had around 7 sessions over 16 weeks (Logan, Gladman, et al., 2004; Logan et al., 2006). Both interventions were similarly effective at improving real-world walking suggesting both activated mechanisms of action responsible for producing sustained change. However, it is not clear from the more conventional synthesis of data how these interventions worked to produce change and what intervention components mattered.

To explore this further, I compared the two interventions to ascertain which intervention components may conceivably be associated with the change in real-world walking (see Figure 14). This process revealed two components that the studies had in common; context specific training <u>and </u>collaborative goal planning. Context specific training referred to exercises or walking practice in real-world settings and encouragement to walk regularly. Collaborative goal planning described a process whereby the therapist and patient jointly identified goals, developed a plan to achieve the goals and identified potential barriers to goal striving. This in-depth comparative analysis produced insights about the synergistic effect of these two factors and I used this finding as the starting point for theory development.
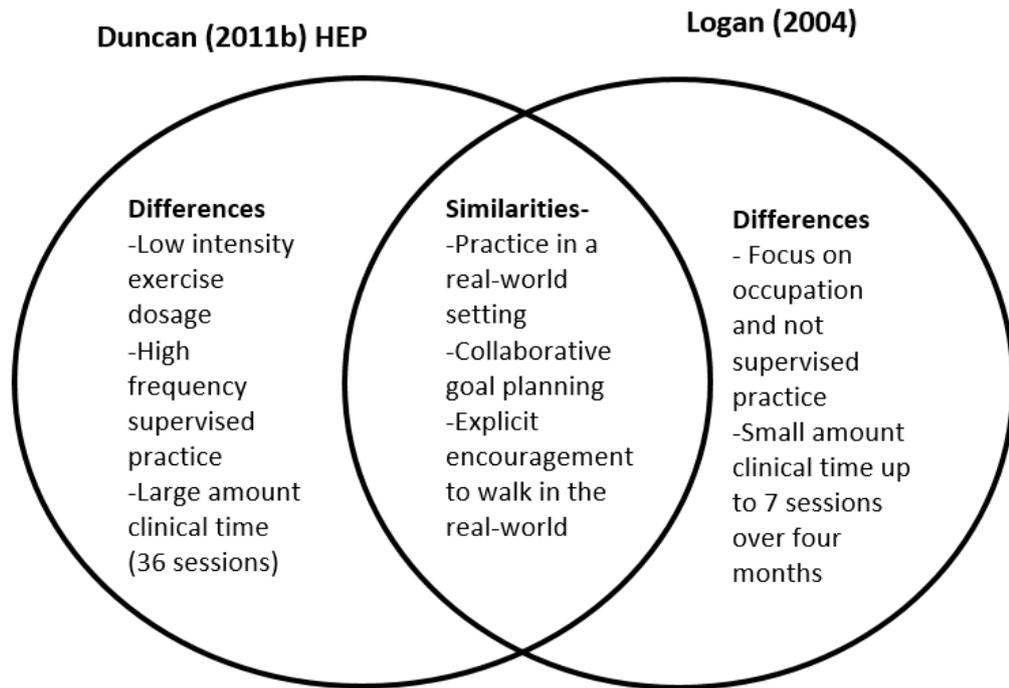
Figure 14: Comparison of intervention components from Systematic Review (Phase 1)

### 6.3.1.1 Control Theory

Realists argue that mid-range theories (or substantive theories) are particularly important to theory building because they explain how and why context limits and influences mechanisms of action (Blamey & Mackenzie, 2007; Wong, Westhorp, et al., 2013). Mechanisms of action are the building blocks of mid-range theories (Astbury & Leeuw, 2010). Mid-range theories can be used to identify which interactions between intervention components matter (Westhorp, 2012). As discussed earlier in Chapter Two, findings in Phase 1 pointed to the potential relevance of a theory of self-regulation known as Control Theory (Carver & Scheier, 1982). And, as noted on page 27, intervention components informed by Control Theory include goal setting and action planning, barrier identification and self-monitoring. The data from the systematic review indicated people with stroke may benefit from these types of intervention components and suggested that Control Theory could be included as a relevant mid-range theory for this research

### 6.3.2 Findings from Qualitative Enquiry

There were several useful insights derived inductively from the qualitative enquiry. The striking similarities between the data and the core concepts of Self-Determination Theory (discussed in depth in Chapter Five, section 5.4.4) suggested it was a second mid-range theory that could provide relevant theoretical insight for theory building (Deci & Ryan, 2000, 2008b). These similarities included: a) the lack of confidence participants had in their ability to walk in the real world and how this perceived lack of competence negatively affected wellbeing; b) the way walking could enhance social connectedness; c) the potential for walking to provide a sense of psychological freedom and support autonomy, and d) the importance of motivational processes to improving real-world walking.

### 6.3.2.1 Self-Determination Theory

As described in Chapter Five, Self-Determination Theory proposes individuals have a natural tendency toward growth and development but that the social context can act to support or thwart this process (Deci & Ryan, 2008b). It hypothesises that psychological wellbeing and optimal functioning can only occur when three basic psychological needs are met: autonomy, competence and social connectedness (Deci & Ryan, 2000; Ng et al., 2012). Support and satisfaction of these basic needs leads to a sense of vitality and energy. Self-Determination Theory has been used to develop effective interventions to increase levels of physical activity for healthy individuals (Fortier et al., 2012; Ng et al., 2012). However, to my knowledge, Self-Determination Theory is yet to be explicitly applied to investigations of physical activity interventions for people with stroke.

Self-Determination Theory distinguishes between different types or quality of motivation; contrasting *amotivation* (the experience of lacking motivation), *controlled motivation* (motivation that comes from a sense of coercion) and *autonomous motivation* (motivation that the individual perceives as coming from their own choice or autonomy due to its inherent pleasure or consistency with personal values) (Deci & Flaste, 1995; Deci & Ryan, 2008b). If an individual is

autonomously motivated then they have motivation that is described as intrinsic or internalised (Deci & Ryan, 2008b; Teixeira et al., 2012).

The concept of autonomous motivation is well accepted by physical activity researchers given the substantial body of research which links it to it to sustained behaviour change (e.g. Fortier et al., 2011; Teixeira et al., 2012). *Internalisation,* has been suggested to be an underlying process which can lead to increases in autonomous motivation (Vansteenkiste et al., 2012). This process involves gradual adoption of personal values that endorse physical activity and there is data to support its significance to sustained change in walking programmes for healthy people (Kinnafick et al., 2014). An alternate motivational process linked to motivation for learning is the management or regulation of emotions (Bell & Kozlowski, 2008; Ryan, 1995). The word motivation was used repeatedly by participants in Phase 2 and motivation to keep on striving was a significant theme identified in the qualitative data. In rehabilitation research, "ambivalent" attitudes toward motivation are commonplace for both clinicians and researchers (Siegert & Taylor, 2004, p. 1) which may explain the lack of exploration of motivational issues following stroke (Maclean, Pound, Wolfe, & Rudd, 2000; Siegert & Taylor, 2004). Little is known about motivational processes following stroke, how reduced motivation relates to a loss of confidence and how or if motivational processes differ between stroke survivors and their healthy counterparts. In the initial treatment theory, I hypothesised that repeated successful mastery experiences would produce positive emotions, experienced as greater confidence and that this would support the process of internalisation which would enhance autonomous motivation for real-world walking. See Table 13 for the proposed CMO configuration describing this process. The motivational processes following stroke are discussed further in section 7.2.1.1.3 and in section 8.2.1

A further strength of Self-Determination Theory is the emphasis on certain types of contexts to promote autonomous motivation (Deci & Ryan, 2008a; Ryan et al., 2011). Proponents of the theory argue that interaction styles which promote choice and control and create a supportive social context can produce an autonomy-supportive environment (Ryan et al., 2011; Vansteenkiste, Lens, & Deci,

2006; Vansteenkiste et al., 2012). The presence of an autonomy-supportive environment has been linked to increased autonomous motivation for behaviour change including engagement in physical activity (D'Angelo, Pelletier, Reid, & Huta, 2014; Fortier, Sweet, O'Sullivan, & Williams, 2007; Patrick & Williams, 2012; Ryan & Deci, 2008), the optimal conditions for human learning (Cozolino & Sprokay, 2006) and motivational transfer between physical activity behaviours in school settings and leisure time activity for school students (Hagger et al., 2009; Hagger & Chatzisarantis, 2007). Section 7.2.1.2.1 on page 162 provides further information about an autonomy-supportive environment. The findings from Phase 2 and the relevant published literature indicated that Self-Determination theory would likely provide a suitable foundation on which to base intervention development (discussed in more detail in Chapter Seven). To illustrate this, Table 10 below provides a summary of how key constructs from Self-Determination Theory were linked to key intervention components during the process of intervention development.

Table 10. Relationship between findings from thematic analysis, Self-Determination Theory constructs and intervention components

| Themes from Qual. Enquiry | Constructs from Self-Determination Theory | Potential Key Intervention Components |
|---|---|---|
| Freedom from dependence | Needs Satisfaction: Autonomy | Collaborative goal setting to support autonomy |
| Step by step progress brings hope | Needs Satisfaction: Competence | Context specific practice to enhance competence |
| Make it social | Needs Satisfaction: Social Connectedness | Family centred goal setting meeting, group based education and walking sessions to enhance social connections |
| Motivating self to overcome | Autonomous motivation | Create autonomy-supportive environment to support autonomous motivation |

### 6.3.3 Deliberating mid-range theories

As noted above (see section 6.2.2) a distinctive feature of realist research is the use of realist logic which involves drawing on theory from diverse sources to

assist with theory building. In this current project sources included: literature from health psychology (e.g. Michie & Johnston, 2012) including stress and coping (e.g. Lazarus & Folkman, 1987); educational psychology (e.g. C. S. Green & Bavelier, 2008; Grossman & Salas, 2011; Reeve, Bolt, & Cai, 1999); sociology (e.g. (Festinger, 1954; Hedström & Ylikoski, 2010; Thoits, 2011), and neuroscience (e.g. Inzlicht et al., 2014; Legault & Inzlicht, 2013).

This section summarises the process of deliberation I undertook to ascertain whether any further theories could provide additional explanatory benefit in the development of the treatment theory. This process involved reading and engagement with various bodies of literature, consideration of end-user perspectives and critical reflection on the data collected in the previous phases. Using the key *thread*s or theory areas identified during integration as a starting point, I travelled widely to seek out research that may help explain how to promote sustained change in real-world walking and develop the CMO configurations for the treatment theory. Three bodies of research; self-efficacy theory from health psychology, social psychological mechanisms from sociology, and feedback loops behind action control and habit formation developed in neuroscience appeared to have potential to provide additional explanatory insights. I consider each of these areas below.

### 6.3.3.1  Self-efficacy theory

Self-efficacy describes an evaluation or judgement that a person makes about how confident they are in their ability to produce certain actions in any given situation and is a key construct of Social Cognitive Theory (Bandura, 1994). Self-efficacy type constructs are found in many mid-range theories of behaviour change including perceptions of competence in Self- Determination Theory. The Theoretical Domains Framework (Cane et al., 2012) overcomes the issue of these overlapping theoretical constructs by grouping such evaluative concepts (e.g. self-efficacy, self-confidence, perceived competence, perceived behavioural control) under the heading *beliefs about capability*. As noted earlier, the thesis takes a similar approach and uses the term self-confidence as an umbrella term referring to an estimation of one's capability to accomplish something. See 2.1.1.3 and 2.3.2 for further discussion of this topic.

While there is an extensive body of research drawing on self-efficacy theory there is a paucity of evidence of its effectiveness as a basis for interventions to improve physical activity (e.g. Ashford, Edmunds, & French, 2010; Rhodes & Pfaeffli, 2010). Bandura proposes that successful performance of a specific behaviour provides information that can enhance self-efficacy; this is known as enactive mastery experience (Bandura, 1982, 1997). Ashford and colleagues (2010) systematically reviewed interventions which sought to increase self-efficacy and improve physical activity for healthy adults. They hypothesised that intervention components which included scheduled or unscheduled practice of the desired physical activity or graded mastery would increase self-efficacy via enactive mastery. Graded mastery is where an individual is set easy-to-perform tasks that are made increasingly difficult, but achievable until the desired behaviour is performed (Michie, Ashford, et al., 2011). One quarter of the 31 studies in the review included graded mastery as a component. However meta-analysis showed graded mastery produced reductions in self-efficacy suggesting such experiences can undermine participants' self-confidence. Similarly attempts to verbally persuade participants of their capabilities, and the process of identifying barriers to goal attainment were associated with lower levels of self-efficacy. In contrast feedback on performance and watching the performance of others (known as vicarious experiences) led to the highest levels of self-efficacy. Study participants in the meta-analysis were healthy and it is not clear if the results point to flaws in self-efficacy theory or how the theory was operationalised and how applicable these findings would be to stroke survivors who already lack confidence in their personal effectiveness or competence (Ellis-Hill & Horn, 2000; Horne et al., 2014).

In light of the limited ability of self-efficacy theory to explain change in physical activity and the conceptual ambiguities noted previously (D. P. French, 2013; D. M. Williams, 2010; D. M. Williams & Rhodes, 2014), I elected to use the construct of perceived competence from Self-Determination Theory as the theoretical basis for intervention components that sought to increase self-confidence. In Self-Determination Theory competence refers to a feeling of being effective in producing desired outcomes and exercising one's capacity (Ng et al., 2012, p. 327). The qualitative literature which explores confidence walking after stroke

(Barnsley et al., 2012; Horne et al., 2014; Nanninga et al., 2017) and the findings of Phase 2 indicated that a type of progressive mastery in real-world settings was important to build self-confidence. In the initial treatment theory, I hypothesised that repeated practice and success in real world walking would lead to gradual gains in confidence and over time progressive mastery. This would provide a type of feedback that would lead to revaluations or reappraisals of personal capability (Lazarus & Folkman, 1987) that would enhance estimations of personal competence. See for the proposed CMO configuration describing this process. The mastery mechanisms following context specific practice are discussed further in section 7.2.1.1.4 and in section 8.3.2.

### 6.3.3.2 Theories relating to enhancing social connections

The influence of social factors on self-regulatory processes was very clear in the qualitative data in Phase 2 and this is consistent with the findings of the wider health literature that social factors shape self-regulation (Carron et al., 1996; De Ridder & De Wit, 2006).

Recent research has explored synergistic mechanisms by studying the therapeutic connection and collaboration in rehabilitation (e.g. Bright et al., 2014; Kayes & McPherson, 2012; Kayes et al., 2015). Similar findings from community-based evaluation literature highlight the importance of trust and collaborative interactions in developing partnership synergies that energises more productive outcomes in community development (Jagosh et al., 2015; Lasker, Weiss, & Miller, R., 2001). In Self-Determination Theory, creating an autonomy-supportive social environment facilitate both the development of motivation for sustained change and the development of a working alliance including a sense of empathy that engenders trust and agreement to collaborate (Mann et al., 2013; Patrick & Williams, 2012; Ryan et al., 2011, 2009). Aside from the contribution of Self-Determination Theory, there has been limited theoretical attention to mid-range theories that can explain the full range of connecting and collaborating mechanisms likely to influence sustained behavioural change or the contexts that enable such mechanisms to be activated. In the initial treatment theory, I hypothesised that the provision of an autonomy-supportive environment would create a social context that would allow basic psychological needs to be satisfied.

In particular, the creation of a supportive and collaborative social environment would energise change and activate mechanism of trust and synergy. See section 7.2.1.1.6 for a more through discussion of collaborative mechanisms.

Several relevant reviews describe other psychosocial mechanisms that can promote social connections in ways beneficial to health and wellbeing (Carron et al., 1996; Hostinar, Sullivan, & Gunnar, 2014; Seppala, Rossomando, & Doty, 2013; Thoits, 2011; Uchino, Bowen, Carlisle, & Birmingham, 2012). For example, Thoits (2011) has provided a particularly accessible summary of these mechanisms by grouping them by source (i.e. significant other, similar other) and by function (active coping mechanisms and emotional sustenance). Appendix L provides more information about the psychosocial mechanism I selected for the treatment theory based on this framework of Thoits (2011), and the research into collaborative mechanisms (Hall et al., 2010; Jagosh et al., 2015; Kayes et al., 2015; Lasker et al., 2001; Norcross & Wampold, 2011)

### 6.3.4  Neural feedback loops

As discussed in the section on realist perspectives in section 3.4, mechanisms represent the capacities held by human beings and can be conceptualised as occurring on several levels (Astbury & Leeuw, 2010; Bhaskar, 2008; Pawson & Tilley, 1997). Bhaskar & Danemark (2006, p. 288) critique disability research using a realist lens and argue that there are different levels of human agency that underpin the control of action. They propose that this *laminated* perspective could involve mechanisms that occur at sub-individual levels (e.g. neurobiological and/or psychological), individual/biographical levels, psychosocial, cultural and normative levels to support human agency (Bhaskar & Danermark, 2006; Bhaskar et al., 2010). From a realist perspective, human agency is very significant mechanism and can be viewed as the power to plan actions to achieve one's goals and produce speech and behaviours directed at attaining such goals (O'Halloran, 2015). In neuroscience, evidence relating to the control of action suggests the existence of two neural feedback loops likely to be relevant to goal attainment and sustained change (Duhigg, 2012; Inzlicht et al., 2014).

The two neural feedback loops involve conscious goal directed behaviour and an automatic control loop that is part of habituated behaviour. The first loop involves the TOTE loop (standing for Test, Operate, Test, Exit) (Inzlicht et al., 2014). This loop is based on a model of self-control and involves a standard of behaviour that acts as a comparator. Explicitly setting a goal is one way of establishing this feedback loop and a neurological structure known as the anterior cingulate cortex is generally recognised to be responsible for the process of monitoring whether the standard is being met or not. Once the standard is met, the loop is exited. This elegant model of self-control informed Control Theory (Carver & Scheier, 1982) and has a strong empirical basis (De Ridder & De Wit, 2006; Inzlicht et al., 2014). In the initial treatment theory, it was hypothesised that the development of a personally meaningful specific plan would start this feedback loop and energise goal striving. The importance of meaningful goals is supported by neural evidence that personally meaningful goals are monitored more urgently (Legault & Inzlicht, 2013). More information about planning mechanisms is provided in section 7.2.1.1.2 on page 155.

The second neural feedback loop describes the learned association between contextual cues in the environment and a specific behaviour which have been neutrally linked through the cue-routine-reward loop (Duhigg, 2012; Lally & Gardner, 2013). Cues act as environmental triggers and relevant cues may include environmental features such as location, time of day, or even a feeling. Once the cue has been triggered, the learned behaviour is enacted without any conscious involvement- experientially referred to as being on autopilot (Bargh & Chartrand, 1999). The reward gained by the behaviour is likely to be subconscious and often involves physical or emotional pleasure, such as the sense of being satisfied, or relief at avoiding unpleasant stimuli. This neural loop is likely be a key aspect of reinforcement learning which in psychology has long been an explanation for how to promote behaviour change (Holroyd & Coles, 2002; Kennard & Lewis, 2007). In the initial treatment theory, the use of if-then planning was hypothesised to be one way to utilise contextual cues to act as a prompt for new walking behaviours that over time could become established routines, embedded

in daily activities. Automaticity mechanisms are discussed in section 7.2.1.1.4 on page 157.

Earlier in this thesis, in section 2.1.1.6, I introduced key features of complexity theories which describe the contribution of feedback loops to emergent outcome which can in turn contribute to the development of virtuous and vicious cycles (Hawe, 2015; Noyes et al., 2013; Petticrew et al., 2013; Shiell et al., 2008). Feedback loops at the simplest level describe a situation where the outcome of the action influences the action itself (Hawe, 2015). An example of a possible vicious cycle influencing walking inactivity was provided on page 18. The concept of feedback loops in complexity theories are largely hypothetical and complexity theorists recommend further conceptual exploration and empirical support (Noyes et al., 2013; Petticrew et al., 2013). It is possible that the neurobiological feedback loops discussed in this section may be a contributor to emergent outcome patterns. If this is the case, this would provide support for the contention of Bhaskar (2008), that a laminated view can explain how mechanisms can occur simultaneously at different levels Even more importantly, the presence of these feedback loops provides a plausible explanation for how interventions that promote goal planning and habit formation can activate feedback loops that work together to support sustained change (Wood & Rünger, 2016). The predicted outcome chain in Figure 18 is depicted as a pyramid where attainment of one outcome provides the basis for the next to occur which alludes to the concept of interacting feedback loops that build over time to produce ultimate outcomes.

### 6.3.5 Summary

This section has described how I synthesised theoretical insights from a range of sources including empirical data, mid-range theories and other relevant research literature to provide information to guide development of the theory of change. In the next section, I move on to describing how I worked through each of the eight tasks needed for theory development. I will also describe how I drew on data from end-user groups throughout the process to iteratively inform the development of the treatment theory and intervention evaluation

## 6.4   Development of Theory of Change

### 6.4.1   Task One: Situation Analysis of context for intervention development

I completed a situation analysis which aimed to identify the nature of the problem being addressed, the extent of the problem, possible contributing factors, opportunities provided by the situation and the consequences of the problem. Chapter Two provided a robust discussion of many of these factors and the key points are summarised below.

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**The main problems**

The main problem to be addressed is the high degree of physical inactivity after stroke and the difficulty integrating any gains in walking skill following clinic-based exercise training into a change in lifestyle behaviours. People with stroke have some of the highest rates of physical inactivity of any clinical population (Tudor-Locke et al., 2009) and take 50% less steps per day than their healthy counterparts often irrespective of actual physical ability. Furthermore, they are often socially isolated and struggle to adapt psychologically to the experience of having a stroke. Adopting new activity habits is often difficult for both healthy and disabled individuals. Little is also known about how to help people with stroke maintain any newly adopted walking activities so that long term gains in health and wellbeing can be achieved.

**Contributing factors and opportunities**

Physical inactivity following stroke is likely due to a complex combination of factors that create a vicious cycle of deteriorating function, loss of motivation, and reduced walking-related confidence. Contributing factors are likely to include negative emotional issues, loss of physiological reserve, reduced capability in real-world settings and lack of guidance and support. Walking is the most popular form of activity and is very accessible requiring no specialised equipment. Walking regularly (e.g. around the block) has been shown to protect against functional decline for disabled older adults and has the potential to similarly help those with stroke.

**Consequences**

Research on this topic has identified several adverse consequences of inactivity for PWS such as increasing loss of physical fitness, muscle weakness, greater loss of cognitive functioning and greater risk of second stroke and dying early. In contrast, being more active through walking regularly could improve physiological reserve, increase muscle and bone strength, increase fitness, improve executive function and reduce the risk of dying by 41% (Billinger et al., 2012; Borschmann, Pang, Bernhardt, & Iuliano-Burns, 2011; Cumming et al., 2012; Pang et al., 2005; Towfighi et al., 2012).

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Figure 15. Situation analysis for an intervention to improve real-world walking behaviour after stroke

### 6.4.2   Task Two: Focusing and scoping to identify priorities and outcomes

End user consultation to help provide focus and scope for the project, to help maximise end user relevance of the treatment theory, to identify features likely to

affect implementation of the intervention, to meet ethical obligations specific to clinical practice in New Zealand (e.g. King & Turia, 2002) and to reduce participant burden for the intervention recipients. Relevant end users were neurological physiotherapy clinicians and rehabilitation academics involved in research and teaching as well as people with stroke and their families. Expert neurological physiotherapy clinicians were recruited through professional networks primarily at AUT University and through the Laura Fergusson Trust and meetings were held at both venues. Rehabilitation academics who had expertise in neurological rehabilitation and experience in developing behaviour change interventions contributed to a second consultation group. For pragmatic reasons, participants in this second group all worked at AUT University and because of their expertise in the topic, were also supervisors on this project. I used end user consultation with the first two groups primarily to develop the treatment theory by encouraging them to articulate their explicit mental models of how sustained change in walking behaviour was likely to occur. This is discussed further in section 6.4.3.

The third end user group (known as the Stroke Advisory Group) consisted of members who had previously participated in the qualitative enquiry or other stroke survivors recommended by colleagues at PCR who were able to articulate the experience of living with a stroke. Family members of these individuals were also invited to participate. The primary purpose of the Stroke Advisory Group was to help maximise the end user relevance of the intervention being developed, and ensure that participant burden was kept to a minimum. Appendix M on page 337 chronicles the process of end user engagement throughout the project as a whole and documents how such input influenced theory development. Appendix N contains verification of the consultation process with the Mātauranga Māori Committee of AUT University.

An early task was to clarify the desired outcome(s). The primary outcome, as described earlier, was sustained change in real-world walking behaviour. I developed the definition of real-world walking behaviour through an iterative process that involved reviewing existing definitions of related concepts and debate and consultation with the review team to reach a consensus on a

definition. The full definition of real-world walking is found in Chapter One on page 3. Consultation with end user groups of expert physiotherapists confirmed the importance of focusing on the question of how change occurs as a first priority (See Appendix M). This provided an important focus for the project and a helpful boundary to help contain the topic.

### 6.4.3 Task Three: Articulation of Mental Models of End Users

One important purpose of engaging with expert physiotherapy clinicians and academics was the opportunity to uncover underlying mental models they hold about how current physiotherapy interventions are expected to work (Funnell & Rogers, 2011). Mental models are a type of implicit treatment theory and are used to provide clarification of current models of practice. One such mental model is the process of *carryover*. There was a strong consensus among participants that *carryover* was an important concept to both real-world walking and neurological physiotherapy generally.

The expert clinicians recruited through my professional networks had at least two years' experience retraining walking in the community for people with stroke. Academic physiotherapists were invited to participate if they were currently working at AUT University, had clinical experience retraining walking and were teaching or researching in fields related to stroke rehabilitation. The first series of consultation meetings explored the importance of carryover using two focus groups comprising academic physiotherapists (n=8) in neurology and expert physiotherapy clinicians (n=3). For example, 90% of focus group participants rated it as 9 or 10 out of 10 for importance to neurological physiotherapy. Focus group participants were then asked to define carryover in their own words and the answers were compared. The definitions shared three key characteristics: learning gains; in motor skill; leading to habitual or automatic improvement. There were some differences, though, as to whether these gains in motor skill learning referred to changes that were retained over time (e.g. between sessions), retained in different settings (i.e. between hospital and real-world settings) or between two closely related tasks (i.e. sit to stand and walking).

Janice Morse has made an important theoretical contribution to the profession of nursing theory through her research into core concepts that underpin nursing practice (e.g. Morse, Bottorff, & Hutchinson, 1995; Morse, Hupcey, Mitcham, & Lenz, 1996; Morse, Mitcham, Hupcey, & Taspm, 1996). She proposes that for a concept to be mature it needs to be: a) well defined; b) have identified characteristics so that it can be differentiated from other concepts; c) have recognised preconditions and outcomes; and d) delineated conceptual boundaries (Morse, Mitcham, et al., 1996). Despite the broad consensus around the definition held by focus group participants, the lack of explicit description and clarity in professional literatures indicated the concept of carryover can be classed as lacking maturity (Morse, Mitcham, Hupcey, & Taspm, 1996, p. 387). This limited its current utility for intervention development (Morse, Hupcey, et al., 1996; Morse, Mitcham, et al., 1996). A concept evaluation was necessary to extend understanding of the concept of carryover.

### 6.4.3.1  Concept Evaluation: Carryover

A focused literature review was completed to help clarify the characteristics of the concept as used by rehabilitation providers. Figure 16 summarises this mini review. Using a search strategy that examined the rehabilitation literature with a single database (Scopus) all papers that used the word *'carryover'* or *'carry-over'* in either the title or abstract were closely examined. The way the term was used in the literature was compared with the definition provided by the focus group participants. Three key characteristics were identified. Carryover is a process that involves; a) sustained learning gains; b) requires cognitive and/or motor skills and, c) leads to change that is sustained over time or across different settings. These characteristics extended the definition provided by expert physiotherapists to include cognitive as well as motor skills. The process clarified carryover does not describe a component of an intervention. For example, nurses doing carryover of activities is not included in the definition (Atwal, Tattersall, Caldwell, & Craik, 2006). One necessary condition is that some form of change needs to occur before carryover is evident and the ideal outcome of the process of carryover is that activities are performed more automatically, efficiently and/or with greater independence. There were occasional examples of studies where the

term referred to change occurring in the same setting and at the same point of time such as improvements in sitting ability carrying over to improvements in standing (e.g. Dean, Channon, & Hall, 2007). However, the majority of studies in the review emphasised change over time and across settings which was similar to the focus of this thesis. At the end of this process, a working definition of carryover was developed to help guide the next stage of theory building. Carryover was defined as an active learning process where gains in learning of a motor and/or cognitive skill are retained across sessions and/or between different environmental settings. Although this process provided some additional clarity, questions remained. For example: under what conditions can carryover develop? What circumstances can influence carryover? And, what kinds of outcomes are expected if carryover has occurred?

Wider reading outside physiotherapy literatures and discussion with other rehabilitation colleagues showed that the concept of carryover may share properties with other related concepts. For example, discussions with academics from occupational theory and educational psychology revealed that the terms *generalisation* and *transfer of training* referred to a similar process. For occupational therapists, speech language therapists and neuropsychologists, the challenges of generalising cognitive or communication skills, learnt in clinic settings, to real-world settings is a well-recognised limitation of current rehabilitation practices (e.g. Basford & Malec, 2015). Similarly, the literature from educational psychology contains extensive discussion about the *transfer problem-* which describes the difficulty experienced by learners applying new skills learned in training opportunities back into work place settings (e.g. Bell & Kozlowski, 2008; C. S. Green & Bavelier, 2008; Grossman & Salas, 2011). Most notably, literature in educational psychology distinguishes between *analogous transfer* which refers to the transfer of skills to problems similar to those encountered during training and *adaptive transfer* which describes a process where learners draw on their existing knowledge to develop a solution to a new problem (Bell & Kozlowski, 2008, p. 296). In summary, I concluded that the concepts of carryover, generalisation and adaptive transfer describe broadly similar learning processes and the terms are largely interchangeable when used to refer to the process of

transferring gains in walking skills into different environmental settings. In particular, given the changeable demands of real-world settings noted in the qualitative data, the need for sufficient skills to promote *adaptive transfer* was recognised.

**Purpose**: The purpose of this literature review is to clarify how the concept of carryover is currently used in the rehabilitation literature as part of an ongoing conceptual evaluation (Morse, Mitcham, et al., 1996).

**Methods**: Using the Scopus database, the rehabilitation literature was searched for any titles or abstracts that used the word 'carryover' or 'carry-over'. Data was extracted and details of purpose and content noted. Studies were entered into a spreadsheet. Findings for each study here was compared to a definition developed by physiotherapy end user groups for similarities and differences

**Findings**: 31 studies were included that used 'carryover' in either title or abstract. Included studies are listed in Appendix O. A range of different usages was evident revealing both similarities and differences to the definition provided by end users. Similarities included a focus on a learning process where gains were transferred. The focus of the learning was usually the person receiving rehabilitation but the term could describe implementation of therapy activities by family members. Many studies referred to not only motor skill learning but also cognitive and communication skills learning. Carryover was used to describe learning gains between two similar tasks where change in one task 'carried over' to change in a related task in the same setting; changes over time 'carried over' between physiotherapy sessions; and changes between two different settings 'carried over' between each setting such as between residential and home settings.

**Conclusion:** This review has shown the variable and inconsistent usage of the concept of carryover in the rehabilitation literature. Comparison of similarities and differences in how the term has been used has produced greater clarity on the definition to be used for this research. In this thesis, carryover refers to a learning process that involves adaptive transfer of gains in learning between rehabilitation and real-world settings. Further theoretical work is needed to understand how to better facilitate this process for rehabilitation clients**.**

Figure 16. Focused literature review of carryover

### 6.4.4  Task Four: Development of 'Initial Rough Theory'

The first end-user consultation of expert neurological physiotherapists and conceptual review revealed that the concept of carryover in neurological physiotherapy lacked maturity. The second consultation group comprised rehabilitation academics who had content expertise in behaviour change. This group was used to extend the knowledge by further exploring how adaptive transfer of walking skills into real-world settings could be optimised. Participants in the second group were experts in the field of behaviour change and/or rehabilitation after stroke- and included supervisors on this project. The COM-B

model of behaviour change was used as a starting point because of the way it elegantly synthesises the extensive body of research in behaviour change (Michie, van Stralen, et al., 2011). The group discussed *how* a change in real-world walking behaviour after stroke could occur. The purpose was for these content experts to articulate their mental models and generate some initial tentative hypotheses about causal change processes.

Nine possible change mechanisms were identified during the discussion group and are summarised in Figure 17. Following further reading of behaviour change literature, reflection on the data in the first two phases, further discussion with supervisors and multiple revisions of the initial rough theory, these preliminary mechanisms of action were condensed into four theory areas akin to 'families' of mechanisms (Pawson et al., 2005). Grouping the potential mechanisms into four candidate theory areas provided a way to group constructs that seemed related. Four candidate theoretical threads (planning for action; self-confidence; social connections; and habit formation) were hypothesised to provide important information that could inform strategies to promote sustained change in real-world walking. Using these threads, I re-examined the data in the first and second phases for empirical support and implementation insights to aid intervention development and theory building.

**9 Initial Mechanisms:**

1. Carryover: active transfer of learning of a **skill** ( cognitive and/or motor) over time or settings ] **Overall process of adaptive transfer**

2. Coaching-self: practice of harnessing executive functioning capacity and thinking processes to achieve a specific desired goal
3. Attentional and self-regulatory processes: Ability to attend to and regulate thoughts and emotions

**Planning for action**

4. Confidence: Self-efficacy or degree of confidence of person to carry out desired task
5. Appreciable progress in mastery

**Self-confidence**

6. Collaborative synergy: sense of team or working alliance **Social connections**

7. Meaningful habit change
8. Sustained practice
9. Context-dependent cueing

**Habit formation**

Figure 17. First grouping of processes behind adaptive transfer

### 6.4.5 Task Five: Data integration-'Tracing a thread'

One technique for integrating data which seemed particularly appropriate to the multiple data sources used in this phase is known as *tracing a thread* (O'Cathain et al., 2010). In this type of conceptual triangulation, I identified key ideas and used them as a starting point to compare data from different sources. For this step, I used the four key candidate groupings or theory areas described in the previous section as a starting point or *thread*. For each thread, I compared findings from the systematic review and other relevant quantitative literature with the inductively developed findings from the qualitative study. The findings of this process are shown in Table 11. This process provided complementary insights around the four theory areas, confirmation of the importance of the areas and some practical guidance for intervention development and implementation. The four theory areas were: planning for action which involves conscious and reflective mechanisms; self-confidence which involves changes in beliefs or judgements around personal capability in response to growing mastery of skill; mechanisms of social connections relating to interpersonal or social

interactions; and mechanisms related to habit formation that supported

sustained change.

Table 11. Integration of deductive and inductive findings using four theory areas

| Theory Areas | Findings Systematic Review (Deductive approaches) | Other published literature (Deductive approaches) | Findings from Qualitative Enquiry (Inductive approach ) | Implications for Intervention Development |
|---|---|---|---|---|
| **Theory Area One**: Planning for action | • Having a goal to walk more needed for change <br> • Working with therapist on planning improved real-world walking <br> • Exercise or training in real-world settings necessary <br> • Developing plan to address barriers supports walking more in real-world | • Significant 'intention behaviour' gap in physical activity (Rhodes 2013) <br> • Behaviour change techniques from Control Theory are effective to overcome this gap (e.g. Michie 2009) <br> • Sustaining the change especially challenging (De Ridder & De Wiit, 2006) | • Having a plan helps to motivate <br> • Features of built environment and social networks can influence planning <br> • Including coping planning can reduce anxiety and increase confidence | • Providing support to aid planning is likely to be important <br> • Need to include range of behaviour change techniques to support goal setting & striving and overcome barriers <br> • Real-world settings likely provide environmental cues to help provide feedback <br> • Need to plan ways to help sustain change and address perceived barriers |
| **Theory Area Two**: Self-confidence | • Not discussed | • Known as self-efficacy and perceived behavioural control but only has small effect on healthy people (Ashford, 2013) <br> • Mixed findings about which techniques increase or decrease self-efficacy (Ashford, 2013) | • Positive mastery experiences lead to positive 'I can do this' emotions which has motivating effect <br> • Taking someone along often boosts confidence <br> • Relates to hope of future progress | • Create opportunities for successful practice <br> • Use familiar walking courses e.g. around the block <br> • Provide escorted community walking opportunities with therapist or walking buddy |

| Theory Areas | Findings Systematic Review (Deductive approaches) | Other published literature (Deductive approaches) | Findings from Qualitative Enquiry (Inductive approach ) | Implications for Intervention Development |
|---|---|---|---|---|
| **Theory Area Three**: Social connections | • Working with therapist to develop individualised plan improves real-world walking<br>• Number of sessions not important | • Therapeutic connection and collaboration enhances outcome (Kayes et al., 2015)<br>• Communication styles to support active involvement patient and family optimal (Hall, 2010)<br>• 'Social connectedness' basic human psychological needs (Deci & Ryan 2000)<br>• Family and health professionals often have 'gate keeping' role which can support or restrain walking decisions (e.g. Barnsley 2012) | • 'Make it social' was underlying and related to many of the themes<br>• While walking was often alone it still had social context; for motivation, confidence, variety<br>• This could enable or constrain | • Developing collaborative relationships with client and family likely optimise outcomes particularly in home-based settings<br>• Communicating in person-centred way encourages active involvement<br>• Including social aspects as much as possible is likely to enhance outcomes and sustained change<br>• Social and attitudinal environment can help or hinder change in real-world walking |

| Theory Areas | Findings Systematic Review (Deductive approaches) | Other published literature (Deductive approaches) | Findings from Qualitative Enquiry (Inductive approach ) | Implications for Intervention Development |
|---|---|---|---|---|
| **Theory Area Four:** Habit formation | Context specific practice essential to changing real-world walking | • Overall people after stroke sit more and stand significantly less than age-matched controls (English 2014)<br><br>• Significant repetition of a task (around 66 days) is needed before a task becomes automatic (Lally 2013)<br><br>• Habits are often prompted by environmental cues (Gardner 2014)<br><br>• Self-regulation and internal motivation needed to keep repeating activity (Rhodes & de Bruijn, 2013b). | • Most people have some sort of regular habit they could describe; many had social aspect to it<br><br>• The need to pay attention while walking in the real-world was commonplace<br><br>•  Many longed for time when not need pay attention. Only few achieved it<br><br>• Finding ways motivate oneself essential<br><br>• A number had set backs which led to difficulty sustaining walking habits | • Extending existing habits maybe one way improve activity levels<br><br>• Explain process of automaticity is possible but requires lots of repetition to make neural connections<br><br>• Consider ways optimising opportunities for context specific practice<br><br>• Consider ways to support ongoing habit formation; e.g. regular phone calls may help (Taub 2013)<br><br>• Explicit discussion about dealing with setbacks likely be important |

## 6.5   Development of Outcome Chain

An outcome chain is a type of logic model that illustrates how the intervention is hypothesised to achieve desired results and address the situation at hand (Funnell & Rogers, 2011). This model links the theory of change with the theory of action. Funnel & Rogers (2011) provide exemplars of five different types of generic outcome chains. One of the exemplars was based on case management programmes and this was used as an initial starting point because it shared several distinctive features with the type of intervention that was likely to be developed in this study. Such characteristics included the need for significant changes in behaviours by recipients, the effort required to implement such changes, effort required to deliver the intervention, the likely need for individual tailoring of intervention components, and the likelihood that intervention mechanisms could work differently for different individuals (Funnell & Rogers, 2011).

The initial model which summarises the treatment theory for the *Walking for Wellbeing* intervention is shown below in Figure 18 on page 139. Rather than an *outcome chain* it is depicted as a pyramid because of the way each level is dependent upon and builds upon previous outcomes being attained. The immediate outcomes include: a meaningful plan identified, establishment of collaborative connections, the enaction of new behaviours and self-monitoring of activities. The next level contains intermediate outcomes related to the development of walking self-regulation, development of autonomous motivation, improved walking-related mastery and automatised walking behaviours that produce sustained change in real-world walking behaviours. Ultimate outcomes related to the achievement of adaptive transfer where walking skills are transferred to new contexts and gains in physical and social integration in turn lead to greater wellbeing.
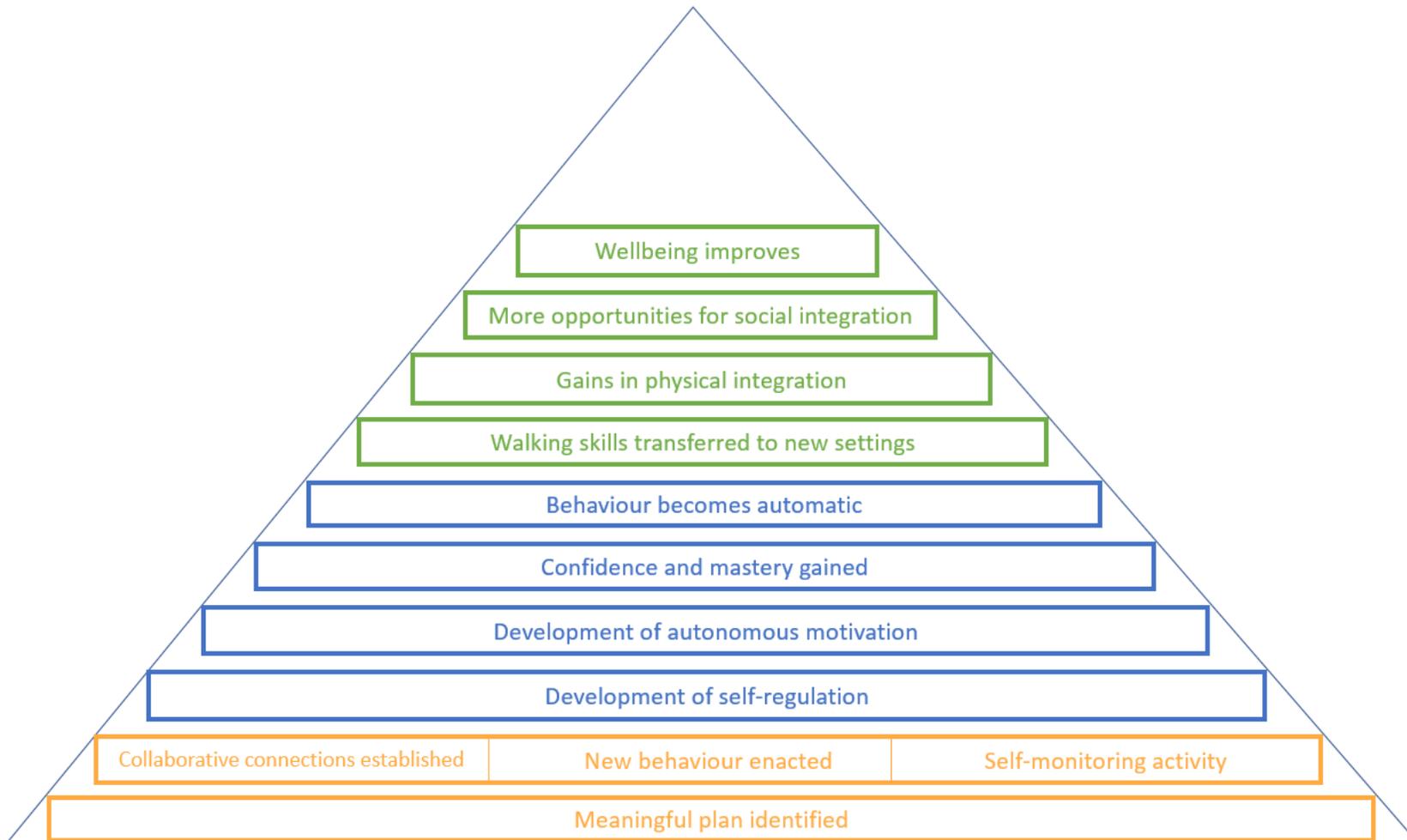
Figure 18. Initial outcome chain- Wellbeing Pyramid

Three sources of information are provided to explain how the outcome pyramid was developed. First, Table 12 provides an overview of the anticipated mechanisms of action. Second, Table 17 describes a more detailed explanation of each of the outcomes, the proposed CMO configurations that contribute to the outcome and the expected mechanism of action. To supplement this information, Appendix L contains more specific information including the definitions and rationale for each mechanism of action, and how each mechanism was expected to link to the intervention components.

Table 12. Summary of anticipated intervention mechanisms of action

| Types of mechanisms of action | Labels |
|---|---|
| Knowledge (Information provision) (K) | Knowledge (K1) |
| | Self-awareness (K2) |
| Planning (P) | Intention (P1) |
| | Goal setting (P2) |
| | Feedback on behaviour (P3) |
| Motivational (Mo) | Autonomy (Mo1) |
| | Internalisation (Mo2) |
| Mastery (Ma) | Cognitive reappraisal (Ma1) |
| | Perceptions of safety (Ma2) |
| | Contextual transfer (Ma3) |
| Habit formation (HF) | Situation-specific automaticity (HF1) |
| | Goal dependent automaticity (HF2) |
| Collaborating and connecting (SC) | Trust and synergy (SC1) |
| | Warm caring and concern (SC2) |
| | Empathetic understanding (SC3) |
| | Belonging, mattering and self-worth (SC4) |
| | Coping informational support (SC5) |
| | Instrumental assistance (SC6 ) |
| | Social influence and control (SC7) |
| | Social comparison (SC8) |

Table 13. Explanation of proposed outcomes and preliminary CMO configurations
*PWS= Person with stroke

| Outcome | Preliminary Context (C) Mechanism (M) Outcome (O) configurations | Proposed mechanisms |
|---|---|---|
| Immediate:<br>1: Meaningful plan developed | If PWS* is provided (C) with relevant information (M) and supported (C) to choose (M) a valued goal (M) THEN a personally meaningful implementation plan can be developed (O) | Knowledge (K1)<br>Awareness (K2)<br>Intention (P1)<br>Autonomy (Mo 1) |
| 2: New behaviour enacted | If implementation intentions (If-then plans) are developed (M) THEN when PWS encounters specific situation or context (C ) they are cued (M) to enact the plan (O) | Goals setting (P2)<br>Situation-specific<br>Automaticity (HF1) |
| 3: A supportive and collaborative social environment is created | If a supportive and collaborative atmosphere is present (C) THEN mechanisms of trust and synergy (M) energise change and produce shared goals and activities (O) | Trust and synergy (SC1) |
| 4: Self-monitoring of activity levels | If there is a written record of activity behaviours (C) THEN feedback is provided for the PWS (M) which sustains their attention on goals striving and provides self- monitoring of behaviour (O) | Feedback on behaviour (P3) |
| Intermediate:<br>5: Improved self-regulation of walking behaviours | If PWS experiences success in goal enactment (C) THEN positive emotions are generated and mastery starts to develop progressively (M) which strengthens self-regulatory skills for walking (O) | Cognitive reappraisal (Ma1) |
| 6: Development of autonomous motivation for walking-related activities | If PWS repeatedly experiences positive emotions from walking (C ) THEN motivation is internalised (M) leading to greater autonomous motivation for walking (O) and more confident expectation of future success (O) | Internalisation (Mo2) |

| Outcome | Preliminary Context (C) Mechanism (M) Outcome (O) configurations | Proposed mechanisms |
|---|---|---|
| 7: Greater confidence and mastery of walking-related skills gained | If PWS experiences greater expectation of success in walking (C) THEN they reappraise their capability to perform the behaviour (M) which leads to increasing sense of mastery in walking-related skills (O) and a desire to repeat the behaviour. | Cognitive reappraisal (M$_1$) |
| 8: Behaviour becomes automatic and new routines established | If a PWS regularly repeats behaviour in a stable setting (C) THEN goal-dependent automaticity is developed (M) leading to sustained change in walking routines (O). These automatised routines are efficient and require less cognitive control (O) | Goal dependent automaticity (HF$_2$) |

| Outcome | Preliminary Context (C) Mechanism (M) Outcome (O) configurations | Proposed mechanisms |
|---|---|---|
| Ultimate:<br>9: Walking skills transferred to new settings | If PWS has more efficient walking skills (C) THEN extra cognitive resources are available to enable learning transfer of walking skills (M) to new environmental settings (O) | Contextual transfer (Ma3) |
| 10: Improved physical integration | If PWS walks successfully across different real-world settings (C) THEN they will feel safer (M) and more confident walking (M) leading to improved physical integration (O) | Perceptions of safety (Ma2)<br>Cognitive reappraisal (Ma1) |
| 11: Improved social integration | If PWS has improved physical integration THEN (C) they will experience more opportunities for social connections (M) which will improve social integration (O) | <u>Emotional sustenance;</u><br>Warm caring and concern (SC2)<br>Empathetic understanding (SC3)<br>Belonging, mattering and self-worth (SC4)<br><br><u>Active coping assistance</u><br>Coping informational support (SC5)<br>Instrumental assistance (SC6)<br>Social influence and control (SC7)<br>Social comparison (SC8) |
| 12: Improved life circumstances and wellbeing | If physical and social integration improves (C) THEN life circumstances will improve leading to greater wellbeing (O) | |

## 6.6   Development of Theory of Action

### 6.6.1   Task Six: Identification of important success criteria

The development of a theory of action involved three further tasks (Funnell & Rogers, 2011). The first one (task six overall) was to identify important success criteria that are linked to the desired outcomes of the intervention. I grouped outcomes into three categories: immediate, intermediate and ultimate. The outcome pyramid is described on page 139 grouped outcomes into three categories: immediate, intermediate and ultimate. The immediate outcomes focus on identifying a meaningful plan and the provision of a supportive and collaborative social environment that can facilitate the adoption of new walking behaviours. The intermediate outcomes in the chain reflect changes in four constructs theorised to represent important stages along the journey to integration and wellbeing. These outcomes are improvements in: walking self-regulation, autonomous motivation for walking, self-confidence for walking and improved automaticity in new walking behaviours. The ultimate outcomes sought by the intervention were the development of adaptive transfer skills, gains in physical and social integration and greater wellbeing. These outcomes are represented in Figure 18 and described in section 6.5.

I selected some quantitative standardised outcome measures identified in the literature to help determine whether desired outcomes were achieved or not. Although measures of learning self-regulation have been developed in education (e.g. Toering, Elferink-Gemser, Jonker, van Heuvelen, & Visscher, 2012), to my knowledge there are no standardised measures of walking self-regulation for healthy populations. In general, there are few appropriate measures of self-regulation after stroke (Al Banna, Abdulla Redha, Abdulla, Nair, & Donnellan, 2015). One  exception is the Self-Regulation Skills Interview (Ownsworth, McFarland, & Young, 2000), but previous research has highlighted complexities in the administration and scoring of this interview-based measure which may impact validity (Kayes, Theadom, Smith, Fadyl, & McPherson, 2011). Ownsworth et al. (, 2000, p. 77) reviewed the difficulties in measuring self-regulation in neurological populations andsuggest one option is to measure task performance and use the findings to infer the use of self-regulatory skills . Consequently, for

this study, instead of a direct measure of walking self-regulation, two measures were selected to provide a proxy indicator of whether this outcome was achieved or not. The first measure was the completion of if-then plans and the second measure was the number of actual daily steps taken as measured by the Stepwatch™ Activity Monitor (Mudge, Stott, & Walt, 2007).

I selected the Behavioural Regulation of Exercise Questionnaire v2 (BREQv2) which assesses five types of motivation (Wilson, Sabiston, Mack, & Blanchard, 2012). Confidence walking in real-world settings can be measured with a questionnaire called the Ambulatory Self-confidence Questionnaire-(ASCQ) (Asano, Miller, & Eng, 2007). Finally, behavioural automaticity has been successfully measured with a subscale of the Self-Report Habit Index (SRHBAI) (B. Gardner, Abraham, Lally, & de Bruijn, 2012). This scale has not been used with stroke survivors but the subscale has demonstrated sensitivity to change following an intervention to improve exercise habits (Kaushal & Rhodes, 2015). These outcome measurement tools were selected to provide standardised ways of measuring theoretical constructs for some of the outcomes in the chain.

The ability to satisfactorily participate in desired activities reflects physical integration and the ability to participate in a range of private and public social interactions reflects social integration (Gottlieb & Bergen, 2010; Trigg, Wood, & Hewer, 1999). The Subjective Index of Physical and Social Outcomes (SIPSO) questionnaire  is a self-report questionnaire designed to measure reintegration into normal patterns of behaviour following stroke (Kersten, Ashburn, George, & Low, 2010; Trigg & Wood, 2003; Trigg et al., 1999) and it includes two subscales for physical and social integration. I selected the SIPSO because it has been used extensively in people with stroke and has established reliability and construct validity (Kersten et al., 2010; Trigg & Wood, 2003; Trigg et al., 1999). This focus on participation aligns with the emphasis of the ICF on outcomes which reflect greater involvement in physical and social realms for rehabilitation recipients (World Health Organisation, 2002).

The ultimate desired outcomes of the intervention were improved wellbeing and gains in physical and social integration (Whittemore, 2005). I had initially hoped to include a measure of vitality which is hypothesised to reflect wellbeing more

broadly (Ryan & Frederick, 1997). However, during the end-user consultation with stroke survivors, (see page 344), one participant felt the vitality questionnaire was superfluous. Given the validity of the vitality scale had not been assessed following stroke and I already had some concerns about the potential to cognitively overload participants, I elected to remove the vitality scale from the list of proposed outcome measures. With the robust psychometric properties of the SIPSO outcome, I theorised that greater integration would lead to better functioning and thus improved wellbeing. To supplement the quantitative data from SIPSO, I planned to include qualitative descriptions of walking in new settings and verbal descriptions of improved wellbeing.

Ideally valid and reliable quantitative outcome measures should be used to provide a trustworthy indicator of whether a clinically significant change in a predicted outcome has successfully occurred or not. The outcome measures selected closely reflected the desired outcome in the treatment theory. Ideally, they also had robust psychometric properties and had been evaluated for use in stroke populations. In some cases, all three criteria could adequately be met (e.g. SIPSO, ASCQ, StepWatch$^{TM}$ Activity Monitor). For other outcomes, I used measures from the wider physical activity literature because they most closely reflected the desired outcome (e.g. BREQv2 and SRHBAI) even when robust data for their use in stroke was not available. As noted earlier, proxy indicators were used if no suitable outcome measure was identified (e.g. self-monitoring, self-regulation). If no proxy measures were identified, I planned to closely peruse the interview data to determine whether there was any indication of successful attainment of the desired outcomes. Table 14 provides more detailed information about the outcome measures selected and the rationale for selection.

Table 14. Outcome measures for treatment theory

| Outcome measure | Desired outcome /level of theory | Description of measure | Items and subscales | Psychometric properties | | Rationale for selection |
|---|---|---|---|---|---|---|
| | | | | Minimum detectable change (MDC)* | Clinically significant difference (CSD) | |
| Completion of If-then plans | Planning for change (immediate) | Daily record | Nil | Non-standardised | Non-standardised | Evidence of planning and implementation of plan |
| Completion of daily records of walking/exercise | Self-monitoring of walking (immediate) | Daily record | Nil | Non-standardised | Non-standardised | Completion of records suggests active self-monitoring; no alternative available |
| StepWatch ™ Activity Monitor: Mean steps per day | Improved walking self-regulation (intermediate) | Ankle mounted activity monitor which records movements | | MDC is 0.21 of baseline (Mudge & Stott, 2008) | Not established | Well established psychometric properties in stroke; indirect indicator of walking self-regulation as records walking actually done |
| Behavioural Regulation of Exercise Questionnaire (BREQv2) | Improved autonomous motivation (intermediate) | Questionnaire which reflects 5 types of motivation, and two subscales of autonomous | 19 items with 3 subscales: (greater = higher amount) Amotivation BREQv2 -AM BREQv2-CM | MDC not able to be calculated as outcome not likely be unidimensional but multi-dimensional | CSD not established; some argue ratio of AM:CM relevant, if AM higher then autonomous | Can provide information about quantity and type of motivation with subscales reflecting autonomous and |

| Outcome measure | Desired outcome /level of theory | Description of measure | Items and subscales | Psychometric properties | | Rationale for selection |
|---|---|---|---|---|---|---|
| | | | | Minimum detectable change (MDC)* | Clinically significant difference (CSD) | |
| | | motivation (AM) and controlled motivation (CM) | | (Wilson et al., 2012) | motivated (Brunet, Gunnell, Gaudreau, & Sabiston, 2015) | controlled motivation; reliability in healthy populations shown (Wilson et al., 2012). |
| Ambulatory Self-Confidence Questionnaire (ASCQ) | Increased self-confidence for walking (intermediate) | Measures degree of confidence in ability walk in outdoor settings | Total 220; 22 items; mean score calculated. | MDC is 0.14x baseline score (Asano et al., 2007) | 8.52 mean score for community dwelling older adults (Asano et al., 2007) | Good psychometric properties, evaluated with stroke survivors, normative values available |
| Automaticity subscale of the Self-Report Habit Index-(SRHBAI) | Improved automaticity (Habit Formation) (intermediate) | Likert scale indicating degree of automaticity for a selected activity | One subscale of SRHI with four questions about automaticity | Not established | > 60% may indicate shift toward automatic processes (Kaushal & Rhodes, 2015) | Most common measure of automaticity in healthy populations, evidence of cut-off |
| Subjective Index of Physical and Social Outcome: | Improved physical and social integration (ultimate) | Self-report measure of impact of stroke on physical and social integration | SIPSO-Physical SIPSO-Social (each subscale out of 20) | MDC is 0.06 x baseline score which is change of 1.2/20 for each (Harrington et al., 2010) subscale or 2.4 /40 for total scale | Harrington et al. (2010) found 1.3 point change in total score 'natural improvement' so CSD = 2 total score | Carefully developed and sensitive measure of community reintegration after stroke. Excellent psychometric properties |

### 6.6.2 Task Seven: Identification of factors that may influence outcome patterns and implementation

The next task in developing an action theory was to identify what factors were hypothesised to affect how well outcomes are achieved and the degree to which intervention mechanisms are able to be activated. Such factors can include programme features as well as features external to the programme including participant characteristics and circumstances. I identified availability of suitably trained physiotherapists able to work collaboratively in real-world settings and sufficient resources to support travel to community settings, were programme factors that have the potential to influence outcomes. Non-programme factors that could potentially influence the outcomes may include: the level of commitment or engagement of participants, their willingness to work collaboratively, a minimum level of physical ability to manage in outdoor settings without falling, desire or capacity to participate in group based programmes, supportive family and adequate cognitive ability to select and adopt new behaviours.

### 6.6.3 Task Eight: Specification of intervention activities

In the final task, I linked specific activities of the intervention to the desired change process and then to specific intervention components. The Behaviour Change Wheel outlines a comprehensive and systematic process for linking identified behavioural targets with intervention components which can work to address identified barriers (Michie et al., 2014). I explored a selection of possible target behaviours , from taking more steps per day, doing daily exercise programmes, recording exercises and walking in a diary, walking regularly outdoors with a family member, walking regularly outdoors with friends and participating in a family based goal setting meeting. Barriers to achieving each target behaviour were carefully considered using the COM-B framework. The following behaviours were selected to be targeted for the intervention; 1) take more steps per day; 2) complete a daily home-exercise programme; 3) record exercises and walking daily in an exercise diary and 4) participate in weekly

outdoor walking with one or more people. Table 15 illustrates this process of behavioural analysis for the target behaviour of taking more steps per day

Table 15. Sample worksheet of behavioural analysis
**Target Behaviour: Take more steps per day**

| COM-B Components | What needs to happen for the target behaviour to occur? | Is there a need for change? |
|---|---|---|
| **Capability- Physical** | Physical skill training to ensure adequate leg muscle strength, balance and reduction in cognitive-motor interference. | Yes |
| **Capability- Psychological** | Scaffolding support of meta-cognitive skills to identify opportunities and turn intention into opportunities. | Yes |
| **Opportunity-Physical** | Select accessible route or activities. | Yes |
| **Opportunity-Social** | Education and involvement of significant others so they can provide supportive social environment. | Yes |
| **Motivation -Reflective** | Provide support and guidance to develop action and coping plans. Create opportunities for successful and positive real-world walking experiences to build confidence. | Yes |
| **Motivation- Subconscious** | Increase awareness of sedentary habits. Identify restrictive beliefs or negative emotions. Provide successful experiences of walking in real-world. | Yes |
| **Behavioural diagnosis of the relevant COM-B components** | **All areas likely to need support and attention to aid change** | |

Figure 19 provides a summary of how the intervention components were linked to each of the theory areas and provided a basis for the development of the *Walking for Wellbeing after Stroke* intervention.
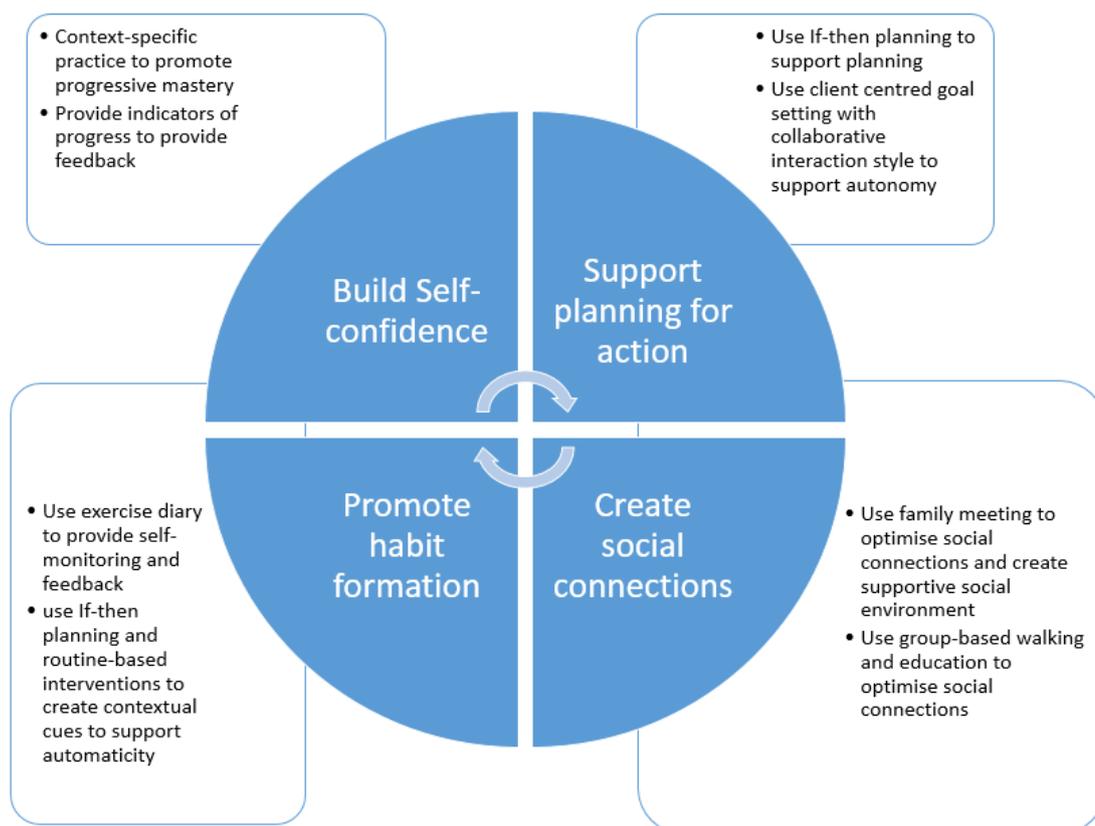
Figure 19. Linking intervention components to families of mechanisms

## 6.7 Conclusions

This chapter has attempted to explain how an intervention could lead to change in daily walking routines. The explanation of how change can occur has been linked to intervention components. Each component has been selected in the expectation that it is able to activate the key intervention mechanisms required to produce change. To illustrate this, an outcome pyramid has been produced which provides a model of the expected process. The next chapter describes the operationalisation of an intervention based on this treatment theory and the evaluation of its impact compared to what was predicted by the initial treatment theory.

# Chapter 7  Phase 3b– Refining the treatment theory

## 7.1  Introduction

This chapter will focus on the *Walking for Wellbeing after Stroke* intervention developed from the research previously outlined in chapters 4, 5 and 6. I will explain how the intervention worked in practice, describe the outcomes experienced by participants, identify which mechanisms of action worked as intended, explore the unanticipated mechanisms of action and explore factors influencing the responses of different participants. Drawing on case-study methodology and related evaluation data, I will discuss which aspects of the treatment theory were supported, and which were not. In addition, I will explain how I refined the treatment theory by exploring how outcomes differed in ways that were different to what was predicted by the treatment theory.

### 7.1.1  Research Questions

The specific research questions for this phase of the study were:

> What was the potential for impact of the intervention and if it appears to work, how and why did it work?

> 1. Did the expected mechanisms of action operate?
> 2. Were there any unexpected mechanisms of action?
> 3. What features of context prevented anticipated mechanisms of action from being activated?

To answer these research questions, I compared the CMO configurations proposed by the initial rough theory with the evaluation data to see if changes occurred as expected.

## 7.2  Methods

### 7.2.1  Intervention Rationale & Operationalisation

The intervention aimed to: create a social environment to support autonomy, build competence and greater confidence in real-world walking, promote adoption and maintenance of new walking habits and routines, and to facilitate social connections to enhance social integration.

As outlined in detail in Chapter Six (see section 6.5.on page 138), the intervention aimed to achieve impact at three levels: a) immediate, b) intermediate and c) ultimate. The immediate outcomes of the intervention focused on implementing new walking behaviours. The intermediate outcomes focused on building self-confidence for walking and developing the autonomous motivation needed to sustain continuous repetition of the new habits, in order for automaticity to develop. The ultimate outcomes focused on promoting physical and social integration. Being able to walk more often in a range of new settings was theorised to create new opportunities for integration thus enhancing wellbeing.

I selected four target behaviours to help achieve these outcomes: 1) take more steps per day, 2) complete a daily home-exercise programme, 3) record exercises and walking daily in an exercise diary, and 4) participate in weekly outdoor walking with one or more people. I selected specific intervention components to help embed each of these behaviours into daily habits and routines.

### 7.2.1.1 Expected mechanisms of action

The mechanisms of action were specified in advance as part of the theory building process and described in the previous chapter. Table 16 below provides an overview of the four theory areas I identified in this process and the proposed mechanisms of action. More specific details regarding each of the proposed mechanisms are in Appendix L.

Table 16. Expected mechanisms of action for intervention

| Theory Area | Expected Mechanism |
| --- | --- |
| Planning for control of action | <u>Information provision mechanisms</u><br>Knowledge recommended activity behaviour (K1)<br>Self- awareness of own behaviour (K2)<br><br><u>Planning mechanisms</u><br>Intentions (P1)<br>Goal Setting (P2)<br>Feedback on behaviour (P3)<br><u>Motivational mechanisms</u><br>Autonomy (Mo1)<br>Internalisation of motivation (Mo2) |
| Habit formation | <u>Automaticity mechanisms</u><br>Situation specific automaticity (HF1)<br>Goal-dependent automaticity (HF2) |
| Building self-confidence | <u>Mastery mechanisms</u><br>Cognitive reappraisal of capability for walking (Ma1)<br>Perceptions of safety in real-world settings(Ma2)<br>Contextual transfer (Ma3) |
| Enhancing social connections | <u>Collaborative mechanisms</u><br>Trust & Synergy (SC1)<br><u>Connecting Mechanisms: Emotional sustenance</u><br>Warm caring and concern (SC2)<br>Empathetic understanding (SC3)<br>Belonging, mattering and self-worth (SC4)<br><u>Connecting Mechanisms: Active coping assistance</u><br>Coping and informational support (SC5)<br>Instrumental assistance (SC6)<br>Social influence and control (SC7)<br>Social comparison (SC8) |

### 7.2.1.1.1 Knowledge mechanisms of action (K1, K2)

Information can provide resources that lead to increased knowledge and awareness (Cane et al., 2012). In relation to activity and stroke, some types of information are aimed at a generic audience and are designed to increase *awareness of recommended levels (KI)* of physical activity after stroke. Individualised feedback can provide personalised information about current levels of physical ability or behaviour in relation to normative data. A cardinal feature of daily habits and routines (including activity) is they are often executed

below conscious awareness (Bargh & Chartrand, 1999). In view of the work of Levack, Dean, Siegert, & McPherson (2006) these knowledge-related mechanisms were hypothesised to work by promoting conscious *self-awareness (K2)* of participants own behaviours. It was predicted that increased awareness of current habits and routines would elicit a desire for change and awareness of recommended levels of activity would enhance communication between the person, their family and the research physiotherapist in preparation for goal setting.

### 7.2.1.1.2  *Planning mechanisms of action (P1, P2, P3)*

An *intention (P1)* refers to a conscious decision to act in a certain way. Having an intention to be active is necessary for change, but on its own is unlikely to be sufficient to create change (Rhodes & de Bruijn, 2013b). *Goals* (P2) were introduced in light of Inzlicht et al.'s (2014, p. 303)definition, that a goal is a "mental representation of outcomes or end states an individual is committed to". The process of setting a goal can create a discrepancy between what one is currently like and what one wants to be like (Inzlicht et al., 2014). Setting concrete or specific goals supports goal striving because it creates a standard by which progress can be monitored, which in turn generates feedback about the degree to which standards are being met (Gollwitzer & Oettingen, 2011; Inzlicht et al., 2014). Self-monitoring is the process of monitoring and recording one's behaviours and this process may provide a type of *feedback* (P3), which can help sustain attention on  goals (Blamey et al., 2013; Inzlicht et al., 2014). Together these three planning mechanisms (*intentions P1, goal setting P2, feedback P3)* were expected to turn desires to walk more, into action.

### 7.2.1.1.3  *Motivational mechanisms of action (Mo1, Mo2)*

Motivation has been identified as a dynamic and multifaceted concept which is undoubtedly significant to behaviour change but its role in rehabilitation is poorly understood (Maclean & Pound, 2000; Maclean et al., 2000; Maclean, Pound, Wolfe, & Rudd, 2002; Siegert & Taylor, 2004). Current conceptualisations tend to reveal an overly simplistic view, which focuses primarily on the individual, and neglects the significance of environmental influences on

motivation. Bright (2015) and Cummins (2016) provide alternate perspectives which consider the influence of the social environment on motivation. Siegert & Taylor (2004) reviewed the concept of motivation in rehabilitation and rightly noted the lack of theoretical underpinnings. They propose one way to advance knowledge is to apply rich theoretical frameworks, such as Self-Determination Theory, to rehabilitation populations. This contention is supported by the findings of Phase 2, which affirmed the relevance of Self-Determination Theory constructs, to motivation for real-world walking after stroke.

Proponents of Self-Determination Theory (e.g. Vansteenkiste et al., 2012; Hagger & Chatzisarantis, 2016;) propose that an autonomy-supportive social environment can help meet basic psychological needs, by encouraging choice, providing opportunity for successful learning experiences and facilitating positive social interactions. The opportunity to freely and voluntarily select meaningful goals and activities, allows people to make choices that are more aligned with their own values. *Autonomy* includes the combination of volition (free will) and personal relevance (Vansteenkiste et al., 2012). The process of acting autonomously is hypothesised to support sustained change, because personally meaningful goals are likely to be actively monitored and acted upon more effectively (Legault & Inzlicht, 2013). This can help a person persist in goal striving.

 Self-Determination Theory also posits that the quantity and the quality of motivation are significant and points to the relative benefits of autonomous motivation over controlled types of motivation (Deci & Ryan, 2008b; Teixeira et al., 2012). Deci Eghrari, Patrick, & Leone (1994) describe *internalisation* as a motivational process, where the control of certain behaviours shifts from external sources, toward more autonomous forms of motivation. This process of internalisation is proposed to enhance autonomous motivation which energises persistence, which in turn produces sustainable behavioural change (Ryan et al., 2009). The *Walking for Wellbeing after Stroke* intervention aimed to activate two motivational mechanisms- *autonomy (M01)* and *internalisation (M02).* I theorised that together these mechanisms would support sustained change in real world

walking behaviours and motivate the person to continue with new behaviours until they become automatic.

### 7.2.1.1.4 Mastery mechanisms of action (Ma1, Ma2, Ma3)

*Coping* refers to a process by which people manage their feelings, thoughts and actions, in response to internal and external demands, which they judge as potentially risky and likely to exceed their existing resources (Harrop, Addis, Elliott, & Williams, 2006; Lazarus & Folkman, 1987). Lazarus and Folkman (1987) describe a process of cognitive appraisal as a way of explaining the cognitive basis of coping.  A cognitive appraisal is an evaluative judgement which considers the personal implications of a situation and anticipates if the situation is likely to be threatening and potentially harmful or not (Lazarus & Folkman, 1987, p. 145). A process of *positively reappraising personal capabilities (Ma1),* following successful task completion may be necessary to  build confidence for walking after stroke, but there is limited guidance in the literature on how to change these perceptions (Ashford et al., 2010). Bandura (1994, 1997) introduced the concept of mastery experiences, to describe successful experiences achieving a desired goal, and postulated mastery to be an important causal mechanism to changing capability beliefs. Participants in the qualitative phase of this research (see section 5.4.2) described such mastery experiences in positive terms and their successes led to a gradual change in their perceptions which was often articulated as changed reasoning "I didn't think I could do it, but now I know I can". Participants in cardiac rehabilitation were initially unsure of their physical capabilities having lost trust in their body after their heart attack (A. M. Clark et al., 2005),. However, participation in a group-based exercise programmes where they felt safe, helped restore the trust of cardiac patients in their "heart diseased body" which contributed to greater confidence in their ability to make future lifestyle changes they desired. It is possible this process of regaining body-related trust came through cognitive reappraisals of capability, although this was not explicitly described in this realist study (A. M. Clark et al., 2005, 2007).  *Perceptions of safety* (Ma2), was found to be the key mechanism behind decisions about whether to walk outdoors or not in a realist review which examined outdoor mobility for older adults (Yen et al., 2014). In the proposed treatment theory, I

hypothesised that *positive reappraisals of levels of capability (Ma1)* in response to successful experiences, coupled with more positive *perceptions of safety (Ma2),* contributed to a growing sense of mastery. I hypothesised that along with these two mechanisms, the greater cognitive efficiency provided by automatic walking behaviours would provide extra cognitive resources that would make it easier to walk in new environmental settings producing *contextual transfer (Ma3).*

### 7.2.1.1.5  Mechanisms of habit formation (HF1, HF2)

Habit formation is generally considered to have three key features: frequency of performance, a stable context, and automaticity (B. Gardner, 2012; Verplanken & Orbell, 2003). In addition, regular habits may also come to be seen as part of someone's identity, producing thinking such as *that is typically me* (Verplanken & Orbell, 2003). Automaticity occurs when a behaviour is either instigated automatically and/or executed automatically, without needing to pay attention (B. Gardner, Phillips, & Judah, 2016). Automaticity is likely to be the active ingredient of habit formation, with the strength of automaticity indicating the strength of habit formation, and context-dependent repetition the antecedent to habit formation (B. Gardner, 2012). Gollwitzer and colleagues ( 2011; 2006). suggest that certain types of action plans (e.g. *If-then plans)* work by strategically harnessing a type of *situation specific automaticity (HF1),* which is proposed to link a specific contextual cue (such as physical location, social context or time of day), to an action. Experiencing the cue will act as a prompt to instigate the planned action. Over time, with frequent repetition, a type of *goal-dependent automaticity (HF2)* develops where both the instigation and execution of the behaviour are below conscious awareness.

### 7.2.1.1.6  Connecting and collaborating mechanisms of action (SC1, SC2, SC3, SC4, SC5, SC6, SC7, SC8)

Collaborative mechanisms, where two or more people work in partnership to achieve shared goals, can be facilitated through interaction styles that create a sense of collaborative working (Lasker et al., 2001; Orlinsky, 2009; Palmadottir, 2006; Peiris, Taylor, & Shields, 2012). This type of interaction style was hypothesised, to support the development of synergistic psychosocial

mechanisms (Pinto et al., 2012; Stretton et al., 2013),which work to facilitate change. A trusting and collaborative relationship can lead to a sense of synergy (Lasker et al., 2001). This can lead to sharing of insights, perspectives and resources which result in new ways of viewing problems and solutions and energises action (Hall et al., 2010; Lasker et al., 2001; Martin, Garske, & Davis, 2000). Collaborative mechanisms of *trust* and *synergy (SC1)* were proposed to help energise behavioural change.

A growing body of research is shedding light on the cascade of biological mechanisms that occur in response to positive social connections (e.g. Cross & Pressman, 2017; Ditzen & Heinrichs, 2014; Hostinar et al., 2014). However, data about the specific psychosocial mechanisms and how these mechanisms act as a resource for coping is not yet clear (Thoits, 2011). This limits the practical applicability of this body of research, and means identifying which mechanisms of social connection are most pertinent to health-promoting behavioural change is particularly challenging.

In response to this difficulty, Thoits (2011) attempted to systematise the body of research into social connections. She suggested connecting mechanisms are likely to provide two main purposes; a sense of emotional sustenance and active coping assistance (Thoits, 2011). Mechanisms of *warmth, caring and concern (SC2), empathetic understanding* from peers (SC3) and a sense of *belonging or mattering (SC4)* could provide emotional sustenance (Thoits, 2011). Assistance with coping can come via family members who can provide *instrumental assistance* (SC6); this practical assistance may help reduce stress levels which may mean the situation is appraised as less threatening (Gottlieb & Bergen, 2010; Thoits, 2011). Additional connecting mechanisms, known as *social influence and control (SC7)* refer to attempts by people in surrounding social networks to monitor, encourage, persuade, remind, person to adhere to health behaviours.

Thoits (2011) also suggested *similar others*, or peer group members, can provide complementary sources of social support to that provided by family members which may be particularly significant to coping. For example, those who have been through similar situations have a personal and in-depth understanding of living with the consequences of a stroke. Peers may also be able to provide

*coping and informational support (SC5)* which can bolster perceptions of being able to cope (Thoits, 2011). Those who have been there can provide a sense of *empathetic understanding (SC3)* and can tolerate expressions of emotional distress which may help reduce stress and physiological arousal. Finally, *social comparison (SC8)* is where people gain normative and behavioural guidance through comparisons with others they view as similar to themselves (Festinger, 1954; Thoits, 2011). Such a process is theorised to involve upward comparison and downward comparison. People compare themselves to others who are either better or worse than they are as a way of evaluating personal worth (Festinger, 1954). *Coping and information support(SC5), empathetic understanding (SC3)* and *social comparison (SC8)*are possible mechanisms of social connection which can only be provided by other stroke survivors (Thoits, 2011).

### 7.2.1.2 Intervention Components

In this section, each of the ten core components included in the *Walking for Wellbeing after Stroke* intervention will be described. Each component was hypothesised to contain activities which would activate the expected mechanisms of action predicted by the treatment theory as described in the previous section. Each of the components is discussed in more detail below. Supplementary information about these components is also included in Appendix P.

The first four components (autonomy-supportive environment, family involvement in the meeting, everyday interview and goal planning) were used to help participants implement new walking behaviours into daily routines. At the start of the programme each participant took part in a family meeting in their home. During the meeting I sought to create a social environment that supported autonomy. I also sought to involve family in the meeting, and together we completed an everyday routine interview and undertook collaborative goal planning. The next four components (self-monitoring, home-based exercise programmes, escorted community walking, and coaching phone calls) were individually focused and took place over 3-4 visits primarily in and around the person's home and local environment. The last two components were group based and took place once a week. In the first month, there were three group education sessions and in the second month, four outdoor walking groups at

local parks. The main purpose of the last six intervention components was to help maintain the behavioural change implemented in the first stage. Specific details about each of the intervention components are described below. An overview of the intervention is provided in Figure 20 also below.

|  | Individual | Group |
|---|---|---|
| Week One | Family Meeting | |
| Week Two | Home Exercise Programme | Education Group 1 |
| Week Three | Escorted Community Walking | Education Group 2 |
| Week Four | Escorted Community Walking | Education Group 3 |
| Week Five | Escorted Community Walking | Outdoor Walking Group |
| Week Six | Coaching Phone Call | Outdoor Walking Group |
| Week Seven | Coaching Phone Call | Outdoor Walking Group |
| Week Eight | Coaching Phone Call | Outdoor Walking Group |

Figure 20. Overview *Walking for Wellbeing after Stroke* Intervention

### *7.2.1.2.1 Autonomy-supportive environment*

The first intervention component was the intentional creation of an autonomy-supportive environment. During all of the interactions with participants, such as the family meeting, one on one sessions and group meetings, I aimed to practise the principles of autonomy support (e.g. Fortier et al., 2011; Reeve et al., 1999; Ryan & Deci, 2008). These principles included the following: a) taking the perspective of the person and their whānau into consideration; b) acknowledging their feelings and thoughts; c) providing relevant information and opportunities for choice; and d) minimising therapist control (Fortier et al., 2011). We previously applied these principles in neurological physiotherapy, using an activity coaching model, which was found to be acceptable to neurological patients who wanted to improve walking (Stretton et al., 2013). Conversational strategies, drawn from health coaching and routine-based interventions, were used to help create an autonomy-supportive environment (Stretton et al., 2013; Gale, 2007; McWilliam, Casey, & Sims, 2009). Table 17 below provides examples of communication strategies consistent with an autonomy-supportive approach.

Table 17. Examples of strategies to create autonomy-supportive environment

| Purpose | Example of open-ended conversational prompts |
|---|---|
| Discuss purpose of family meeting while taking perspective of person into account and acknowledging feeling and thoughts | "What are your main concerns in relation to your physical wellbeing right now?" "What do you want to get out of this programme?" |
| Promote collaborative interactions and minimise therapist control | "While I am an expert in prescribing exercising to improve physical abilities, you are the expert in what it is like to live with a stroke...I would like to support you to help develop a plan..." |
| Develop ecology map of social networks to help understand social context of person and their whānau | "I would like to get a better understanding of your social networks" (explain Eco map)." If something cool happened who would you call?" "How often do you see them or talk to them?" "How do you get along with them?" |
| Routine interview to provide relevant information about usual habits and routines | "Tell me about how a usual day begin? What happens next? How well is this routine working for you?" |
| Collaborative goal planning | "It can be overwhelming to work on too many things at once. Is there something that would make the most positive difference that you are ready to work on today?" "Are you ready to proceed to the next stage to develop a plan?" |
| Identify and address barriers | "What might get in the way of you doing these things? What could you say to yourself that would give you the most chance of success?" |

During the family meeting, I sought to embed these autonomy-supportive principles into how I interacted with the participant and their family. This interaction style enabled my role to be primarily facilitative rather than directive, and helped ensure the perspectives, thoughts and feelings of the participant were kept central (Cott, 2004). Furthermore, I explicitly stated the value of shared expertise early (Gale, 2007; Stretton et al., 2013; Vansteenkiste et al., 2012). I took this approach to minimise the well-recognised tendencies of health professionals to control and direct interactions by taking on the role of the expert (e.g. Mudge et al., 2015; Jones et al., 2012). My goal of interacting in this way was to protect and promote *autonomy (M01),* to build *trust* and to develop *synergistic* perspectives *(SC1)* to activate collaborative mechanisms.

### 7.2.1.2.2 Family Meeting: Involvement with family

I also made considered attempts, throughout the intervention process, to involve the participant and the family members they identified, in the collaborative goal setting process. I made this a priority because psychosocial mechanisms such as *mattering and belonging (SC4)* are theorised to reduce anxiety and physiological arousal leading to greater perceptions of emotional support (Thoits, 2011; Uchino et al., 2012).To do this, I encouraged participants, to identify people they wanted to invite to their family meeting and scheduled the meeting at a time that would allow these family members to attend. As well as helping create an emotionally supportive environment, I anticipated family members would provide contextual detail to help with goal planning and barrier identification. Finally, I hypothesised that drawing the family members' attention to the participant's current lifestyle patterns and their perceptions and priorities, would mean family members would use their *social influence (SC7)* to support the behaviour change process.

At the start of the family meeting I introduced the activity pyramid, which is a pictorial image summarising physical activity guideline recommendations (See Appendix Q). The purpose of introducing these guidelines was to promote *awareness about recommended behaviour (K1)* and to provide a common basis for discussion about walking goals in preparation for the goal setting stage. I provided individual feedback about leg strength, aerobic fitness, and usual daily steps based on the findings of each participant's baseline and screening assessments. These measurements are discussed in 7.2.3 on page 170. This information was provided to build *self- awareness (K2)* of a discrepancy between the recommendations and current behaviour; with the goal of helping create a shared understanding of the desirable levels of walking activity.

### 7.2.1.2.3 Family Meeting: Interview about everyday routines

The next part of the family meeting involved an interview about everyday routines (McWilliam et al., 2009). This style of interview was adapted for use from family based educational interventions for children with learning needs (e.g. Boavida, Aguiar, & McWilliam, 2014; Hwang, Chao, & Liu, 2013; McWilliam et al.,

2009). It contained two parts: first an exploration of usual daily routines and second, the creation of a simple map of existing social connections. To identify daily routines I asked the participant, "Tell me about a typical day for you". This process of recording usual daily routines helped to identify potential opportunities to *piggyback* any future changes into existing daily routines. Following that, I completed an eco-map. This was a hand drawn summary of the participant's social connections where the participant was asked to describe people with whom they interacted. (A generic example of an eco-map is provided on page 351.)

### 7.2.1.2.4 *Family Meeting: Goal setting and barrier identification with If-then planning*

During the family meeting, the participant was encouraged to identify key areas of benefit to their health and wellbeing, using the agenda setting tool (shown in Appendix R). They were then asked to think of an activity they could do, and were prompted to identify a situational cue, using the if-then framework. Two or three plans were developed during each family meeting. The participant wrote each plan on a piece of paper as a visual reminder, and they placed it in a carefully selected place in the home to act as an environmental prompt.

I also used a process of barrier identification was used to identify potential barriers to goal striving. Coping plans were developed using the same format to help address any barriers identified by the participant. The purpose of this process was to develop problem-solving strategies to support goal setting and goal striving. I hypothesised this process would help activate planning mechanisms: *intentions (P1)*, *goal setting* (P2), *feedback on behaviour* (P3) and *situation-specific automaticity* (HF1).

### 7.2.1.2.5 *Home-based exercise programme*

I provided an individually tailored home-based exercise programme based on progressive lower limb strength and balance activities, and gave encouragement given to record the exercises undertaken. Participants were also encouraged to walk regularly if this was not already part of the goal planning process.

### 7.2.1.2.6  Self-monitoring

Keeping an exercise diary provides a way of self-monitoring behaviour, potentially providing feedback, because it provides a way of seeing if goals were attained (Blamey et al., 2013). The person was encouraged each day, to: complete a record of whether they had completed the if-then plans, any exercises completed as part of the home exercise programme and to record the amount of daily walking completed (See Appendix S). It was theorised that this process of self-monitoring would also provide *feedback on behaviour* (P3).

### 7.2.1.2.7  Escorted community walking

Escorted community walking refers to the practice of accompanying an individual into real-world community settings.  Escorted community walking is proposed to work by helping people with stroke overcome fear and apprehension to restore confidence (Logan, Gladman, et al., 2004, p. 1). Although not explicitly stated in the research, the likely rationale stems from the extensive body of stress buffering research, which indicates social support can provide resources that protect the individual from appraising situations as stressful and reduce physiological arousal (Cross & Pressman, 2017). In the *Walking for Wellbeing* intervention participants were encouraged to go out for their usual walk with me, and the distance taken was measured and recorded. Two or three further opportunities for escorted walking were available, to help develop self-confidence when walking in real-world settings. I hypothesised that escorted community walking would improve perceptions of safety in real-world settings *(Ma2).*

### 7.2.1.2.8  Group Education Sessions

During weeks one to four, I facilitated a group session with the participants once a week at a community facility. The purpose of these group education sessions was to: 1) develop positive attitudes and beliefs towards physical activity, 2) help develop planning and problem-solving skills for staying active, and 3) develop a sense of cohesion as a group. Family members were encouraged to join the group and group discussion and interaction was encouraged. Education sessions focused on the benefits of exercise, distinct types of motivation, developing a trial and error mind-set to encourage willingness to give things a go, overcoming

barriers and promoting different ways to wellbeing. Appendix T contains examples of some of the resources provided to support these concepts. It was theorised that meeting as a group would help activate the mechanisms of social connection, which provide emotional sustenance, and opportunities to experience *empathetic understanding (SC3),* and a sense of *belonging* to the group *(SC4)* (Thoits, 2011).

### 7.2.1.2.9 Weekly coaching phone calls

During the second half of the intervention, in weeks five to eight, I phoned each participant once a week to discuss how they were going at working on their goals and plans. We reviewed their plans and discussed whether they had experienced any barriers to achieving their goals. The purpose was to support the maintenance of new walking habits and routines by providing opportunities for *feedback* (P3).

### 7.2.1.2.10 Outdoor Walking Group

In the second month of the intervention, I introduced an outdoor walking group.. I chose to include this walking group, because I hypothesised it would facilitate social connections, promote positive attitudes toward physical activity and create a sense of shared camaraderie to help sustain long term behavioural change. Walking outdoors may also have a positive emotional impact due to the restorative qualities of natural settings, but how this occurs is not yet clear (Calogiuri & Chroni, 2014; Marselle, Irvine, & Warber, 2013). Hanson & Jones (2015) evaluated the effectiveness of walking groups in natural settings; they also found evidence of a wide range of physiological and psychological health benefits for people with a variety of health conditions, including sedentary individuals and those with Parkinson's disease. However, to my knowledge, this case-study has provided the first evaluation of outdoor walking groups following stroke. Walking in a group with other stroke survivors in natural settings around a pre-specified course was hypothesised to provide opportunities for context-specific practice and task mastery through *reappraisals of capability for walking (Ma 1), contextual transfer (Ma 2)* and enhanced social connections by creating opportunities to experience *belonging* (Sc4).

A careful risk management plan was developed in relation to walking outdoors. Four potential areas of concern were identified in the plan: the challenge of dual tasking such as talking while walking (Lord & Rochester, 2007), the increased fall risk for individuals with mobility impairments, the increased risk cardiac events, and finally, tailoring the walking group to meet the needs of people with different degrees of physical impairments. Figure 21 provides a summary of the risk management plan for the outdoor walking group and more details are in the research protocol in Appendix U.

Screening to identify level of likely risk for outdoor walking
- Assessment of walking capability for outdoor walking using 10m walk test-minimum criteria of 0.8m/s for inclusion (D. Taylor et al., 2006)
- Assessment of level of fall risk using Falls Risk Assessment Test-(FRAT) ((Stapleton et al., 2009)
- Assessment of readiness for physical activity using Physical Activity Readiness Questionnaire (PAR-Q), and permission from GP sought if indicated to determine if medically suitable for exercise programme
- Assessment for cognitive-motor interference using 10m walk test with secondary cognitive task (counting backwards in 3's from 100) to determine if participant likely to struggle with secondary tasks when walking outdoors
- Assessment of walking endurance using six minute walk test to determine ability cope with outdoor distances

Preparation for outdoor walking sessions in local park
- Close observation of individual's capability for outdoor walking during one on one escorted community walking sessions, including measuring distances walked with odometer
- Individual risk management plan including: contact details of significant others, GP contact details, consideration of continence issues, current physical capacity (e.g. walking endurance), any medications needed or other relevant issues
- Generic strategies: having a cell phone, group leader trained in First Aid, simple first aid kit, physically able support person, portable chair, discussion with park management staff.
- Environmental screening of pre-specified route: accessible parking spaces, reasonably even terrain, seating enroute, accessible toilets etc., café or seating for socialising after walk
- Measurement of length of selected route
- Selection of wet day walking option (hardware store)

During outdoor walking group sessions in local park
- Pre-marked course using cones for markers of around 800 -1200 m (measured with walking odometer)
- Provision of short loop and long loop alternatives for people of different ability
- Check in with participants at start and end of walk
- Check in with physically able support person
- Reminder to go at own pace
- Start and finish together
- Group leader wearing visible clothing and carrying portable chair, cell phone with contact details of park staff if needed, first aid kit
- Attentive group leader available to support any participants who are struggling

Figure 21. Risk management plan for outdoor walking group

## 7.2.2 Methodology

In this project, a case-study approach was used as a primary evaluation method (Yin, 2014). According to Yin (2014), designing realist evaluations based on an explicit treatment theory is particularly advantageous because such evaluations provide the ability to capture complexity. This complexity includes exploring

changes over time and the influence of contextual factors. Such a design is further strengthened by careful attention to rival theoretical explanations (see page 420 for a worked example of this).

This research sought to understand both the impact of the intervention and the underlying causal process which produced the impact. Broadly speaking, the quantitative outcome data were used as a primary data source to evaluate outcomes and the qualitative interview data were used as a primary data source to understand mechanisms and context (Pawson & Tilley, 1997). However, both types of data were carefully integrated along with field data to optimise the complementary nature of the different types of data (Collins & O'Cathain, 2009). This process of integration is discussed further in section 7.2.5. The study was approved by AUT University Ethics committee. Appendix V contains the Participant Information Sheet for the study.

### 7.2.3 Recruitment and Sample selection

The primary source for participant recruitment was the database of a charitable trust. For many years, the trust had been delivering one-off short-term gym-based exercise programmes to stroke survivors across the large urban area where the study was based. Purposeful sampling was used to identify potential participants. Physiotherapy staff, who organised the gym-based programmes, reviewed the database and identified potential participants on my behalf. They used two criteria: walking speed at programme discharge and relatively similar geographic location. The first criteria were used to identify participants who had the physical ability to manage in real-world settings. Research into community walking (e.g. Perry, Garrett, Gronley, & Mulroy, 1995; D. Taylor et al., 2006) shows that people who have a walking speed of at least 0.8m/s have sufficient physical ability for community walking. I included the second criteria, to encourage geographical accessibility to group activities and to minimise potential barriers to maintaining ongoing social connections, due to transport difficulties in a large city. Potential participants received a letter inviting them to contact the researcher if they were interested. A second source of recruitment was through the local field officer of the Stroke Foundation, who was asked to recommend any

participants in the area who would be suitable, and I visited them to ascertain their suitability.

Transport was provided to help any potential participants attend the assessment session. At the session, I assessed each potential participant to determine if they had adequate physical and cognitive capability to walk safely in real-world settings. Figure 21 outlines the tools and process I used to determine this. A participant was deemed to be safe to participate in the study if they had: a falls risk score less than 12/20 on the FRAT (Stapleton et al., 2009), walking speed around 0.8m/sec or better (D. Taylor et al., 2006), sufficient walking endurance to complete the six-minute walk test without needing to sit down (American Thoracic Society, 2002), and no balance instability during simultaneous cognitive and motor tasks (Patel & Bhatt, 2014). I sought to recruit 4-6 participants for the case study who had a diversity of characteristics that might influence responses to the intervention

### 7.2.4  Data collection

I collected both quantitative and qualitative data to provide in-depth information about the impact of the intervention and how it was implemented (Moore et al., 2015). Implementation data included: if-then plans, eco-maps and my reflective field notes taken during delivery of the intervention. Impact data included quantitative outcome measures (self-report questionnaires and activity monitor data) and qualitative data. Information about the quantitative outcome data was provided in section 6.6.1 and details on their psychometric properties are provided in Table 14. Quantitative outcome data were collected by the independent research assistant at four time points: baseline (TO), mid intervention (T1), immediately post- intervention (T2) and three months after completion of the intervention (T3).  Actual daily steps were recorded with the StepWatch™ Activity Monitor, which was worn for three consecutive days prior to each assessment (Mudge & Stott, 2008). The research assistant, who was not involved in the delivery of the programme, also interviewed participants at mid-intervention (T1); post-intervention (T2) and follow-up (T3) time points. The independent assessor had four hours of training in qualitative interviewing (Hunt, Chan, & Mehta, 2011).

Prior to the study starting, I ascertained the likely respondent burden of the self-report measures using the Stroke Advisory Group as described in section 6.6.1. Member of the Stroke Advisory Group completed the self-report measures and provided feedback about any area of difficulty with the measures and the length of time taken to complete the measures. I aimed to ensure the total assessment time for both quantitative and qualitative data was no more than 90 minutes. to minimise the cognitive burden for the participants. (See Appendix M on page 337).

### 7.2.5 Iterative data analysis

The process of analysis was iterative which meant that findings in one cycle shaped future analytic decisions. It also means that findings and interpretation will be presented in this chapter in integrated ways to more accurately reflect this process. This section summarises the process of analysis and includes both descriptions of what was done and how this influenced later analytic decisions.

Four sources of data were used during analysis: quantitative outcome data from four time points, qualitative interview data from three time points, field data which included if-then plans, activity diaries and field notes from either the independent assessor or my own notes taken during intervention delivery, and the initial treatment theory. Analysis was iterative, as recommended by Bazeley (2009, p. 205) and involved several sequential stages. Analysis of preceding phases helped guide how analysis of the next phase was conducted. I used a mixed methods matrix to integrate data at two different points during analysis (O'Cathain et al., 2010). The treatment theory provided the basis for comparison using desired outcomes (Matrix 1) and CMO configurations (Matrix 2). Areas of convergence and divergence were carefully noted (Bazeley, 2009; Farquhar et al., 2011; Onwuegbuzie & Teddlie, 2003). To guide analysis, I included the stages of data reduction, data transformation, data display and data comparison as suggested by mixed methodologists Onweugbuzie & Teddle (2003).

#### 7.2.5.1 Data reduction

The goal of data reduction was to gain a broad overview of the quantitative and qualitative data to help sharpen, focus and organise the data  (Onwuegbuzie &

Teddlie, 2003, p. 373). For the quantitative outcome data, I plotted the change for individual level outcomes for each participant to determine whether clinically significant change had occurred or not (Di Fabio, 2013). I chose not to do any statistical testing due to the small number of participants (Kravitz, Duan, & DEcIDE Methods Center N-of-1 Guidance Panel, 2014). Before plotting the outcome data, I reviewed the available literature to determine whether MDC levels were available for each measure, and what was currently known about how much change was considered likely to be clinically significant. (See Table 14 on page 147 for a description of this process for each measure). The quantitative outcome data, at each of the four time points, were entered into an Excel spreadsheet and total scores or sub-scales calculated for each measure, according to the recommendation of the developers. Appendix W contains the raw quantitative data. For each outcome measure, at each time point, the direction of change, the size of change, the pattern of change over time and the clinical significance of any change was determined (Di Fabio, 2013) in relation to the MDC (Haley & Fragala-Pinkham, 2006) and CSD if available. Change over time was plotted using line graphs in Excel (see Appendix X for examples of this). In the absence of MDC levels, a rough rule of thumb of 10% change was used to indicate whether change was likely to be true change and not due to measurement error.

Exploratory content analysis was used to capture initial impressions of the qualitative interview data and field data (Elo & Kyngäs, 2008; Onwuegbuzie & Teddlie, 2003). To prepare for this content analysis: I listened to audio-recordings of interviews, transcribed the data verbatim, reviewed and collated field notes written throughout the intervention period and extracted details of if-then plans and exercise records. All 11 transcripts of the five participants were read through 2-3 times to enable familiarisation and jottings made of key phrases or ideas that stood out in the transcripts. In particular, words that reflected emotion, evaluative phrases and commonly repeated phrases were noted (Miles, Huberman, & Saldana, 2014, pp. 75–76).

### 7.2.5.2  Data transformation

Data transformation describes conversion of one type of data into another; i.e. the data can be "qualitised" or "quantitised" (Onwuegbuzie & Teddlie, 2003, p. 375). For this study the quantitative outcome data was "qualitised". To do this I wrote a description of change for each outcome, for each participant, which indicated whether clinically significant change had occurred, in what direction, at what time point and to what degree (e.g. small, moderate or large). Whether a change was considered significant (i.e. true change and not due to measurement error) was based on the calculation of MDC levels as determined earlier (see Table 14). For example, a change from 2/10 to 8/10 between baseline and post intervention on the *A*mbulatory Self-Confidence Questionnaire (see Table 14 on page 147 for information on ASCQ), could be written as a *large clinically significant increase in self-confidence at post-intervention*. In contrast, an average daily step count of 2319 at baseline and 2147 at mid intervention would be described as *small non-clinically significant reduction in average daily steps at mid-intervention.*

### 7.2.5.3  Data display using mixed methods matrix

For the next step, I created a matrix based on the outcomes specified in the treatment theory (Matrix 1). Figure 22 provides an overview of the process of developing Matrix 1. Table 20 contains a brief summary of the findings which are displayed in more detail in Appendix Y on page 414. For each expected outcome for each participant, interview data, field data, and outcome data  were displayed in summary form to assist with data triangulation to identify areas of convergence and divergence (Wendler, 2001). Areas of convergence and divergence; either between qualitative or quantitative findings or between expected and actual outcomes were noted. Analytic jottings were written in response to these findings (Miles et al., 2014). Appendix Z shows an example of this. One of the key findings to emerge from this matrix was the intervention impacted participants differently. This finding guided the next stage of analysis.
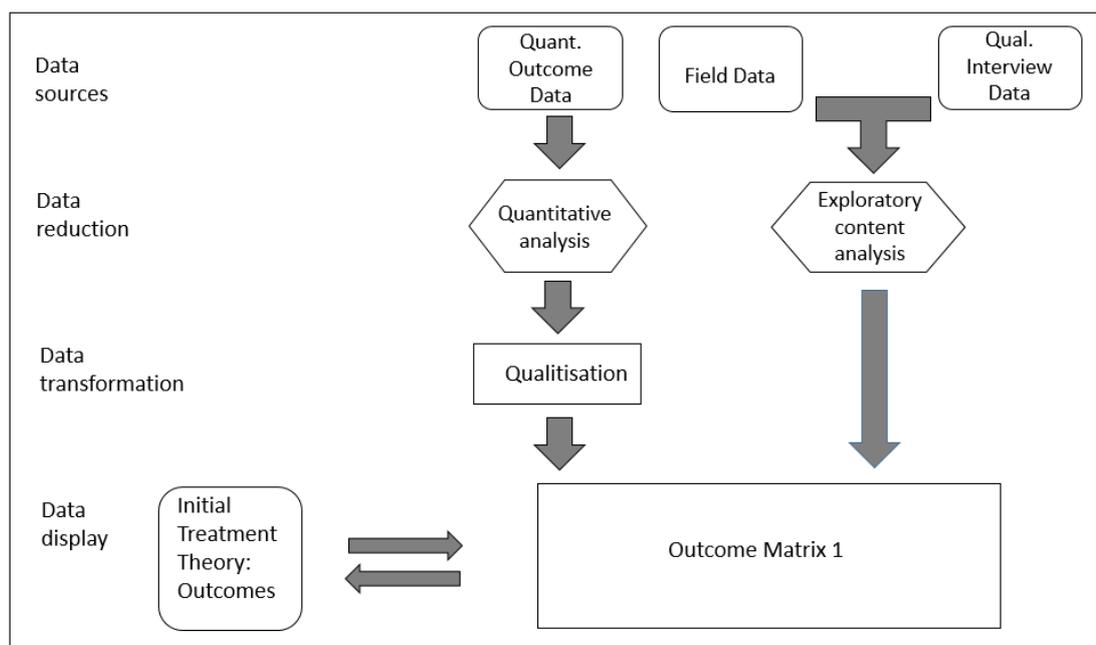
Figure 22. Development of Outcome Matrix 1

### 7.2.5.4   Data comparison

There are two common alternate approaches to tackling data analysis in case-study research (Carolan, Forbat, & Smith, 2016; Miles et al., 2014; Yin, 2014). The first one, which was used in this evaluation, is to study one case in-depth and often using a theoretical framework, and then move on to see if the pattern identified can be replicated. This is known as a case-oriented approach. The alternate approach is to look for themes or patterns that cut across data sets-known as variable-oriented strategies, however this approach runs the risk of missing the individual contextual features that are likely to influence the activation of mechanisms. The outcome pattern shown by two of the participants (Sione and Robert), broadly converged with the pattern of outcomes predicted by the theoretical framework (see analytic jotting A in appendix Z).

Informed by these findings, I elected to compare the perspective of these two participants in more detail, to determine if the intervention was in fact working in similar ways over time and activating similar causal processes., This type of approach is more consistent with a case-oriented approach to analysis (Carolan et al., 2016). Figure 23 illustrates the process of data comparison, where the focus shifted from determining whether clinically significant change had occurred, to

clarifying how it occurred. During the data comparison phase, I drew on the work of Miles, Huberman & Saldana (2014) because I felt their focus on understanding process and patterns would help me explore and articulate the mechanisms of action at play in the data, and their research philosophy seemed consistent with a realist approach. Miles, Huberman & Saldena (2014) propose iterative cycles of coding can help to progressively develop insight into underlying causal processes. The transcripts from Robert and Sione were used for the first and second coding cycles. All 11 transcripts from the five participants were included in the final third cycle. The next sections explain each of these coding cycles in more detail.
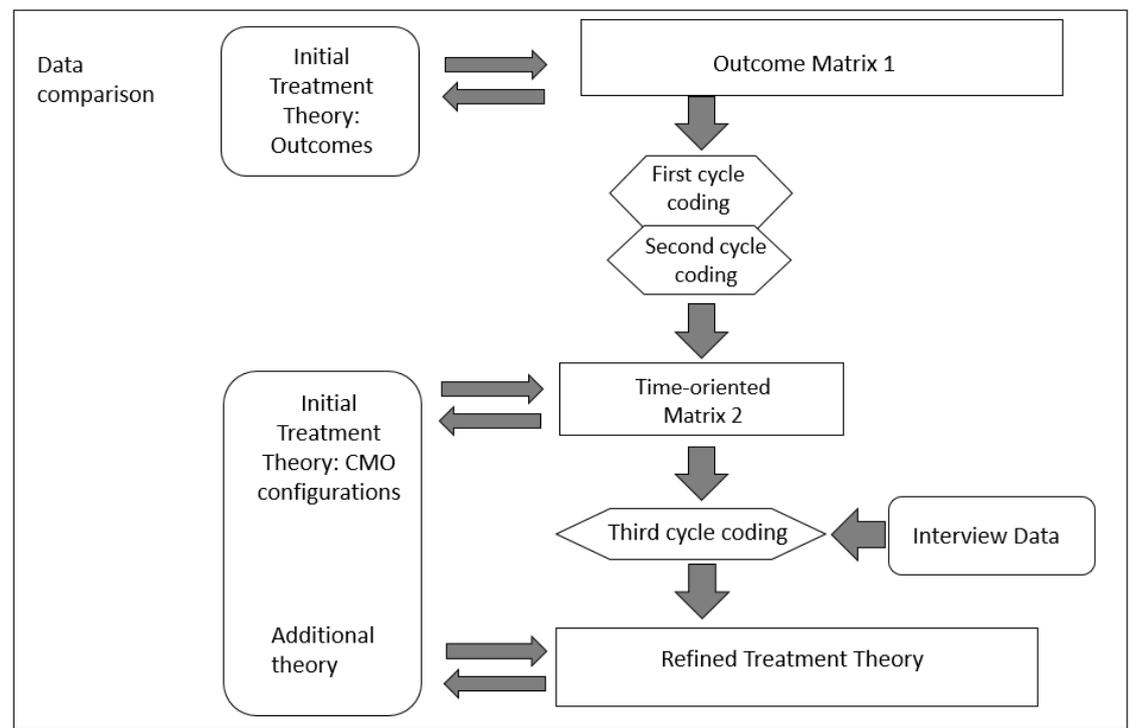


Figure 23. Development of Refined Treatment Theory

### 7.2.5.5 First cycle coding

First cycle coding is a way of initially summarising segments of data and Miles et al. (2014) suggest a range of coding strategies they call *process* codes. These process codes commonly have 'ing' gerunds, reflect "actions intertwined with time" and describe how processes emerge, interact, change or become implemented (Miles et al., 2014, p. 75). Examples of data driven process codes included values coding (which seeks to explore values, attitudes and beliefs of participants) and emotion coding (using in vivo coding in quotation marks)(Miles et al., 2014). Each of the process codes was compared for similarities

and grouped into categories. Table 21 contains a summary of categories (sub-processes) from the first cycle coding which is discussed in section 7.3.4.1 . Appendix AA contains illustrative quotes for each of these categories.

### 7.2.5.6   Second cycle coding

The purpose of the second cycle coding was to take the process codes from the first cycle and develop a more detailed understanding of the underlying causal processes, by moving from descriptive process codes toward *pattern* codes (Miles et al., 2014).  I used pattern codes to help identify features of context, mechanism and outcome configurations in the data, as a way of clarifying why and how different outcomes were produced.  Each of the sub-processes identified in the previous cycle (see Table 21) was examined separately. For each sub-process, I created a narrative description, which described the influence of the context in which any process is embedded, the conditions which give rise to the process, the action and interaction strategies used to manage the process and the consequences of these strategies (Miles et al., 2014; Strauss & Corbin, 1998). Each of these descriptions contained extensive quotes. See Appendix BB for a sample of this for the *Gaining Confidence* process.  These descriptions were discussed and reviewed in an analysis meeting with the supervisory team. I then created a second meta-matrix using an excel spreadsheet for each process. Using causation coding (Miles et al., 2014, p. 79), a summary of each causal process over the four time points was developed  (Bazeley, 2009; Miles et al., 2014; O'Cathain et al., 2010; Wendler, 2001). Matrix 2 is presented in a simplified form in Appendix CC.

### 7.2.5.7   Third cycle coding

The next stage was to compare the causal processes identified in Matrix 2 to the CMO configurations predicted by the initial treatment theory in Chapter Six (see page 138). This process revealed that some unanticipated mechanisms appeared to be at work. For this third cycle of coding, I returned to the full data set which contained all 11 transcripts and recoded using a combination of data driven and researcher driven codes (e.g. unanticipated mechanisms of action, intervention components and any areas of divergence).

Rival explanations for these findings were explored using additional mid-range theories which were compared to the data set. Rival theoretical explanations

included other self-regulatory theories (e.g. Siegert, McPherson & Taylor, 2004), COM-B (Michie et al., 2014), Social Cognitive Theory (Bandura, 1982, 1986, 1994), Theory of Planned Behaviour (Ajzen, 1991), Sense of Coherence (Harrop et al., 2006 ) and Normalisation Process Theory (May et al. 2009). Normalisation Process Theory was selected as the best fit to because it most fully explained the range of unanticipated mechanisms identified in the data; it had a robust empirical and theoretical basis that was consistent with a realist view of mechanisms, and because it explicitly addressed the issues around implementing new behaviours. By moving back and forth between the empirical data and relevant mid-range theories I developed more refined understandings of the CMO configurations activated by the intervention. This allowed me to refine the initial treatment theory. For each of the initial and refined mechanisms, I rechecked across the transcripts to identify examples of these processes and examples of illustrative quotes for all of the mechanisms of action (both anticipated and unexpected) are contained in Appendix DD.

## 7.3   Findings

### 7.3.1   Participants

Eight people responded to the invitation and attended an assessment session. Two of them lived within the desired location but were not invited to participate in the intervention as they described a consistent exercise programme and active social life indicating they already had high levels of physical and social integration. One further person was invited to participate but declined as he did not want to just focus on walking. Five people met the criteria, agreed to participate and their demographic characteristics are outlined in Table 18. On inclusion to the study each of the participants selected a pseudonym and this name was used for data analysis and presentation of findings.

Table 18. Characteristics of case-study participants

| Self-selected Pseudonym | Eva (P1) | Lily (P2) | Joy (P3) | Robert (P4) | Sione (P5) |
|---|---|---|---|---|---|
| Demographic characteristics: | | | | | |
|   Age | 54 | 32 | 63 | 55 | 49 |
|   Ethnicity | NZ European | Cook Island Māori | Indian | Māori | Pacific Islander |
|   Gender | Female | Female | Female | Male | Male |
| Date last stroke | 3 years ago | 2 years | Less than 6 months | Less than 6 months | More than 1 year |
| Physical ability: Gait speed m/s | 1.0 m/s | 1.0 m/s | 1.0 m/s | 0.8 m/s | 0.8m/s |
| 6MWT (m) | 380 m | 280 m | 250m | 410 m | 347 m |
| Living situation | Lives with husband and adult children | Lives alone | Lives alone | Lives with wife | Lives with wife and teenage children |

In week three of the intervention, one participant (Joy) developed medical complications. Although Joy and her family were both keen for her to continue, the decision was made, in consultation with the ethics committee, to withdraw her from the intervention. The primary source of concern was the potential negative impact on other group members if she continued to deteriorate. Despite this, data was collected at the mid-intervention (T1) and follow-up point (T3) for this participant. Data from a participant who was not able to complete the group-based components may offer relevant insights to address the research questions, in particular what worked for whom, and in what circumstances. A second participant (Robert) did not complete the assessment at the mid-intervention point due to family circumstances but was able to provide StepWatch ™ data for this time point and did continue with the intervention.

### 7.3.2  Intervention delivery

Table 19 shows the provision of intervention components to each of the five participants as planned in the research protocol (See Appendix U) and delivered in practice.

Table 19. Intervention components intended vs. actual participant engagement

| | | Intended | Eva (P1) | Lily (P2) | Joy (P3) | Robert (P4) | Sione (P5) |
|---|---|---|---|---|---|---|---|
| | | No. planned sessions | | | | | |
| 1. | Autonomy-supportive environment | daily | √ | √ | √ | √ | √ |
| 2. | Family meeting and goal setting | 1 | √ | √ | √ | √ | √ |
| 3. | Routine-based interview | 1 | √ | √ | √ | √ | √ |
| 4. | If then planning | 1 | √ | √ | √ | √ | √ |
| 5. | Self-monitoring | Daily; 56 days | 1/56 | x | x | x | x |
| 6. | Home-based exercise programme | 3x week/8wks | √ | x | √ | x | √ |
| 7. | Escorted community walking | 3 | 2 | 2 | 1 | 0 | 2 |
| 8. | Weekly phone calls | weekly | √ | √ | x | √ | √ |
| 9. | Group education sessions | 4 | 0/4 | 4/4 | 0/4 | 4/4 | 1/4 |
| 10. | Outdoor walking group | 4 | 2/4 | 4/4 | 0/4 | 4/4 | 4/4 |

√ used to indicate component delivered as intended and participant engaged with component
x used to indicate suggested but participant did not engage with component

### 7.3.3 Quantitative outcome data

As noted previously in section 1.3, I have included particularly lengthy tables as appendices rather than embedded in the text to improve clarity and the flow of information. For example, Appendix W contains the raw quantitative outcome data for all participants at all-time points with all outcome measures and Appendix X contains graphical displays plotting changes in: walking self-regulation (StepWatch[TM] Activity Monitor), walking self-confidence (ASCQ) and physical and social integration (SIPSO) for each participant in relation to the MDC. (See page411 for the figures displaying this data and Table 14 for how MDC was calculated). The quantitative data showed that the intervention worked broadly as expected in relation to the ultimate predicted outcomes, with four out of the five participants (the exception being P5-Sione) reporting a clinically significant change in integration- as indicated by a change of at least 2 points on the total SIPSO findings (Harrington et al., 2010).

In terms of the intermediate outcomes, there was more variation in the quantitative outcome data. For example, in relation to self-confidence, an average

score on the ASCQ of 8.52/10 is considered normal in a sample of community dwelling relatively healthy older adults (Asano et al., 2007). The MDC for the ASCQ is 0.14, which is around 15%, but levels of CSD for this measure have not been established. At baseline Eva had a score of 8.59/10 and Lily had a score of 9.55/10 indicating they had high baseline levels of walking self-confidence that did not change over time. Figure 24 below displays the ASCQ scores for P3 (Joy), P4 (Sione) and P5 (Robert) with the levels of MDC marked by the dashed line. This shows that P3 (Joy) had a small change in confidence at the three month follow-up point but it is not clear how clinically significant it was for her. Both P4 (Robert) and P5 (Sione) had large increasing gains in self-confidence over the course of the intervention. Starting at 2.64/10 and 3.6/10 respectively, and increasing steadily to near normal levels of confidence, the magnitude of the gains over time was around 200-300% and therefore likely to be clinically significant for these two participants.



Figure 24. Changes in self-confidence for P3 (Joy), P4 (Robert) and P5 (Sione)

Consistent with other research into activity levels after stroke (e.g. English et al., 2013), study participants in this case study were very sedentary with mean daily

step counts between 2000 and 5000. (Appendix W on page 410 provides specific data to support this). Daily step counts for activity monitors such as the StepWatch™ are highly variable (Mudge & Stott, 2008) with an MDC of 0.21 meaning that at least 21% change from baseline is needed to be sure any change is true change. Levels of clinically significant change in daily steps have not been established, although some researchers argue even relatively small gains in walking activity are likely to be meaningful for the most disabled, who have the most to gain (e.g. Powell et al., 2011). In the systematic review in Chapter Four on page 74, gains of 973 steps per day were shown for the home exercise programme group (HEP) who had the most robust effect sizes for change in real-world walking. Given a mean baseline score of 2622 (SD 2769) for the HEP; this is a gain of around 37%. Neither Eva nor Lily showed any change in daily step counts over the course of the intervention. Joy increased her daily step counts at the end of from 2342 to 3464 mean steps per day which is likely to represent a large clinically significant change of around 50% on baseline scores. At the mid-intervention point Robert also showed a 50% increase on baseline, as did Sione. At the follow-up point at 3 months, both Joy and Sione had a clinically significant change in daily steps indicating that sustained change in walking behaviours had occurred. Robert's daily steps at the follow-up point was just below the MDC level however, in his interview data, he talked about removing the Stepwatch ™ during his daily water walking sessions at the local pool, which meant this walking was not captured. (Stepwatch ™ figures for Robert are in Appendix X).

### 7.3.4  Theory refinement using evaluation findings

#### 7.3.4.1  What was the overall impact of the intervention?

The first integration matrix provided additional insights about the variable impact of the intervention on the five participants and revealed both convergent and divergent information in relation to the outcomes of the intervention. Table 20 contains the predicted outcomes of the treatment theory and summary information of the integrated findings. More detailed information including the source of the data is included in Appendix Y on page 414. The immediate predicted outcomes related to the phase of implementation: developing a meaningful plan, creating a collaborative connection and enacting new walking

behaviours. All five participants appeared to successfully implement their plans as predicted and as indicated by the field data collected. The next stage involved embedding the walking behaviour into daily routines and three participants were able to develop their walking self-regulatory skills sufficiently so that the new walking behaviours appeared to became automatic and embedded in daily routines as shown by changes in daily step counts and increases in automaticity (Participants: P3 Joy, P4 Robert and P5 Sione). The ultimate outcomes of the treatment theory focused on walking confidently in new settings (i.e. adaptive transfer) and improving physical and social integration in order to improve wellbeing. Both Robert and Sione showed gains in physical and social integration over the intervention with the pattern of outcomes broadly as predicted by the treatment theory. Following the intervention, they were able to walk more confidently in a variety of settings and described gains in both physical and social integration, particularly in the interview data. This matrix also showed some areas of divergence between what was expected by the treatment theory and the actual findings and between the quantitative and qualitative data, both of which are italicised in the table and discussed later in this section.

Table 20. Outcome Matrix 1 (Summary)

*Outcomes italicised when divergent between predicted outcomes and theory and quantitative or qualitative data

| Predicted Outcomes | P1 (Eva) | P2 (Lily) | P3 (Joy) | P4 (Robert) | P5 (Sione) |
|---|---|---|---|---|---|
| 1. Was meaningful plan identified? | Yes | Yes | Yes | Yes | Yes |
| 2. Were new behaviours enacted? | Yes | Yes | Yes | Yes | Yes |
| 3. Were collaborative connections established? | *Partly* | *Unclear* | Yes | Yes | Yes |
| 4. Was there self-monitoring of activity? | *Minimal* | *No* | *Unlikely* | *No* | *No* |
| 5. Were gains in walking self-regulation evident? | *No* | *No* | Yes | Yes | Yes |
| 6. Did autonomous motivation increase? | *No* | *No* | Yes | Yes | No |
| 7. Were gains in confidence evident? | *No* | *No* | *No* | Yes | Yes |
| 8. Did behaviour become automatic? | *No, disengaged from goal* | *No* | Yes | Yes | Yes |
| 9. Were walking skills transferred to new contexts? | *No* | Yes | *No* | Yes | Yes |
| 10. Were there gains in physical integration? | *No* | *No* | Yes | Yes | *No (SIPSO)*<br>Yes (interview) |
| 11. Were there opportunities for social integration? | Yes | Yes | Yes | Yes | Yes |
| 12. Improved wellbeing? | Some change | Some change | Moderate change | Marked change | Marked change |

The primary finding, from the first cycle of coding of qualitative data, was that the change processes appeared related to behavioural self-regulation, a process of striving to keep on going despite the challenges experienced.

> *So I have just got to keep going, to motivate myself to keep going*
> *and get stronger and stay there (Robert T3: 161-163)*

Social factors seemed to provide a resource for these self-regulatory processes as Sione noted:

> *I want to walk. So, every day I keep on fighting. And I am looking*
> *around for sources to help me out. Yeah that is why I want to go to*
> *those people and walk together with them. (Sione T2:77-79)*

Table 21 summarises the sub-categories from first cycle coding and Appendix Z contains illustrative quotes to supplement this table.

Table 21. Summary of categories (sub-processes) from first cycle coding

| Major Process | Sub- Processes | Overall outcome |
|---|---|---|
| Self -regulatory processes & social processes | Gaining energy<br>Being active everyday<br>Thinking positive<br>Gaining confidence<br>Walking, talking and sharing together<br>Impacting daily routines<br>Impacting others<br>Keeping on going | →Life changing |

The purpose of the second cycle of coding was to understand how these processes changed over time, what conditions influenced them and what the consequences or impact of these processes were. The key findings of this second cycle (which as described above in section 7.2.5.6) came from the data provided by Sione and Robert, given their outcomes were most consistent with what was proposed in the initial theory. This data showed that over time the impact of the intervention appeared to steadily increase. Over time the generative processes activated involved: cognitive, emotional and behavioural processes.The reported outcomes of these processes included: gains in energy, improved confidence, reduction in

negative emotions, sustained change to walking routines, and gains in physical and social integration.

> *Because I feel more energetic, yeah, because I walk every day,..because if I stay here I feel useless, I don't do anything so I just sit in the couch but now .. I think that I have got the power to do whatever I want to do. (Sione T3: 68-70)*

And

> *Robert: My whole life has changed.*
>
> *Interviewer: Can you give me some examples. Any stories you can tell me?*
>
> *Robert: Oh even my eating, my sleeping, it all changed for the better. You feel healthier, it is good to wake up in the morning, have a good stretch you are awake, I really enjoy it.*
>
> *Interviewer: How has that impacted others around you? Has it impacted anyone else in our whanau or family? Have they noticed a change or have they said anything?*
>
> *Robert: Oh yes all of them. "He is a different man, he is outside, he is having breakfast. Everything changes for the better, more friendlier and talk to him, he is not ignoring us or walking away" (T2:255-263)*

Overtime, Sione and Robert described changes in eating and sleeping patterns which they ascribed to the intervention. They also reported becoming more engaged in household tasks and their communication improved with family and friends. The majority of the gains in confidence occurred during the intervention but continued in the three months following the intervention as well. These gains in confidence appeared primarily related to overcoming negative emotions, but managing this required considerable effort and investment. The effort needed was both cognitive - for example: *those obstacles you have to think and rethink (Robert T2: 234-237)* and emotional.

*Sometimes I feel that [there] might be someone come and push me*
*away from the walkway so I try to put it aside. I try to forget so*
*that I keep on walking...yeah (Sione T1: 170-174)*

Both Sione and Robert reported stories of initiating new social connections at the follow-up interview. For example, Sione who was an immigrant from a Pacific Island, took the initiative to visit other Pacific people newly arriving in New Zealand. In the post-intervention interview Robert described how he had become more sociable and surprised a local shop owner by stopping to chat which he had never done before. Soon after the intervention finished, Robert's wife passed away after a long-term illness. At the funeral of his wife, an unexpected visitor gave everyone a surprise:

*You know when [wife] passed he come over with some bread and*
*drinks and stayed over for a few hours. Everybody was amazed!*
*That is the shopkeeper isn't it? Without realising it I made an*
*impact on his life or it might be just getting the newspaper or*
*bread or something but we started sharing with each other. That*
*was bloody awesome! He turned up here with a bloody tray of*
*bread and all his wife and kids over...everybody, even I got a bloody*
*shock. I didn't see that coming! (Robert T3: 387-393)*

Once the intervention had finished, Robert continued to organise the outdoor walking group for several weeks and invited friends from the local Stroke Foundation to join them.

The programme impacted the remaining three participants to lesser degrees. It is likely personal and contextual factors interacted to constrain the impact of the intervention by affecting either the ability and/or willingness to engage with the programme. For example, Joy did not participate in the group-based activities due to medical complications, so although she was willing to engage with the programme, she was not able to attend. As noted earlier in section 7.3.3, although Joy increased her daily steps by 50%, through her own efforts walking in and around her garden, she did not appear to improve in walking self-confidence. In

her interview she did not report any efforts to walk in new settings. The influence of personal and contextual factors on Lily and Eva is discussed in more detail in section 7.3.4.4 on page 198.

### 7.3.4.2  Did the expected mechanisms of action operate?

Each of the five participants set a goal to be more active and there was evidence from the exercise records, field notes and qualitative data that all participants were able to implement the plans they had chosen. (See Appendix Y for more information to support this finding). This finding appears to indicate successful activation of planning mechanisms of intention (P1) and goal setting (P2).  Over time, four out of five participants gave verbal descriptions of how enacting their plan had become automatic indicating the situation-specific automaticity mechanisms (HF1) were activated as expected through the if-then plans.

> *I do them automatically (Joy T1: 144)*

> *Yeah. In the evening if I lie on the couch for nearly one hour, two hours. It is like someone said to you. 'Stand up and go for a walk' so I stand up and go for a walk (Sione T1: 134-138)*

> *It is automatic now. You just know what to do (Robert T2: 387-389)*

> *If am get bored and I don't know what I am going to do I say, I get up walk and then what am I supposed to do when I walk? I say 'library!', and then I walk and walk and walk until to the library I sit down. (Lily T3: 110-112)*

A collaborative and supportive interaction style was employed during the family meeting to help activate mechanisms of trust and synergy (SC1). When asked about how they found the family meeting, two participants responded positively and suggested the role of the physiotherapist was helpful. Although the presence of an autonomy-supportive environment was not directly measured, it does seem likely for some these mechanisms were activated early in the intervention during the family meeting and early home visits:

> *Caroline is supportive of me...talking with Caroline, talking with*
> *son, just as a friend talking to a friend (Joy T1: 267-268)*

> *When she comes here and we gather together and discussed*
> *...about stroke, it is helpful (Sione T1: 13-14)*

For others like Robert, it took longer to build up trust. At the final follow-up interview he was asked his perspective about the role of health researchers in providing assistance with behaviour change programmes.

*Robert: How is that going to help me? I am an angry bastard, slog away at the grinder you will break down those barriers. Those barriers are put there for a reason. And those reason are 'Do I want the help?' or 'do I need the help? My family can look after me. I will be a burden to them. What do you want? What do you get out of it?*

*Interviewer: So are you saying that someone involved needs to have a lot of persistence because there will be quite a bit of resistance?*

*Robert: Yes (T3: 343-346, 353-355)*

There was no interview data to suggest the development of collaborative mechanisms for Lily or Eva.

Some mechanisms of action appeared to be activated but did not seem to operate exactly as predicted in the treatment theory. For example, none of the participants was consistently able to record their daily exercise or walking in the activity diary. It was hypothesised that keeping an activity diary would provide a type of self-monitoring to assist with the implementation of new exercise behaviours. In the treatment theory, I proposed that keeping daily records would work by providing feedback to help sustain attention on goal attainment (P3). However, the difficulty participants had with this means of recording daily activity suggests this was not the case.

> *I found it a bit annoying because I had to keep writing it down...*
> *because I am doing it so, because it is probably more important*

> *just to do it rather than having to write it down (Eva T3: 152, 159-*
> *161)*

A second mechanism of action that did not appear to always operate as predicted was internalisation (M2). Internalisation is a process where an individual over time comes to personally endorse values that come from external sources. The BREQv2 contains three subscales related to amotivation (or the lack of motivation), controlled motivation and autonomous motivation. Table 22 shows that most participants (with the exception of Lily), already had relatively high levels of autonomous motivation at the start of the intervention as indicated by low scores in the amotivation category and high scores in the autonomous motivational subscale at baseline. There was some increases in both autonomous and controlled motivation between baseline and follow-up, but as suggested in the research of Brunet et al. (2015), the ratio favoured autonomous over controlled motivation. This suggests that overall, most participants remained autonomously motivated for walking throughout the course of the intervention. I did not find much evidence in the data to indicate a process of internalisation at work over the course of the intervention. For example, when Sione was asked relatively early in the intervention, how the programme affected his motivation he said; *no one told me to do my exercises. ..it is in me(Sione T1: 134).* This may indicate that the desire to walk and exercise came from inside himself, meaning motivation to walk was already internalised.  Similarly, Robert spoke of a type of internal self-confidence when asked a similar question.

> *Interviewer: Can you tell me about an experience recently when*
> *you had more motivation than usual?*
> *Robert: I feel confidence in myself, I feel good*
> *Interviewer: So in a general sense?*
> *Robert: Yes (T2: 300- 302)*

It appears from the quantitative and qualitative data, that most participants were already autonomously motivated to walk more and that the intervention may have activated a process to translate motivation into action- producing behaviour

change. This alternate motivational process related to emotional regulation is discussed in the next section 7.3.4.3.

Table 22. Change in motivation over time for participants using BREQv2

| | Eva (P1) | | Lily (P2) | | Joy (P3) | | Robert (P4) | | Sione (P5) | |
|---|---|---|---|---|---|---|---|---|---|---|
| | T0 | T3 | T0 | T3 | T0 | T3 | T0 | T3 | T0 | T3 |
| **Amotivation** | 0/16 | 0/16 | 13/16 | 12/16 | 2/16 | 3/16 | 1/16 | 0/16 | 4/16 | 0/16 |
| **Controlled Motivation (CM)** | 4/32 | 0/32 | 18/32 | 23/32 | 12/32 | 10/32 | 6/16 | 16/32 | 17/32 | 22/32 |
| **Autonomous Motivation (AM)** | 32/32 | 22/32 | 24/32 | 19/32 | 27/32 | 31/32 | 25/32 | 32/32 | 32/32 | 32/32 |
| **Ratio CM: AM** | 4:32 | 0:22 | 18:24 | 23:19 | 12:27 | 10:31 | 6:25 | 16:32 | 17:32 | 22:33 |

The rationale for including escorted community walking in the intervention was that the presence of a therapist was likely to reduce anxiety by helping the person feel safe, and this experience would provide optimal conditions to aid skill mastery and confidence. For one participant, the support of a therapist did seem to work this way:

> *I walked freely, with somebody else, Caroline was there, if anything happen Caroline was there to support me... Walking alone is not right for me (Joy T1: 26-28)*

However, for Eva, the presence of the therapist, along with her family member seemed to provide more practical than emotional support. Neither she nor her family member could drive, which meant she could not otherwise access the community settings in which she wanted to walk. Eva said *"The helpful part was the practical aspect" (Eva T1: 148)*. For both Sione and Robert, confidence building and mastery did not seem at all affected by the presence of a therapist when walking. Instead, the process of overcoming negative emotions, such as frustration, shame and fear, was central to improving their confidence and mastery.

### 7.3.4.3 Unexpected mechanisms of action

Data indicated a number of mechanisms of action not predicted by the treatment theory and also mechanisms that worked differently to what was predicted. Table 23 below summarises these unexpected mechanisms and provides some samples of quotes to support these mechanisms. (Further illustrative quotes are provided in Appendix DD on page 437 for all of the refined mechanisms included in the treatment theory).

Table 23. Unexpected mechanisms of action with illustrative quotes

| Type of mechanism | Name | Illustrative quotes |
|---|---|---|
| Biological | Energy-related mechanisms | Oh even my eating, my sleeping, **it all changed for the better**. (Robert T3: 372-373<br><br>I **felt lazy and sleepy but now, No it has gone!** ... I find it is different. ( Sione T2: 12-25) |
| Mastery/ Motivational | Emotional regulation | ...sometimes I feel that might be someone come and push me away from the walkway **so I try to put it aside**. I try to forget so that I keep on walking...yeah (Sione T1: 170-174)<br><br>I can explore a lot of things and open up a lot of things,... you know going around the block once. "Oh hang, I had better do it again, I am not ready for this yet" (Robert T2: 201) |
| Mastery/ Motivational | Growth mindset | [the programme] put a lot of positives in front of me, to challenge, to take one step at a time, climbing the ladder, take one step at a time, you will get there. It might seem miles away but **one step at a time**. (Robert T2: 211-213)<br><br>I try to look at that ... in positive way, because if I look at that with negative side it press me down so **I try my best to look at that, forget it , don't worry about it, and keep going** (Sione T1: 56-71) |
| Mastery/ Motivational | Motivational (contextual) transfer | **Even going out into the community changes along the way**. You don't see it, people will tell you. 'You sit down and talk to us'[they say].... (Robert T3:380-391)<br><br>Before I never go around, I used to stay here all day but now I can go anywhere, **anywhere and whenever I want to go. I will go**. (Sione T3 29-30) |

| Habit Formation | Reappraisal of self-concept | I calm myself. **I am not lazy**. I do activities… **Everyday, I exercise**, exercise (Joy T1: 198) |
|---|---|---|
| | | ..that I haven't done anything stupid or reached for anything stupid either. **I know I am over all that things**. (Robert T3: 101) |
| Normalisation | Coherence | I exercise everyday so **it makes me more active** (Sione T1: 127*)* <br> **Sometimes I forgot that I am disability and I don't know why, I just go like a normal [laughing]**. It is funny eh? But I think that is the difference that I find. (Sione T3 43-47) <br> It has **opened our eyes** to varieties of strokes that affected us and our families and our mates and where we are today (Robert T2 44-47) |
| | | It make me feel confident; and help me a lot because what his experience is different from my experience so when we share and **put it together** it helps me a lot (Sione T1: 44-52) |
| Normalisation | Cognitive participation | Everything…  I forgot, just devote [to] my walking (Joy T1: 14) |
| | | When walking you just take one step at a time, but those obstacles you got to think you have to **think** and **rethink.** (Robert T2: 234-237) |
| | | …heaps of those things **will come to my mind,** that what I think to myself but if I keep me busy walking, and going to the park… it is really good (Sione T2: 94-103) |
| Normalisation | Collective action | We share more…when you are walking you have got time to think and share our experience and what happened and how come and when and what **we all want to try and achieve** (Robert T2:32-35) |
| Normalisation | Reflexive monitoring | I really don't know how to explain it, but within me I find  there is a different between before and now (Sione T2:94) |

Improvements in energy and sleeping patterns led to increased awareness of eating patterns and seemed to provide extra resources to undertake additional daily activities. The practice of taking a daily walk seemed to lead to more energy and an openness to do other activities.

Effective regulation of negative emotions such as fear, anger or other forms of emotional distress appeared particularly relevant to gains in confidence. The adoption of a thinking pattern that involved an intentional commitment to approach situations in a positive way rather than focusing on negative aspects and being open to learn was considered particularly important by participants Sione and Richard for whom the intervention seemed to provide the most benefit. (See Appendix AA on page 429 for supplementary data on the process of *Gaining Confidence).*

Participants who had become more active and/or integrated, described changes in the way they viewed themselves. They no longer saw themselves as 'lazy' but instead saw themselves as people who were active, and this change in physical self-concept was viewed positively, as their new habits came to be part of how they felt they typically did things.

Greater ability to walk confidently in different environmental settings (i.e. adaptive transfer) was hypothesised to develop over the course of the intervention as more efficient and automated walking behaviours developed. However, there were signs that willingness to try new activities and greater confidence emerged very early in the programme, even in the family meeting or early group meetings. Sione, for example, in his mid-intervention interview described greater confidence in tackling walking in public settings once he developed a plan in the family meeting for a way to manage his sense of shame while out walking. Eva tried washing her hair in the first weeks of the programme after early success in walking. For Robert, managing his anger helped him to feel more confident that he would continue to improve in other areas. The common factor in this ability to transfer success in one arena was greater

willingness to try activities in other areas- a type of motivational transfer between contexts.

During qualitative data analysis, I found that two key findings were difficult to reconcile fully with my current understandings of the existing theoretical frames of self-determination and control theory. The first was the ongoing self-regulatory challenge expressed by participants. For example, Sione described the need to *keep on fighting,* and Robert talked about needing *to think and rethink,* and Joy repeatedly expressed *'walking is the most important thing'* when describing her daily efforts to keep on going with her walking goals. Such comments were made throughout the interviews, even at points where automaticity mechanisms were at the highest. The effort described applied to walking in real-world settings and also pursuing other important goals and activities. Mastery sought by participants seemed to require ongoing cognitive and emotional investment and effort.

 It was also difficult to fully reconcile how talking and sharing with peers was repeatedly described as beneficial, beyond what was proposed in the treatment theory. The mechanism of social comparison was first described by Festinger (1954) and includes upward and downward comparison, as a way of evaluating one's abilities in relation to others. For Robert and Sione, the process of comparing similarities and differences in others' stories to their own seemed to provide a way of making sense of their journeys with stroke.

Normalisation Process Theory is a sociological mid-range theory developed to explain the work needed to integrate new practices into daily routines (Gallacher, May, Montori, & Mair, 2011; May & Finch, 2009; May et al., 2009). It proposes three stages are involved in this work of normalisation; implementation, embedding into daily routines and integration. Four mechanisms of action interact over these stages to achieve normalisation; 1) *coherence* which refers to a process of sense making often by drawing attention to similarities and differences in others; 2) *cognitive participation* which describes work needed to engage and participate with a new practice; 3) *collective action* which describes the work individuals and groups do to enact a new practice; and 4) *reflexive monitoring –*

the process of reflecting and appraising the effects of the new practice. As noted below, Sione found the process of comparing his experiences with those of other stroke survivors boosted his own confidence and helped him develop a more coherent understanding of his experiences. This energised him to keep on putting in the physical, cognitive and emotional efforts needed to keep on going to achieve his goals.

> *Because I found out the difference, so all I have to do, I keep on that level. I don't want to go back down, I just keep on fighting, yeah because when I walk in the morning every day it comes to my mind to keep on fighting, don't like, don't lose hope or something, because I knew that there is somebody that had stroke now is doing alright now. So I think to myself, 'if he can do it- I can do it', that's the sort of thinking that push me to stick into these plans (Sione T3 78-81)*

The theory of Normalisation Process has primarily been used to inform behaviour change interventions for health care professionals, but there are examples of its use to examine the individual work of health care consumers (e.g. Gallacher, May, Montori, & Mair, 2011). Reviewing the data through this theoretical lens provided a way to explain the work needed to implement, embed and integrate change processes into daily life. Normalisation Process Theory also provided a better explanation of the process of meaning making during group sessions. Finally, the theory was used to focus the outcome chain to be more explicit about the stages of implementation, embedding and integrating needed to promote adaptive transfer and greater integration.

### 7.3.4.4 Context preventing anticipated mechanisms of action from being activated?

It was likely Lily had a marked cognitive and communication impairment and this became particularly evident during the data analysis of her interviews. These interviews showed a lack of reflective capability consistent with impairments in executive functioning which likely affected her self-regulatory ability. This made it difficult to determine which mechanisms (if any) were at work for her. In contrast, Eva was cognitively able, but not willing to fully engage in the

programme and decided part way through the intervention to give up her goal of walking. For Eva, her decision to stop walking was a way of coping with her inability to control the availability of family members to walk with her. As a result, she chose to give up her plan to walk regularly outside and focusing instead on doing the daily exercises:

> *...but the walking is dependent on other people to take me whereas the daily exercises I can do it on my own and I am more reliable than other people. So that is the reason why (Eva T2: 11-13)*

However, the reason for this decision only came to light at the end of the final interview, when she explained she would only walk with a family member because of her fear of being kidnapped.

> *It is irrational, that I don't want to walk on my own because someone <u>could take me </u>and I recognise that is an irrational fear ...you know my family can go with me so that won't stop me from walking because I can overcome it through those other things.* (Eva T3: 178-182)

Eva had an elevated level of walking self-confidence at the start of the study as shown on the ASCQ (8.6/10) which is considered a normal level of confidence for community dwelling older adults (Asano et al., 2007). However, despite her high level of confidence in walking, she still felt emotionally vulnerable when walking outdoors and was concerned *someone could be lurking around and pounce on someone who is not 100%.* (Eva T1: 246).

Eva's story demonstrates how her personal fear coupled with the unavailability of her caregiver to walk with her to allay her fears led her to disengage from her walking goal in favour of exercises over which she had more control. This allowed her to protect her sense of autonomy, but meant, despite her early pleasure from walking, she was not able to embed this activity into her daily routines.

Lily was not able to describe any benefit from the intervention despite achieving her goals set in the family meeting in relation to social integration. She had discernible aphasia and her interview data showed limited communications skills with particular difficulties reflecting on her reasons for the decisions she made.

During the family meeting it was evident Lily was socially isolated as shown in her Eco-map (which identified showed 3 people with whom she had contact over several months) and physically inactive as shown by her description of her daily routines (which involved sitting and watching TV from 9 am till 11 pm). In the family meeting, she voiced several long term goals related to her desire to travel, improve her social connections and increase opportunities to practise speaking. During the final follow-up interview she described her recent trip overseas, and her now weekly visits to two different groups of family members, both which involved walking long distances. However, despite reviewing her if-then plans and the difference in her Eco-map, she was unable to provide any insights into what had motivated her to adopt these new behaviours.

> *Interviewer: Has anything changed, has the programme changed anything or facilitated anything?*
>
> *Lily: Nah*
>
> *Interviewer: Before the programme were you visiting them?*
>
> *Lily: Only now and then (Lily T3: 166-169)*

Normalisation Process Theory proposes *reflexive monitoring* and *cognitive participation* are both an important mechanisms for the work of integration (May et al., 2009). Similarly, cognitive impairments can affect the ability of a person to transfer learning to new situations (Bell & Kozlowski, 2008; Grossman & Salas, 2011). Difficulty with meta-cognitive skills (i.e. thinking about thinking) is a common area of difficulty after stroke, especially for people with evident communication impairments like Lily (Cumming et al., 2013; G. H. Taylor & Broomfield, 2013). Reduced executive functioning is likely to constrain the activation of normalisation mechanisms and this lack of cognitive capability maybe explain why Lily felt the intervention had minimal impact.

Finally, due to health circumstances, Joy withdrew early from the programme having participated in the family meeting and one session of escorted community walking but none of the group based interventions. Although Joy did walk more often, as shown in her daily step counts (i.e. she had sustained change in walking behaviours), she only walked around her home and she did not venture past the

letterbox. Unlike Robert and Sione, Joy's outcome data she did not show any increase in walking-related mastery and confidence. The lack of opportunity to be exposed to the support of her peers and to walk in different environmental settings may have limited the activation of mastery and normalisation mechanisms such as a *coherence* and *collective action,* needed to produce greater physical integration.

There were some unexpected findings on the SIPSO measure which can only partially be explained by the qualitative data. Eva demonstrated an unexpected increase in social integration (up 3 points to 15/20 on the SIPSO-S) at follow-up, despite her lack of attendance at the group-based sessions (attending 2/8 of them). In the final follow-up data, she described how she had made efforts to reconnect with several people with whom she had lost contact after her stroke. Therefore, although the programme itself did not meet her social needs, reflected in her non-attendance, it is possible it spurred her on to take the initiative to increase opportunities for social connections outside the programme.

 For Sione, the lack of gains in the SIPSO at follow-up is hard to reconcile with the extensive qualitative data and field data observations which indicated substantial improvements in this area. One possible explanation for the difference between quantitative and qualitative data maybe some type of response bias (i.e. the desire to please the researcher). In this case, an independent assessor collected the quantitative and qualitative data for Sione, and he encouraged all participants to speak openly and honestly about the programme. As the SIPSO data showed less change than expected, this explanation is unlikely. The most likely explanation for this finding, is the effect of response shift, a well-recognised issue with the use of patient-reported outcomes (Barclay-Goddard, Epstein, & Mayo, 2009; Blome & Augustin, 2015; Sprangers, 2010). Over the course of the programme, Sione began to see himself differently, as less disabled *(Sometimes I forgot that I am disability and I don't know why, I just go like a normal [person] T3: 45-47).* This shift in perspective may have led to a type of internal recalibration which influenced the standards with which Sione measured his level of satisfaction. This may have produced a type of bias in his satisfaction ratings in the SIPSO- meaning he rated them differently at

different time points as his internal frame of reference shifted (Blome & Augustin, 2015).

### 7.3.4.5 Revised treatment theory

A summary of the changes to the treatment theory is provided in Figure 25 below. The revised outcome pyramid is displayed below in Figure 26. Table 25 shows the refined CMO configurations. Appendix CC provides additional illustrative data from all five participants which provides additional support for all the refined mechanisms of action.

- Promotion to Outcome 1 : collaborative connections
- Removal of Outcome 4: self-monitoring
- Promotion and adaption (to include confidence) of Outcome 4: walking self-regulation outcome
- Addition of Outcome 5: normalisation
- Removal of Outcome 6: autonomous motivation

Figure 25. Summary of changes to the refined outcome pyramid
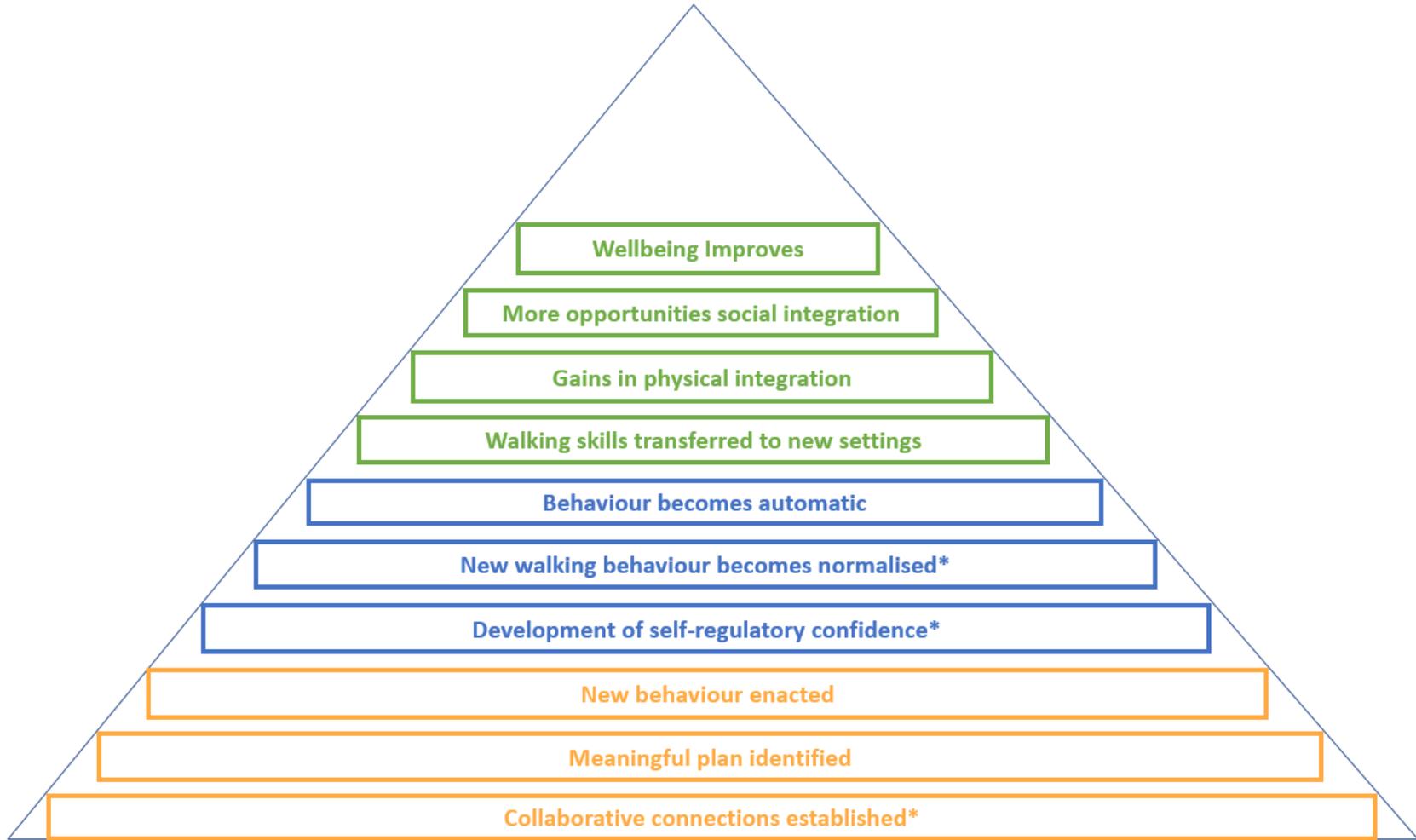
Figure 26. Refined Outcome Pyramid

Table 24. Refined mechanisms of action

*New mechanisms in italics

| Level of mechanism | Mechanism* |
| --- | --- |
| Biological | *Unspecified energy balance (EB1)* |
| Psychological | <u>Information provision mechanisms</u> |
| | Knowledge about recommended behaviour (K1) |
| | <u>Planning</u> |
| | Intentions (P1) |
| | Goal Setting (P2) |
| | <u>Motivational mechanisms</u> |
| | Autonomy (Mo 1) |
| | *Motivational* (contextual) transfer (Mo3) |
| | <u>Progressive mastery mechanisms</u> |
| | Cognitive reappraisal of capability for walking (Ma1) |
| | Greater perceptions of safety (Ma3) |
| | *Emotional regulation (Ma 4)* |
| | *Growth mindset (Ma 5)* |
| | |
| | <u>Habit formation mechanisms</u> |
| | Situation specific and goal-dependent automaticity  (HF1, HF2) |
| | *Reappraisal physical self-concept (HF 3)* |
| Psychosocial | <u>Normalisation mechanisms</u> |
| | *Coherence (including social comparison) (N1)* |
| | *Cognitive participation (N2)* |
| | *Collective action  (N3)* |
| | *Reflective action (N4)* |
| | <u>Collaborating</u> |
| | Trust and synergy (SC1) |
| | <u>Connecting</u> |
| | Belonging and empathetic understanding  (SC3, SC4) |

Table 25. Refined Context Mechanism Outcome (CMO) configurations

| Outcome No. & Description | | Revised CMO configurations | Mechanisms of Action |
|---|---|---|---|
| Outcome 1 | A supportive and collaborative social environment is created | If a supportive and collaborative interaction style is used (C) THEN patient autonomy is enhanced (M) and synergistic mechanisms (M) energise engagement which creates a supportive and collaborative social environment (O) | Autonomy ($M_{01}$) <br> Trust and synergy ($SC_1$) |
| Outcome 2 | Meaningful plan developed | If PWS* is resourced with relevant information (M) and supported (C) to choose a valued goal (M) THEN a personally meaningful plan (M) can be developed (O) | Knowledge ($K_1$) <br> Intention ($P_1$) <br> Goal setting ($P_2$) |
| Outcome 3 | New behaviour enacted | If implementation intentions (if-then plans) are developed THEN when specific situation (C) is encountered the person is cued (M) to enact the plan (O) | Situation-specific Automaticity ($HF_1$) |
| Outcome 4 | Improved self-regulation and confidence in walking behaviours | If PWS experiences repeated success in goal attainment (C) and manages negative thoughts and emotions (M) then mastery starts to develop progressively by revising estimates of capabilities (M) which strengthens confidence and motivation for repeated walking (O) | *Emotional regulation ($Ma_4$)* <br> *Growth mind-set ($Ma_5$)* <br> Cognitive reappraisal ($Ma_1$) |
| Outcome 5 | New walking behaviour becomes normalised | If PWS experiences repeated successful mastery or watches a similar other experience mastery (C) then they adapt their cognitive beliefs (M) which normalises the new behaviour (O) | *Coherence ($N_1$)* <br> *Cognitive Participation ($N_2$)* <br> *Reflective action ($N_4$)* |

| Outcome No. & Description | | Revised CMO configurations | Mechanisms of Action |
|---|---|---|---|
| Outcome 6 | Behaviour becomes automatic and new routines established | If a behaviour is regularly repeated in a stable setting (C) THEN goal-dependent automaticity is developed (M) which is more efficient (O) and leads to sustained change in walking routines (O) | Goal dependent automaticity (HF2) |
| Outcome 7 | Walking skills transferred to new settings | If PWS has established routines (C) more energy (M), more confidence (M) and revised self-concepts (M) THEN they are more willing to walk in new environmental settings (O) | Energy (EB1) *Reappraisal self-concepts* (HF 3) Motivational (contextual) transfer (Mo3) |
| Outcome 8 | Improved physical integration | If PWS walks successfully in different real-world settings (C) THEN they will feel safer (M) and more confident (M) leading to improved physical integration (O) | Perceptions of safety in unfamiliar real-world settings (Ma3) Cognitive reappraisal (Ma1) |
| Outcome 9 | Improved social integration | If PWS has improved physical integration (C) THEN they will experience more opportunities for social connections (M) which will improve social integration (O) | Empathetic understanding (SC3) Belonging (SC4) Collective action (N3) |
| Outcome 10 | Improved life circumstances and wellbeing | If physical and social integration improves (C) THEN life circumstances will improve leading to greater wellbeing (O) | |

Key: (C) Context, (M) Mechanism, (O) Outcome; *PWS (Person with Stroke)

## 7.4  Discussion

This evaluation established that the proposed treatment theory was largely supported, with a few exceptions. The intervention appeared to lead to sustained change in walking behaviours and improved physical and social integration for some participants. Sustained change in walking behaviours appeared to occur through the implementation of action plans, and over time, these behaviours became automatised. Self-regulatory confidence is an estimation of one's ability to regulate thinking, emotions and behaviours.  Adaptive transfer (or walking in new settings) seemed to require the development of this self-regulatory confidence. Self-regulatory confidence seemed to develop best through the combination of mechanisms elicited following real-world (or context-specific practice) and through social mechanisms.

*Walking for Wellbeing after Stroke* sought to increase competence for real-world walking through progressive mastery experiences. It was theorised that successful walking experiences would produce positive reappraisals of capabilities for walking and lead to confidence to try walking in new situations. In our study, mastery for walking was dependent on the ability to manage negative emotions such as anger, fear and shame. Participants described not only a fear of falling, but a wider sense of vulnerability when walking outdoors which influenced their decisions to be active.  Their ability to learn ways to cope with negative emotions, through *emotional self-regulation* (Ma4), appeared to be pivotal to developing mastery and confidence in real-world walking and this process influenced participants' willingness to reengage in other desirable activities as well.

In this case study, key practices that appeared to support self-regulatory confidence included: enjoying a daily walk, having a plan to overcome barriers, adopting a growth mindset, and walking and talking with other stroke survivors. Participants who reported growing self- confidence also adopted other positive lifestyle changes, such as eating better , and interacting more positively with others (Prochaska et al., 2008). These findings suggest undertaking these practices had the potential to create a virtuous cycle of change.

Virtuous cycles are recognised features of complex adaptive systems (such as an individual human), and such cycles consist of positive feedback loops where effects magnify over time (Glouberman & Zimmerman, 2002; Hawe, 2015; Petticrew et al., 2013). The study of health behaviour change across multiple areas is still developing (Prochaska et al., 2008), but there is growing a recognition that certain practices can act as a catalyst or *gateway* behaviour to facilitate other health promoting behaviours (Mata et al., 2009; Schwandt et al., 2015). Physical activity has been suggested to be one such gateway behaviour (Dohle et al., 2014; Duhigg, 2012.).  For example, Mata et al (2009) closely examined the effects of a programme based on Self-Determination Theory for overweight individuals which showed improving physical activity produced a type of motivational *spill-over* that produced a change in eating behaviours.  Two participants in our study Robert and Sione, reported a desire to eat more healthy food, experienced greater energy, slept better and described more positive interactions with family and friends. They attributed these benefits to the programme and in particular the practice of walking regularly.  Qualitative and quantitative data showed these changes appeared to increase (i.e. magnify) over time, suggestive of a virtuous cycle at work. Figure 27 below provides a simplified illustration of the synergistic relationship between task confidence and self-regulatory confidence needed to build confidence, and the influence the three types of cognitive appraisals have, depicted as green cogs.
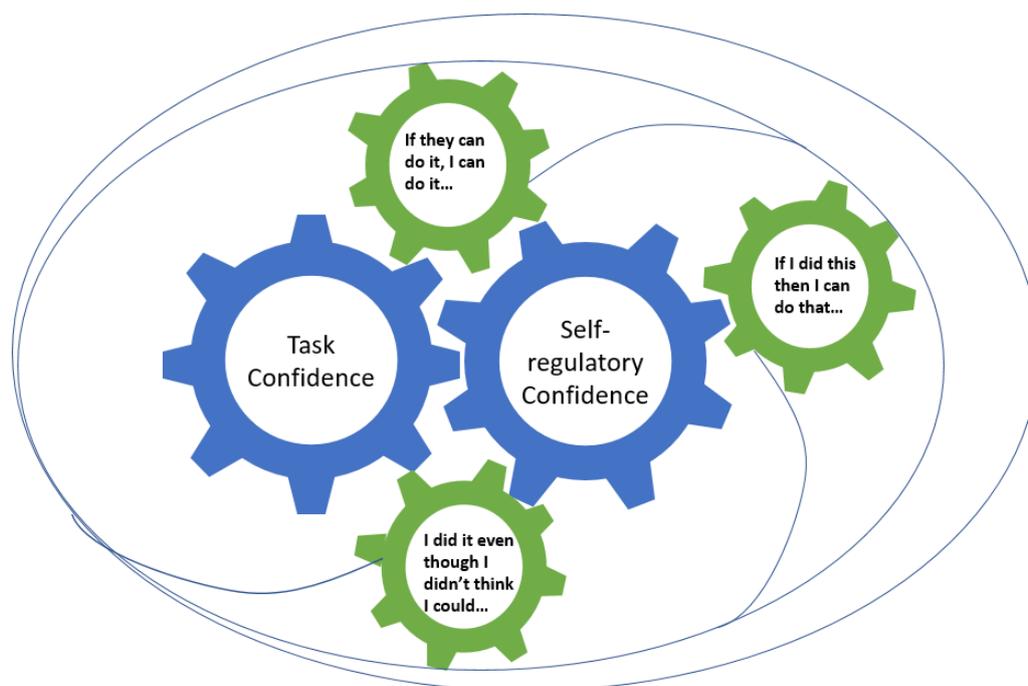
Figure 27. Virtuous cycle of confidence building

This virtuous cycle of confidence building evident in the data seemed to include at least three different cognitive reappraisals that supported the development of self-regulatory confidence. Successful completion of a specific and challenging task was often followed by a sense of elation; and there was evidence of changed thinking along the lines of *I can do it (after all)!* Improvement in energy is a well-recognised benefit of becoming more physically active (Dishman et al., 2006; Puetz, 2006; Puetz, O'Connor, & Dishman, 2006) and the practice of taking a daily walk appeared sufficient to produce gains in energy for participants who did this. This sense of elation following task mastery, additional energy and an openness to approach challenges positively led participants to be more proactive and willing to try new things. This type of reasoning is encapsulated thus: *if I did that, then I can do this!* – which may be one type of reasoning that is behind the multiple changes in healthy behaviours (Mata et al., 2009; Schwandt et al., 2015). For those who participated in the outdoor walking group, the effect of a type of social comparison mechanism was apparent. This was expressed in the interview data: *if they can do it, I can do it!* Group participants used the process of comparing themselves to other stroke survivors to help them make sense of their own stroke journey and build a sense of coherence by differentiating between

what was similar and what was different. The significance of this meaning-making process is supported by a growing body of research showing a greater sense of coherence can lead to better ability to cope with stressful situations and produces greater health and wellbeing (Eriksson, 2006; Harrop et al., 2006; Johansson, Börjeson, Nordin, & Langius-Eklöf, 2010).

The proposed route by which gains in physical and social integration were expected to occur was through gains in autonomous motivation via a process of *internalisation*. However, the data gathered did not support this hypothesis. All study participants seemed to have a deep desire to be more physically active but did not know the way to go about it. It may be that changing levels of physical activity after stroke does not require greater will power ( i.e. more motivation) but rather a greater sense of confidence and individualised knowledge of the best *way* forward, or in other words "how to get things done" (van Woerkum & Bouwman, 2014, p. 278).

Features of the social and physical environment influenced how the intervention worked. The intervention sought to create an attitudinal atmosphere that supported autonomy and built a sense of competence to meet basic psychological needs. The autonomy-supportive environment was reinforced with educational material to facilitate the development of a growth mind-set to support problem solving to overcome barriers (Gale, 2007). A growth mind-set is a set of beliefs that an individual's capabilities are not fixed but can be changed through effort (Moser, Schroder, Heeter, Moran, & Lee, 2011; Yeager & Dweck, 2012). This attitude encourages willingness to *give things a go*. Decades of psychology research have consistently shown adopting a growth mind-set leads to long term success in several domains of life (Yeager & Dweck, 2012). Recent clinical research supports the importance of supportive conversations on shaping mind-sets about the effectiveness of treatments and capacity for change (Crum & Zuckerman, 2017). Interestingly, there is also evidence of a neural mechanism which underpins this mind-set; people with a growth mind-set make better adaptive changes when they make mistakes (Moser et al., 2011). In relation to the built environment, all participants were able to identify an accessible walking route. Such a route usually involved variations of walking around the block. The

availability of safe and accessible walking routes and an autonomy-supportive social environment seemed to provide optimal contextual conditions to enable the mechanisms of action to be activated.

### 7.4.1 Strengths and limitations

This case study has provided the first steps toward identifying probable intervention mechanisms and contextual features needed to help people integrate gains in walking skills into daily life. The purpose of this case study was to add to existing knowledge in the area rather than provide evidence for practice. As such, it does have some distinctive weaknesses.  The intervention was delivered to a specific subset of stroke survivors who lived in a similar geographic setting and who already had the physical ability to walk independently. This means intervention mechanisms may work differently for less physically able stroke survivors. Two of the participants (Eva and Lily) had very high levels of walking-related self-confidence which meant there was little room for improvement in task-specific self-efficacy for them. The presence of an autonomy-supportive environment was not measured directly and only proxy indicators of walking self-regulation were used. Finally, the relatively small number of participants and the exclusion of one woman part way through the intervention limited the pool of data available to evaluate the impact of the intervention.

This case study does have a number of unique strengths. In-depth data was collected over four time points which helped to develop insights into causal change processes over time (Plano Clark et al., 2015). The development of an explicit treatment theory measured against relevant outcomes provided an explicit theoretical framework to aid theory building (Yin, 2014). Several case-study participants came from ethnic groups at higher risk of developing stroke (e.g. Māori, Pacific and Asian), and who often have poorer outcomes after stroke (Feigin, Carter, Hackett, & Anderson, 2006; McNaughton et al., 2011). Such populations can find engaging in traditional rehabilitation programmes difficult (Dyall, Feigin, Brown, & Roberts, 2008; McNaughton, Thompson, Stinear, Harwood, & McPherson, 2014) but overall these participants were highly engaged in the intervention. Furthermore, intervention components were relatively simple

and low-cost but still appeared to activate mechanisms of action that could lead to seemingly sustainable change in walking and wellbeing.

## 7.5 Conclusions

This case study has shown that the *Walking for Wellbeing after Stroke* intervention, as predicted by the treatment theory, can create a virtuous cycle for some participants and lead to sustained changes in daily walking routines and improvements in physical and social integration. Contextual barriers that appeared to constrain change included fear and reduced capacity to reflect on the change processes. Intervention components that seemed to contain the *active ingredients* responsible for sustained change in real-world walking included: participating in if-then planning, the practice of taking a daily walk, the provision of an autonomy-supportive social environment, education sessions that promoted a growth mind-set and an outdoor walking group that provided the opportunity for participants to walk and talk in natural settings. This case study has provided evidence to help refine the initial rough treatment theory regarding the likely process of change behind sustained change in real-world walking. This refined treatment theory, and the associated mid-range theories which informed it, can now be recommended for future intervention development because of their potential to explain how sustained change in real world walking can occur. Furthermore, this refined treatment theory is theoretically informed and supported by empirical data. Although future refinements are likely, it may provide a type of framework or prototype that can provide a basic frame for interventions to promote wellbeing in rehabilitation.

# Chapter 8  Discussion & Conclusions

## 8.1  Revisiting aims and objectives

This doctoral thesis sought to answer the clinical question- how can therapists help integrate gains from therapy into sustained change in daily routines? It aimed to address this issue by providing a theoretical explanation on how physiotherapists can help people with stroke walk more often. The resultant theory can be summarised in the following way:  *collaborative planning plus context specific training* plus *caring connections builds confidence and creates carryover*.  This thesis has developed a detailed explanation of the process of adaptive learning transfer, which appears necessary to produce sustained change in walking behaviours after stroke and promote improvements in physical and social integration. The proposed treatment theory has identified specific intervention components, contextual factors and mechanisms of action for key outcomes to address the problem of walking inactivity after stroke.

Four specific aims were outlined at the start of this thesis:

1. To determine the effectiveness of current intervention to improve real-world walking for people with stroke and whether benefits were sustained?
2. To clarify what real-world walking meant to people with stroke and how they thought it could be better?
3. To build a treatment theory and operationalise this theory into an intervention that can support sustained change in real-world walking behaviours.
4. To evaluate the potential for impact of the intervention and, if it worked identify how it worked.

## 8.2  Novel findings

This thesis has produced several important findings. First, sustained change in walking behaviour does not occur automatically. Second, an implementation phase followed by a phase where the new behaviours are embedded in daily life is needed before new walking habits and routines can be fully integrated into daily life. Third, walking more after stroke appears to require ongoing self-regulatory

efforts including learning how to manage negative emotions. These findings suggest the primary change process needed to walk more in the real-world can be seen to be a type of self-regulated learning.

The findings of each phase of this doctoral research are described in the relevant discussion sections of chapters 4, 5 and 7. The key messages from each chapter are summarised in Table 26 below. In this final chapter, I outline three further contributions this thesis makes over and above the development of the treatment theory already discussed. These include the application of self-regulated learning processes to understanding walking more in the real-world, the development of real-world walking behaviour as a valuable rehabilitation outcome and the explanation of how to improve real-world walking and promote carryover. These contributions are important because they have the potential to assist therapists in selecting the right intervention components for the right reasons which could optimise the real-world impact of rehabilitation.

Table 26. Key findings from this thesis

| Review of literature | Walking inactivity after stroke is likely to be the result of complex factors that interact to produce a vicious cycle of inactivity. Sustained behaviour change requires adoption of new behaviours and repetition of these behaviours until they become automatic. |
|---|---|
| Phase 1- Systematic review | Sustained change in real-world walking behaviour is possible. Interventions that use a combination of context specific practice and behaviour change techniques that support goal planning and goal striving are more effective than exercise alone. |
| Phase 2- Qualitative enquiry | Walking in the real-world is a meaningful concept to people with stroke and is inherently motivating. Successful walking can provide a way to meet basic psychological needs for autonomy, competence and social connectedness. Walking in the real-world is perceived as demanding and risky by stroke survivors. Negative emotions are a significant barrier to walking in the real-world. People with stroke use a range of strategies such as preplanning and confidence building to help motivate themselves to overcome the difficulties they experience. Walking in the real world occurs in a physical and social context. |
| Phase 3- Theory building | Carryover refers to the practice of transferring learning from one time to another or one context to another. This concept is also called adaptive transfer but is conceptually undeveloped in rehabilitation theory. Any intervention that seeks to promote carryover will need to support planning for action, build confidence using context-specific practice, promote the formation of new walking habits and routines and enhance social connections to promote wellbeing. |

| Phase 3- Theory refining | Self-regulating learning is the core process behind sustained change in real-world walking behaviours. Mastery of walking related skills requires steady gains in walking-related confidence and this leads to reappraisals of capability for walking. Gains in confidence come by developing mastery over thoughts, feelings and actions which improves self-regulatory skills. Gains in self-regulatory confidence can produce motivational transfer which can enable further gains in physical and social integration. |
|---|---|

### 8.2.1  Self-regulated learning

Self-regulated learning was the core process behind learning to walk more in the real-world. Self-regulated learning processes are much like an engine in a car. Like the engine, they are the driving force behind the behaviours needed for adaptive transfer (Baddeley, 1993; Bell & Kozlowski, 2008; Zimmerman & Schunk, 2001).  Self-regulatory skills enable a person to direct their attention and energy toward setting goals and also striving to achieve it through ongoing action (De Ridder & De Wit, 2006; Mann et al., 2013). Goal striving requires a person to work to control their thoughts, their emotions, their actions and their inner levels of motivation. This level of behavioural regulation needs to be sustained over time to enable people to repeat behaviours enough to ensure automaticity can develop (Lally et al., 2010). Such persistence is required to learn a new skill and to apply a well learnt skill to a new situation (Bell & Kozlowski, 2008).  After stroke, survivors need to relearn how to walk with a new and often untrustworthy body and reconsider which daily activities to abandon and which new ones to adopt (Ellis-Hill et al., 2000; Jellema et al., 2016; Wallenbert & Jonsson, 2005b). In the current study, the work of regaining control over one's life and developing confidence to walk freely in real-world settings required ongoing self-regulatory efforts, from planning, to monitoring progress, to appraisals and reappraisals of abilities and adaptation to new situations. In the case study, participants who had the most positive outcomes achieved this mastery progressively, literally step by step.  The primary finding of this thesis is that self-regulated learning does appear to drive skill enhancement and the sustained change in behaviour necessary to walk more in the real-world, and keep on walking.

Self-regulatory processes can explain many of the learning processes that are inherent in rehabilitation interventions and that require patient involvement

(Hart, Tsaousides, et al., 2014; Hart & Evans, 2006; Whyte, 2008). Human learning refers to sustained or relatively permanent change in behaviour as the result of experiences (Bell & Kozlowski, 2008; Kantak & Winstein, 2012; Zimmerman & Schunk, 2001). As a concept, self-regulated learning is most well developed in education and describes how learners control their thoughts, feelings and actions to achieve in academic settings (Zimmerman & Schunk, 2001). A self-regulated learner has the skills needed to adapt to changing environments.

In recent times, prominent rehabilitation theorists have focused their search for the active ingredients of rehabilitation interventions on the development of a treatment taxonomy that can cogently categorise rehabilitation interventions (e.g. Dijkers, 2014; Hart et al., 2014c; Whyte, 2014b). Creating such a taxonomy was an arduous process, and some argue its most valuable contribution was the development of a tri-partite treatment theory which outlines how treatment activities, mechanisms of action and outcomes work together (Cieza & Bickenbach, 2014; Hart, Tsaousides, et al., 2014). This tri-partite theory influenced my thinking in the initial stages of this research. However, despite their concerted efforts, the authors were unable to provide specific detail about the learning mechanisms behind rehabilitation interventions that require active involvement (Dijkers et al., 2014; Hart, Tsaousides, et al., 2014). Instead they resorted to an artificial distinction between performance/action and cognitive/affective categories. This dichotomy is not supported by neuro-biological research which links behaviour (or actions) intimately with emotions and cognition as part of the feedback loops foundational to self-control (Holroyd & Coles, 2002; Inzlicht et al., 2015, 2014) and skill learning (C. S. Green & Bavelier, 2008). The significance of actions, feelings *and* thinking to the self-regulation of walking was a clear finding from the data in this thesis. Self-regulated learning may provide a helpful theoretical framework to understand the learning mechanisms behind the long-term acquisition of skills vital to improve real-world walking following stroke. However, self-regulated learning has to date, rarely been referred to in the physiotherapy literature.

### 8.2.2  Mid-range theories

Three theories were identified that collectively help explain the study findings: Control Theory (Carver & Scheier, 1982), Self-Determination Theory (Deci & Flaste, 1995) and Normalisation Process Theory (May et al., 2009). Layering these three mid-range theories (Westhorp, 2012) made it possible to explain self-regulated learning mechanisms at neuro-biological, psychological and psychosocial levels. Figure 28 displays the way that the three theories could be layered together to more fully explain the data, thus providing an explanation of the self-regulated learning processes needed to promote physical and social integration. The individual and collective contribution of these theories are discussed in more detail below.

Experiencing success and progress following the introduction of the *Walking for Wellbeing* intervention seemed to produce positive emotions for participants. This was indicative of self-regulatory success and this finding can be explained by Control Theory (Carver & Scheier, 1982). Control Theory explicates the emotional basis of self-control by specifying at a neurobiological level the relationship between action and emotion  (Holroyd & Coles, 2002; Inzlicht et al., 2015). Success in achieving desired goals leads to a greater sense of confidence and other positive emotions in response to self-regulatory success (Balleine, Delgado, & Hikosaka, 2007).

Self-regulatory failure occurs when an organism is not moving toward a desired goal, at a desired rate, leading to the release of neurochemical signals designed to stimulate action and remediation of that failure (Legault & Inzlicht, 2013; Lewandowska et al., 2012).Organisms respond in one of three ways when they face these aversive neural signals: fight, flight or freeze (Holroyd & Coles, 2002; Lewandowska et al., 2012). Negative emotions described by participants prior to taking part in the intervention, may have led to an adaptive protective responses- a type of behavioural shutdown akin to freezing (Lewandowska et al., 2012; Luu, Tucker, & Poulsen, 2012). Behaviourally this could (and did) manifest itself with the stroke survivor spending extended periods of time in prolonged sitting prior to the intervention. Once the intervention started, and participants experienced a sense of self-regulatory success, confidence and hope developed. Control Theory

was a useful theory to explain study findings because it could explain the presence of negative and positive emotions from a neurobiological level

Self-Determination Theory was a particularly valuable theory to inform the treatment theory and intervention development in this study. This was because it could explain psychological, emotional and social factors behind the motivation for change in walking habits and routines. The theory also explained how the surrounding contextual conditions, such as an autonomy-supportive environment, could enable or constrain change (Deci & Flaste, 1995; Deci & Ryan, 2008b). Significant motivational factors included personal beliefs about capability, the importance of social connections to motivation, the relevance of distinct types of motivation and how certain types of interventions can influence both the quantity (i.e. amount) and quality (i.e. type) of motivation.

Earlier versions of Self-Determination Theory (e.g. Ryan 1995) proposed three motivational pathways: intrinsic motivation, internalisation and emotional regulation. The first pathway describes motivation which is driven by internal satisfaction or fulfilment; the second describes a process where external values become internalised so that motivation becomes more autonomous (i.e. self-driven) and the third refers to a process where a person learns to manage their emotions and needs (Ryan, 1995, p. 409) and develop a sense of their own competence. Ongoing research informed by Self-Determination Theory has largely focused on how to develop autonomous motivation in order to sustain behaviour change (D'Angelo et al., 2014; Fortier et al., 2011; Teixeira et al., 2012), the initial aim of this intervention. However, the study data demonstrated that emotional regulation appeared most relevant to confidence building and was pivotal to sustained change and improved integration (Kanske, Heissler, Schönfelder, Bongers, & Wessa, 2011; McRae, Ochsner, & Gross, 2011).

Although the study data appeared to show that the major motivational process activated by the intervention was emotional regulation and not internalisation (as predicted by the initial theory) (see Chapter Six), the revised treatment theory still provides support for the general tenets of Self-Determination Theory. For example, a sense of competence seems to be a key contributor to motivation following stroke. Confidence building through progressive task mastery required

the active management of negative emotions such as fear and shame which could undermine perceptions of competence. Self-Determination theory proposes interventions which help satisfy the basic psychological needs of competence, autonomy and connectedness can enhance motivation for sustained change. Study findings indicate that rehabilitation interventions that help people enhance their sense of competence through confidence building experiences are likely to enhance motivation.

Normalisation Process Theory argues that effort (or *work*) is needed to implement new behaviours and embed them in daily routines so that they become integrated into daily life. A surprising finding from the data was the ongoing effort required by participants during goal striving. This was not predicted by the initial treatment theory which focused on the development of automatic mechanisms. Most research using Normalisation Process Theory has focused on the work of implementing change in health service delivery systems rather than the work needed by individuals in managing chronic conditions. However, Gallacher, May, Montori & Mair (2011) found Normalisation Process Theory could usefully explain the experience of living with Congestive Heart Failure and the work involved in managing the burden of treatment. The psychosocial mechanisms proposed by Normalisation Process Theory, of coherence, cognitive participation, reflective monitoring and collective action were discussed in section 7.3.4.3 on page 197. Normalisation Process theory was particular useful to explain the implementation work required to embed activities in daily lives and how psychosocial processes could influence this work of implementation.
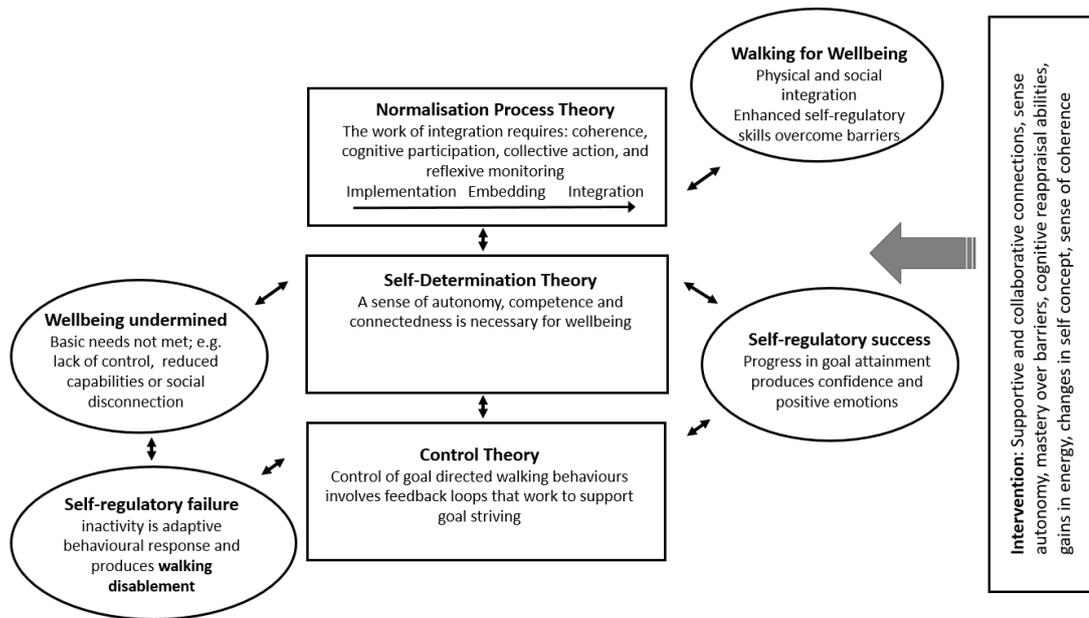
Figure 28. Theory map showing how the three theories interact to explain physical and social integration

### 8.2.3 Conceptual development of real-world walking as an outcome

The process of conceptual development undertaken in this thesis extends previous conceptual work in community ambulation (e.g. Lord, 2006; Mudge, 2008) and proposes the adoption of a new term: *real-world walking*. This concept has practical and conceptual advantages over alternate terms like community ambulation ( Lord et al., 2004); community walking (e.g. Park, Oh, Kim, & Choi, 2011); mobility (Pollock et al., 2014); functional gait (e.g. Lord & Rochester, 2007) and societal participation (e.g. Barclay, Stevenson, et al., 2015). Perhaps the greatest advantage of the phrase *real-world walking* is that the term is more easily understand by people with stroke in contrast to words like ambulation, gait and mobility. The second advantage is it focuses on actual performance and not ability (Holsbeeke et al., 2009). This contrasts with the term *community ambulation* which describes "the ability to confidently negotiate desired destinations" ( Lord et al., 2004, p. 236). Mixing confidence to do an activity with the act of doing it risks obscuring the two related, but distinct, concepts. A third advantage of focusing on actual walking practices, rather than the destination of the walking means that walking that occurs incidentally during the day, for

example around home, can also be included. Fourth, while improving real-world walking did require participating in social interactions, the outcome itself sits squarely in the ICF framework as a type of activity. In contrast, it is not clear whether community ambulation as an outcome reflects an activity or social participation construct (World Health Organisation, 2001). The key features of the concept of real-world walking developed in this thesis are summarised in Figure 29. Focusing on real-world walking as defined in this thesis helps overcome conceptual ambiguities and measurement difficulties which have plagued research into the study of walking in the real world (Barclay, Stevenson, et al., 2015; Corrigan & McBurney, 2008a; Lord & Rochester, 2008).

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- Real-world walking describes actual walking in usual settings
- It includes walking for exercise, walking for transport and incidental walking which is the most common type of walking
- Most walking occurs during daily routines and can occur in a range of environmental contexts which include both indoor and outdoor settings
- Real world walking can be measured with activity monitors or appropriate self-report measures including the phrase: 'how often do you?
- Individuals appear to undertake a process of risk appraisal when deciding whether to walk outdoors which involves estimations of personal capability in relation to the demands of the task
- Real world walking is often an implicit behaviour that occurs automatically triggered by environmental cues
- Being able to walk in the real-world is highly valued and inherently motivating for stroke survivors but walking requires careful attention especially when walking outdoors
- People with stroke often feel very vulnerable when walking outdoors
- Contextual factors such as the presence of outdoor seating and support from others can influence decisions to walk for older adults and stroke survivors

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Figure 29. Key features of real-world walking

This thesis has reinforced the utility of real-world walking for physiotherapy. The concept itself was intuitively appealing and programme participants described the personal meaning of real-world clearly and consistently. Most participants could describe a small walking route that they occasionally used which indicated the relevance of real-world walking to them. This familiarity meant adding more frequent walking into daily routines was relatively easy to achieve for all participants, especially in the early stages of the intervention. The data collected in this research in Phases 2 and 3 has shown that walking regularly in the real-world can promote wellbeing indicating its value as a desirable outcome for

rehabilitation interventions. Real-world walking also met basic psychological needs related to autonomy, competence and social connectedness and thus may serve as a psychological resource to stroke survivors.

This thesis has uncovered insights into the cognitive and emotional difficulties experienced by stroke survivors when walking in the real-world. For healthy individuals, walking is a behaviour that in most situations is initiated and executed automatically below conscious awareness (D. J. Clark, 2015; Frensch & Rünger, 2003). One of the key findings from the qualitative enquiry was the loss of automaticity following stroke during the execution of walking. Although this phenomenon is not usually described in terms of loss of automaticity, there are examples in the qualitative rehabilitation literature of qualitatively similar experiences (Ellis-Hill et al., 2000; Kitzmüller, Häggström, & Asplund, 2013). For example, Caroline Ellis-Hill (2000) interviewed stroke survivors over three time points using narrative enquiry. She found interview participants described a different relationship to their body; a body which had previously operated automatically, now required conscious management. They experienced a type of body-self split and they felt their bodies to be unpredictable and untrustworthy (Ellis-Hill, 2000). The experience of needing to consciously manage aspects of walking has a neurophysiological basis (D.J. Clark 2015). Other cognitive difficulties, such as slowness in neural processing affecting decision making and slowness of adaptive balance responses exacerbated by the anxiety provoked by outdoor settings, are also likely to contribute to a loss of automaticity when walking outdoors (Yogev-Seligmann et al., 2008). Identifying factors that may influence walking automaticity may facilitate further exploration of the cognitive and emotional constraints that stroke survivors experience with real-world walking. Automaticity was discussed in detail in Chapter Five (see page 96).

One of the encouraging findings of this research is the way that a simple real-world activity, taking a daily walk, appeared to produce flow-on benefits in mood, energy and improved sleep for participants who did this regularly. The actual distance walked was usually modest (around 200-300m) meaning the number of steps taken was well below the 5000 steps per day recommended by physical activity guidelines (e.g. Powell et al., 2011). However for those who walked

regularly, these small distances appeared sufficient to produce perceived improvements in energy and sleep and also appeared to act as a gateway behaviour (Dutton, Napolitano, Whiteley, & Marcus, 2008; Schwandt et al., 2015) to other lifestyle changes (e.g. eating more healthily). There are some examples from other research outside rehabilitation, where changes in physical activity habits can be particularly effective at facilitating change in other behaviours such as healthy eating (Dohle et al., 2014; Mata et al., 2009) and smoking cessation (Nagaya, Yoshida, Takahashi, & Kawai, 2007), although it is not always the case. Taking a daily walk in the real-world is a simple regular practice that appeared to provide sufficient physiological challenge and may act as a gateway behaviour to facilitate changes in other health enhancing habits.

For a theoretical concept to be considered "mature", and therefore useful for theory building, it needs to meet certain criteria (Morse, Mitcham, et al., 1996). These include a clear definition that has broad consensus, clearly described characteristics, a detailed description of how the concept fits within its context, and clear boundaries regarding what is and is not part of the concept. This thesis has attempted to address many of these issues by defining real-world walking, describing its boundaries and characteristics, and explaining what factors may influence real-world walking following stroke. This process has helped to advance theoretical understandings of the concept of *real-world walking* but the true test of its utility will be its future uptake by rehabilitation practitioners and researchers.

### 8.2.4 Identification of active ingredients to promote carryover

Carryover of gains in walking skill from one context to another appears possible but it does not happen automatically and instead requires ongoing self-regulatory efforts. One of the primary goals of this thesis was to understand how to structure rehabilitation interventions to promote the carryover of any benefits from therapy into sustained behavioural change in walking habits and routines. The findings of Phase 3 showed that carryover can be best understood as a type of adaptive learning transfer that involves self-regulatory skills. This learning was progressive and involved implementing new walking behaviours, embedding the new practice into daily routines and then integrating them into daily life. The

intervention activated several key mechanisms of action including goal planning, automaticity, mastery and motivation, and psychosocial mechanisms which together lead to change in daily habits and routines. In the next section, specific mechanisms will be discussed in light of the available literature for each of the phases. Table 27 below summarises the active ingredients needed to promote carryover as indicated by this research.

Table 27. Active ingredients for carryover (adaptive transfer) of walking skills

| Active ingredient | Related contextual feature | Related intervention component |
|---|---|---|
| Knowledge | Relevant information | Family meeting |
| Autonomy | Collaborative interactions | Autonomy-supportive environment |
| Trust & Synergy | Collaborative interactions | Autonomy-supportive environment |
| Intention | Relevant information; collaborative interactions | Goal setting |
| Goal setting | Relevant information; collaborative interactions | Goal setting |
| Emotional regulation | Success in goal attainment | Goal setting/ education group |
| Perceptions of safety | Success in goal attainment | Home exercise: take daily walk |
| Reappraisal of capability | Repeated success in goal attainment | Home exercise: take daily walk |
| Automaticity | Specific context identified in if-then plan | Home exercise: take daily walk |
| Energy | Repetitive exercise | Home exercise: take daily walk |
| Cognitive participation | Progress and challenge in goal attainment | Home exercise: take daily walk |
| Sense of coherence | Watching or hearing experiences of similar others | Walking group |
| Belonging | Warmth and positive regard from similar others | Walking group |
| Empathetic understanding | Opportunity to share and be understood | Walking group |
| Collective action | Involvement in group with similar goals | Walking group |
| Reflective action | Adequate opportunity and capability to reflect | |
| Growth mind-set | Relevant information, | Education group |
| Reappraisals self-concept | Sustained changes in behaviour | Home exercise: take daily walk |
| Motivational (contextual) transfer | Growing self-confidence, examples of others, revised self-concept, and greater energy | Walking group |

### 8.2.4.1 Planning and automaticity mechanisms

The core learning process behind the adoption of new walking behaviours required an interaction between reflective and automatic mechanisms over time (Rhodes & de Bruijn, 2013b). Hart emphasised the importance of explicit (i.e. reflective) and implicit (i.e. automatic) mechanisms when discussing learning in rehabilitation interventions (Hart, Tsaousides, et al., 2014). In the implementation stage, key active ingredients include: *having an intention* and *goal setting*. The process of goal setting creates a discrepancy between what one wants to be like and what one is currently like thus creating the neural feedback loop of action control (see page 123 for more discussion of this). This raises the question about what resource does the goal setting intervention provide.

At the simplest level, the setting of a goal sets up a standard for comparison. Through a process of action, monitoring for discrepancies and adaptation, using neurochemical reinforcement via positive and negative emotions, this process is reinforced (Inzlicht et al., 2014). Levack et al. (2006) reviewed the mechanisms behind goal planning and suggested an alternate explanation is that goal planning works by promoting ownership, engagement in the rehabilitation process and influences conscious motivation. Legault and Inzlict (2013) recorded neural responses to self-regulatory failure in college students and found those participants who were able to choose activities they engaged in, paid more attention to errors in their performance. This greater level of attention and engagement helped them to make better adjustments to the way they performed. Selecting meaningful goals in the context of an autonomy-supportive environment is likely to activate the active ingredient of *autonomy* which can optimise engagement and motivation and this makes individuals more attentive to mistakes and correcting their behaviours accordingly (Legault & Inzlicht, 2013).

Developing a specific plan that can be easily embedded into daily routines is a relatively simple adaptation to current goal planning approaches.  During the family meeting, to better understand the practical and social ways that people organised their daily lives (van Woerkum & Bouwman, 2014), I adapted two simple tools used in the field of Early Intervention for helping change daily

routines (McWilliam, 2010; McWilliam et al., 2009). These two tools were: the usual day interview and the creation of a hand-drawn eco-map of meaningful social connections. (The TIDieR template in Appendix P on page 350 provides a specific example of this eco-map). These tools provided insights to help embed new actions into existing routines. The use of these tools, before developing if-then plans, appeared to be a particularly effective feature of the intervention with all five participants able to implement the goal they set in the first few weeks relatively easily. There are few examples in the rehabilitation literature of interventions that explicitly seek to embed plans into daily routines but the work of Clemson and colleagues ( 2004, 2010, 2012)  provides encouraging support for the usefulness of this approach. In their trial which sought to improve functioning in fall-prone older adults, those participants who were encouraged to incorporate their exercises into daily activities reported greater reduction in falls, greater adherence to the programme and improved physical functioning compared to groups who had seated flexibility exercise or traditional separate exercise programmes (Clemson et al., 2012).

Constant repetition of any new behaviour in a stable context is needed to develop *goal-dependent automaticity* (Bargh & Chartrand, 1999; Orbell & Verplanken, 2010). Available evidence in healthy individuals indicates it takes around six weeks to develop automaticity in new activity behaviours (Kaushal & Rhodes, 2015; Lally et al., 2010). In the case study (Chapter Seven), new walking behaviour seemed to become automatised more quickly and for some automaticity was relatively high to start with indicating that walking as a daily practice may have already been partly automatised.  In this PhD study, an autonomy-supportive environment plus: *autonomy*, *intention*, *goal setting* and *situation specific automaticity* appeared to support and extend the implementation of new behaviours, which  helped embed the changes into daily routines. The development of goal dependent automaticity more quickly than expected provides some support for the contention that improving physical activity levels through changing walking habits and routines is a simpler approach than adopting new activity routines such as starting gym classes for example (Aarts et al., 1997).

### 8.2.4.2 Mastery and motivational mechanisms

The concept of mastery is often associated with work the of Bandura who proposed that task mastery is an important contributor to self-efficacy (Bandura, 1997). There is some debate though (e.g. Williams, 2010), about whether the concept of self-efficacy refers to task specific self-efficacy (i.e. walking self-confidence) or self-regulatory self-efficacy (i.e. perceptions of one's ability to self-regulate behaviour). It is also unclear how self-efficacy affects motivation and/or physical activity;  if it can be improved and how to do so (D. P. French, 2013; Rhodes & Pfaeffli, 2010; D. M. Williams & Rhodes, 2014). A systematic review of interventions which aimed to increase self-efficacy and physical activity in healthy people showed little support for the hypothesis that gains in self-efficacy could lead to changes in physical activity for healthy people (Ashford et al., 2010). In fact, interventions which provided graded tasks, (presumably as a way of improving task mastery) actually decreased self-efficacy (Ashford et al., 2010).

In this study, relearning skills needed to walk confidently in real-world settings after stroke did seem to require a process of progressive mastery. In our case study, two participants displayed large and steady gains in self-confidence for walking to near normal levels, as indicated by the ASCQ - and they also described marked gains in self-regulatory confidence in the qualitative interviews. Most participants used the words motivation and confidence interchangeably and did not seem to distinguish between walking-specific motivation and the more general aspects of motivation associated with self-regulatory processes. This link between motivation at a local level (e.g. for walking) and global motivation (i.e. for self-regulation)  is reminiscent of the model of trans-contextual motivation (Hagger & Chatzisarantis, 2007; Vallerand & Lalande, 2011) which proposes that motivation in a specific context (similar to our task related confidence) can spill over to global motivation and vice versa. This process describes a type of motivational transfer between contexts, which appears to be similar to the virtuous cycle of confidence building shown in Figure 27. Virtuous cycle of confidence buildingon page 209. In this figure, task confidence and self-regulatory confidence were interconnected and influenced each other suggesting the interacting nature of these two types of self-efficacy on motivational transfer.

This gain in self-confidence through mastery differs from the findings of the Ashford review (2010). One possible explanation for the differences is that case study participants who had lowered belief in their capability, due to stroke related limitations, had considerable room for improvement. A second explanation may relate to the way that graded task activities were assigned to participants in the Ashford review, meaning participants had little choice and control over the activities they had to do. In our case-study, mastery mechanisms appeared to be activated as part of a voluntarily driven process where the participant was personally motivated to rebuild their confidence on their own terms (Ryan & Deci, 2006). However, both participants who appeared to make gains in confidence explained feeling more able to manage their behaviour and emotions rather than just greater confidence in walking per se. This suggests self-regulatory efficacy is particularly important to motivational transfer.

Contextual factors that related to individual characteristics and personal circumstances could enable or constrain activation of mastery and motivational mechanisms. One particularly influential individual characteristic appeared to be the type of mind-set adopted by some participants. Thinking positively, characterised by a willingness to learn and try new things, was consciously adopted by some participants early in the programme and considered by those who did so to be an influential factor in confidence building. I did not explicitly plan to actively include this ingredient when developing the intervention, but this mind-set seemed to be facilitated by the problem solving approach ( informed by health coaching) that was embedded throughout the intervention.

A growth mind-set refers to an attitude that considers difficulties in learning as opportunities that can be overcome (Dweck, 2006). In fields outside of rehabilitation most notably in education the use of a growth mind-set pioneered by the work of Dweck and others is a consistent indicator of success in many domains of life where adaptive learning is needed (Dweck, 2006; Moser et al., 2011; Yeager & Dweck, 2012). Evidence from education supports the essential role teachers' play in either enabling or constraining the development of growth mindsets, depending on the characteristics of the learning environment that they create (Reeve et al., 1999). In a similar way, psychologists have explored the

significance of conversational behaviours and positive expectancies of health professionals on changing the mind-sets of patients to influence treatment effectiveness (Crum & Zuckerman, 2017). What both of these bodies of research show, is how careful framing of information by teachers or clinicians can positively change a person's belief in their capacity for change which, in turn, influences their level of motivation. Table 17 on page 163 provides some examples of the conversational behaviours used in this study.

### 8.2.4.3  Psychosocial mechanisms

Psychosocial mechanisms activated through the intervention appeared to influence the development of self-regulatory skills. The intervention sought to encourage social connections in line with Self-Determination Theory and used three specific intervention components to do this: the creation of an autonomy-supportive social environment, a family based goal setting meeting, and group based activities. A common theme in this thesis, emerging from the literature reviewed and the case study findings is the behaviour of clinicians delivering interventions has an impact on outcomes. Converging bodies of evidence from mental health (G. King, 2017), psychotherapy (Kazdin, 2007) community based partnerships (Jagosh et al., 2015; Lasker et al., 2001) and rehabilitation (Bright, 2015; Kayes et al., 2015) suggest a likely explanation for these differences may relate to whether the clinician is able to create a sense of  therapeutic connection and collaboration. Trust and synergy are central to the development of collaborative partnerships and the presence of these mechanisms as part of the intervention was described in Chapter Seven.

The influence of therapeutic relationships on change process is clearly important and is an understudied topic (Kayes et al., 2015), but it was not the primary focus of this thesis. To contain the size of the project, I chose to focus primarily on the behaviours of people with stroke. I recognised that the time frame was reasonably short (i.e. 8 weeks) and that if sustained change was to occur that would last three months or more, then the focus needed to be on developing the skills to support self-management for the stroke survivor. I chose, therefore, to see my role as a therapist, who is creating the conditions to facilitate change (e.g. G.

King, 2017) and selected behaviours accordingly to reflect this role. (See Table 17 for practical examples of how I did this).

### 8.2.4.4 Contextual features to support carryover

This thesis has explicitly examined the role of context in promoting adaptive transfer, and Table 27 lists the contextual features that can influence the learning mechanisms identified in this project. Hagger and colleagues (González-Cutre, Sicilia, Beas-Jiménez, & Hagger, 2014; Hagger et al., 2009) identified an important environmental feature that influenced motivational transfer in their study of the physical activity habits of high school students. These authors have repeatedly shown, across different geographical populations, that greater perceptions of autonomy support from physical education teachers in school can result in increases in the leisure time physical activity for students- a concept they described as  trans-contextual transfer (González-Cutre et al., 2014; Hagger et al., 2009). The potential for an autonomy-supportive environment to act as a catalyst to encourage motivational spill-over between local (e.g. walking in specific contexts) and global (self-regulatory skills for a range of health conducive behaviours) has noteworthy potential to optimise the long-term impact of rehabilitation interventions and warrants further exploration.

## 8.3   Clinical applications

At the start of this chapter, I summarised the clinical implications of this research by suggesting that collaborative planning <u>plus</u> context specific training <u>plus</u> caring connections appeared to build confidence and create carryover.  The provision of an autonomy-supportive environment provided a social context that facilitated all these elements. Therapeutic strategies used in this project to create an autonomy-supportive environment are summarised below in Figure 30 and described in more detail in the TIDierR intervention description on page 346 in Appendix P. In this section, I will discuss suggestions for clinical practice that have emerged from this research including how to create the conditions for an autonomy-supportive environment, promote collaborative planning, create opportunities for context-specific training and facilitate caring connections.

> **Core principles**
> - Support autonomy by using carefully selected conversation techniques. (See Table 17 for examples).
> - Build perceptions of competence by creating opportunities for mastery and learning; minimise advice giving and support problem solving skills.
> - Facilitate conditions for change through supportive relationships, positive expectancies and encourage a trial and error approach (See Appendix T)
> - Foster social connections by engaging support from significant others and similar others through family based and group based interventions.
> - Support intrinsic motivation through enjoyment enhancement by encouraging selection of personally meaningful goals and taking notice when out walking.

Figure 30. Summary of therapeutic principles to create an autonomy-supportive environment

### 8.3.1 Collaborative planning

This intervention drew on several simple strategies to support collaborative planning such as creating an environment that promotes trust and synergy and encourages autonomous motivation, use of if-then planning to optimise situation-specific automaticity, and the facilitation of a growth mindset which helps develop better monitoring of mistakes and supports resilience. Of all the methods for supporting collaborative planning in the intervention, the one that was most acceptable, consistently effective and easiest to implement was *if-then* planning. These findings adds further support to the research of Kersten et al.(2014, 2015) who also concluded that if-then planning was an acceptable way to provide self-regulatory support for rehabilitation populations. The table below provides some examples of strategies to support the collaborative planning used in this research.

- Create an autonomy-supportive environment that promotes the development of synergistic mechanisms – See Figure 30.
- Provide relevant information about physical activity to promote awareness - use public health infographics (e.g. activity pyramid) to start conversation about different types of activity (See Appendix Q).
- Provide feedback on actual daily steps from wearing activity monitor for at least 3 days; discuss recommended minimum of around 5000 steps per day.
- Keep an activity diary and use the findings to discuss current levels of activities and barriers to walking more.
- Provide information about benefits of taking a daily walk.
- Complete everyday interview by asking client to describe usual day and record details and use to inform goal planning including if-then planning.
- Teach clients about use of if-then plans for action planning. Explain that different things can act as a cue for behaviour such as certain location, time of day or a specific feeling. Provide examples of different types of If-then plans. E.g. IF it is 9:00am THEN I will go for a walk around the block. IF I am outside and people are staring at me, THEN I will think of something funny to distract myself.
- Complete Eco-map and use findings to help prompt conversation about different family members or friends who might be a resource to support the behaviour change process.
- Support the person to develop plans to cope with any barriers that arise.

Figure 31. Possible strategies to support collaborative planning to promote real-world walking

## 8.3.2 Context specific training

Context specific training describes walking practice that occurs in settings as close as possible to desired real-world settings. Undertaking training in settings as similar as possible to those that will be encountered in daily life is likely to assist with the transfer of learning. This is due to the well-established principle of specificity in training induced learning which means that transfer of learning is unlikely to occur when settings are different (e.g. C. S. Green & Bavelier, 2008). Figure 32 summarises the key considerations to support context specific training for people after stroke.

- Help each stroke client find an accessible walking route such as walking around the block near their home.
- Encourage them to walk outside every day.
- Discuss with them how they can progress their walking by adding an extra house each time or support them to select an alternate strategy to help progress distance or time walking.
- Encourage them to enjoy the walk by taking notice of variety when out and about.
- Discuss with them how to: 'pre-plan' to reduce anxiety (such as taking a cell phone, taking a walking buddy, developing a plan to distract thinking if getting anxious etc.).
- Explain that it is normal to feel anxious when walking outdoors, and that fears are common. Explore any specific fears they may have when walking outdoors. Help them develop a plan to manage their fears using if-then planning.
- Discuss with the client how walking in the real world is likely need intense concentration but this can improve with regular practice.
- Encourage them to invite family and friends to walk with them.
- Encourage family and friends to find local walking routes that have seating and support the stroke survivor to make most of opportunities to walk.
- Identify any locations that are particularly challenging for the client and develop a plan together on how to build confidence and competence to help them walk successfully in these locations.

Figure 32. Strategies to support context specific training to encourage real-world walking

### 8.3.3 Caring connections

This thesis has consistently highlighted how social connections impact walking self-regulation. Efforts were made to enhance social resources by including significant others (i.e. families) and similar others (i.e. peers who have had a stroke) as far as possible in the intervention. The impact of social connections may partly explain the positive findings of other group-based interventions for stroke survivors that promote physical activity and have also produced gains in physical integration (e.g. Carin-Levy, Kendall, Young, & Mead, 2009; Harrington et al., 2010). This study provides examples of the way that some participants used the stories of others as a resource which helped them make sense of their personal experiences of life after stroke. This process of meaning making by comparing what was similar and different in their own story to the stories of others seemed to create a greater sense of coherence, greater confidence and could energise behavioural persistence.

The resilience and coping literatures describe *resilience* to be a process whereby people successfully adapt to adverse conditions; developing a sense of coherence

is considered to be an essential resource in this process (Harrop et al., 2006). However, there is only limited empirical support or guidance on ways to enhance resilience (Harrop et al., 2006). The explicit consideration of the concepts of resilience and wellbeing and their application to stroke rehabilitation is still emerging in the stroke literature (e.g. Sarre et al., 2014), and remains relatively unexplored. Dodge, Daly, Huyton & Sanders (2012) reviewed the diverse definitions of wellbeing in the psychology literature and concluded wellbeing occurs when an individual has sufficient resources to meet the challenges of life. Figure 33 below provides a pictorial summary of this process. In a similar way, this thesis, along with an extensive body of qualitative literature (e.g. Satink et al., 2013; Walsh, Galvin, Loughnane, Macey, & Horgan, 2014; Woodman, Riazi, Pereira, & Jones, 2014) highlights the overwhelming physical, psychological and social challenges experienced by stroke survivors and the negative impacts this has on their wellbeing. It has also shown that enhancing social connections through family meetings and group based activities, can provide social resources that have the potential to enhance positive wellbeing. Leveraging such social resources to help stroke survivors respond to the adverse impacts of stroke is an area worthy of further exploration by clinicians and academics seeking to optimise the impact of rehabilitation interventions.
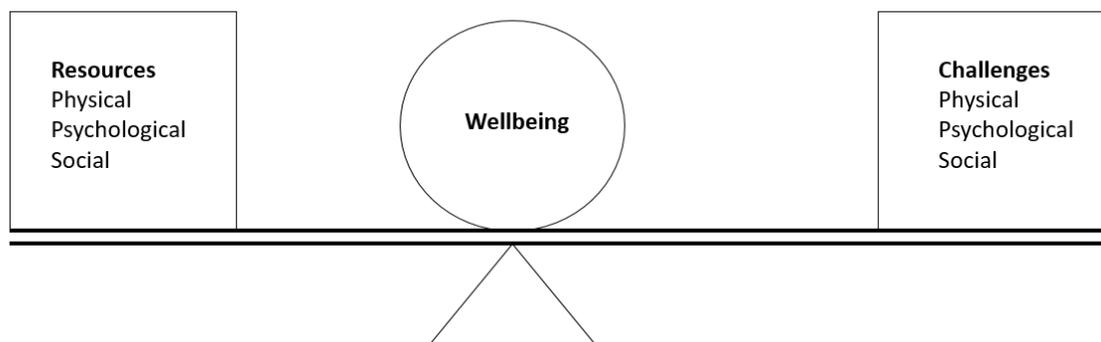


Figure 33. Wellbeing develops when personal resources are sufficient to overcome challenges experienced (Taken from Dodge, 2012)

### 8.3.4 Summary of clinical implications

The problem of walking inactivity after stroke is due to multiple factors which, together, produce a negative downward spiral leading to a lifestyle of inactivity which adversely affects wellbeing.  My analysis of this problem highlighted issues

relating to physical and psychological capability, constraints in the physical and social environment and difficulties with motivation stemming from difficulties with behavioural self-regulation. Inactivity is indeed a complex problem which develops in response to the considerable physical, psychological and social challenges experienced by stroke survivors. In practice, addressing this problem is likely to require input from several sources. Having a clear and compelling goal (walk more); identifying key behaviours (enjoy a daily walk of at least 20 minutes) and optimising multiple sources of social influence appear to be the most likely ways to leverage interventions to successfully support people to walk more in the real world and optimise wellbeing.

## 8.4   Limitations

When designing this project, I intentionally selected one clinical population (community dwelling people with stroke); one outcome (sustained change in real-world walking) and one health profession (physiotherapy) on which to focus. One disadvantage of this choice is that generalisability to other populations and problems was not examined. However, targeting in research is necessary and justifiable.

A further limitation was the relatively small number of participants in both phase 2 and phase 3 who contributed to the data collected. Similarly, the sampling processes selected meant most participants were recruited from the database of a charitable organisation in a large rural New Zealand city. Although I did seek to recruit a diverse range of participants in relation to ethnicity and age, it is likely that the voices of other stroke survivors are not adequately represented, such as those living in rural parts of New Zealand for example. In a similar way there is some research that indicates gender might influence perceptions of capabilities and influence outcomes ( e.g. Chang, Latham, Ni, & Jette, 2015), but I was unable to gather sufficient data to explore this due to the exclusion of one female participant part way through the intervention and the very high self-confidence levels of the remaining two female participants. For safety, participant recruitment excluded those with a low level of gait speed (i.e. <0.8m/s) meaning the applicability of the intervention to less physically able participants was not established. Any future research designs extending this work would ideally

include larger numbers of participants and greater diversity of characteristics and contexts to build more nuanced understandings of what works for whom.

This research focused on developing a treatment theory as recommended in the first phase of the MRC guidelines rather than addressing questions about feasibility or intervention effectiveness. A lack of suitable outcome measures for walking self-regulation and autonomy-supportive environments meant that proxy measures were used to record this outcome. To my knowledge, there are few suitable outcomes for behavioural self-regulation, but appropriate measures for assessing the presence of an autonomy-supportive health climate are available (e.g. Ng et al., 2012) and on reflection may have been useful. However, earlier in the project, largely to contain its burgeoning size, I elected to focus primarily on the behaviour of the person with stroke and had to carefully prioritise the self-report measures to minimise the cognitive burden associated with collecting quantitative and qualitative data over one time point. The more pointed limitations of this research though, relate to the applicability and utility of the findings to clinical practice.

Neurological physiotherapists are familiar with the selection of intervention components that promote active ingredients of intensity and progression that produce physiological overload and adaptive physiological changes (Bowden, Woodbury, & Duncan, 2013). Physiotherapists are less familiar with the motivational, habitual, emotional and psychosocial factors this thesis suggests are particularly relevant to ensure sustained change in walking behaviours. The findings of this thesis may challenge some core assumptions of neurological physiotherapy practice including task specific vs. context specific training, focusing on the individual vs. group processes, passive recipients vs. active learners, and biological mechanisms vs. psychological and psychosocial processes. Professional barriers are likely to constrain further development and rapid uptake of these concepts into practice (Anderson & Funnell, 2005; Mudge et al., 2013). Despite these professional barriers and the limitations of this research, my hope is that the research journey documented in this thesis can it itself provide a starting point for new ways of thinking about core rehabilitation practices.

## 8.5   Recommendations for future research

As recommended by the MRC guidelines for intervention development, now that a likely explanation for how change can occur has been established, the next step is to examine feasibility and effectiveness of the intervention in preparation for larger scale evaluation at later time points (Medical Research Council, 2006). Moving into this next stage is likely to require careful design planning to ensure the following issues are considered: a) the likely heterogeneity of outcomes due to different contextual factors, b) design issues related to the underlying learning mechanisms at the heart of the intervention and c) issues related to intervention implementation. Careful consideration of these factors will be needed to optimise the effectiveness and potential sustainability of the intervention over the longer term.

The challenge of heterogeneity in outcomes following physical activity interventions is an important finding as shown by a recent high-level review which concluded despite decades of research, researchers still struggle to explain the wide variation in outcomes evident even in in healthy individuals (Rhodes, Janssen, Bredin, Warburton, & Bauman, 2017). Similarly, this case-study also identified several contextual factors that seemed to either enable or constrain how well the intervention worked for different participants. Such factors included psychological factors: adequate cognitive capacity, the presence of a growth mind-set and the ability to regulate emotions successfully. It is also likely that other factors (e.g. gender) may influence how an individual responds (Chang et al., 2015) but these factor was not able to be fully explored due to the relatively small number of case study participants. Randomised controlled designs are generally unable to provide insights into how different individuals respond to interventions because of the way outcomes are averaged out which can obscure individual factors that are most relevant to change (Fletcher et al., 2016; Kravitz et al., 2014). One research design which can examine the influence of contextual factors is the use of n-of-1 trials designs where the individual acts as their own control (Kravitz et al., 2014; Nikles & Mitchell, 2015; Perdices & Tate, 2009; Sniehotta, Presseau, Hobbs, & Araújo-Soares, 2012). An n-of-1 design provides individual-level data and therefore insights into how different sub-populations

respond to different intervention elements- this can produce greater clarity on what works for whom (Fletcher et al., 2016; Tate & Perdices, 2015). Designing a series of no-of 1 trials that seek to include participants with different contextual factors could help to successfully build greater understanding of why variability in outcomes exists thus building evidence of effectiveness that can be readily applied to patients who share similar characteristics.

Some advocates of n-of-1 research, suggest an important feature is the presence of a washout period to demonstrate a loss of intervention effectiveness once the intervention has been withdrawn (Kravitz et al., 2014). This concept is drawn from a pharmacological ideal of immediate biochemical change that develops once a drug is ingested and effectiveness which ceases once the medication is no longer given. However, active learning mechanisms (unlike pharmacological interventions) are generally difficult to withdraw (i.e. unlearn) and indeed it would be undesirable from a patient's perspective to do so (Bell & Kozlowski, 2008). An alternative n-of-1 design known as a multiple-baseline single system design can overcome this difficulty by randomising the start of the intervention (Perdices & Tate, 2009; Tate & Perdices, 2015). Designs such as multiple-baseline single system designs can provide a robust way that help address validity concerns that would be suitable for research seeking to change walking behaviours that involve learning and self-regulation (Tate & Perdices, 2015).

The *Walking for Wellbeing after Stroke* intervention was a complex multi-component intervention. It contained ten intervention components, was carried out across three phases (family centred goal planning, ongoing individual support for implementation, and group-based activities) and the intervention was delivered by a single physiotherapist who had training in health coaching who was also responsible for the intervention development. Some intervention components appeared to be more valued by participants than others. For example, participants described significant value form the experience of walking outdoor with other stroke survivors, but most did not seem to value self-monitoring or escorted community walking. Implementation issues related to which of the intervention components contain the essential active ingredients and whether the intervention can be successfully delivered by other people will

need to be clarified to ensure the intervention can be feasibly and effectively delivered in usual clinical and community settings before moving into larger scale evaluations.

One unanticipated finding of this research was that problems with emotional self-regulation appeared to directly impact on the motivation to walk. The process of learning to overcome the negative emotions that influenced goal striving required concerted effort by study participants. The adverse effect of negative emotions on learning to walk again in real-world settings is a novel finding for research into walking after stroke.. However, the impact of negative emotions on learning is not new to those involved in teaching and learning in other fields. For example, in education, class room teachers are very familiar with the impact of emotions on a student's capacity to learn (e.g. Bell & Kozlowski, 2008) and there are proven educational strategies, based on decades of research designed to address this very problem (e.g. Foley & Kaiser, 2013; McGinty, Radin, & Kaminski, 2013). Two key practices to help self-regulated learning are helping students to develop a mind-set that promotes active engagement in problem solving; (see Dweck, 2006) and the practice of intentionally creating autonomy-supportive environments (Reeve et al., 1999). Both these strategies were used successfully in the *Walking for Wellbeing* intervention and have the potential to be used more widely in rehabilitation.  In education as well as rehabilitation, using such strategies though does require a suitably trained workforce.  Several training courses to enhance the capability of health professionals are available for clinicians to develop the relational practice skills needed, such as training in health coaching (e.g. Gale, 2007) and communication skill training using principles from Self-Determination Theory (e.g. Murray et al., 2015). However professional barriers can affect the acceptability of these new ways of working (Stretton et al., 2013). This means that further scholarship, research and training will be needed if these concepts are to become incorporated into routine practice.

In addition to developing ways to enhance capability for clinicians, a second area for future research is the applicability of Self-Determination Theory as a basis for intervention development for clinical populations. To date there are few examples of Self-Determination Theory informed rehabilitation interventions

(e.g. Sweet, Fortier, Strachan, Blanchard, & Boulay, 2014) but there are a number of initiatives in the wider health domain that paint a compelling picture of the value of this theory to inform interventions to promote sustained change and enhance health and wellbeing (Ng et al., 2012). Finally, more conceptual work is needed to explore the role of capability beliefs in rehabilitation populations, including the concept of self-regulatory confidence as identified in this thesis. For example, a realist review examining interventions to improve self-efficacy and related capability constructs may be the next logical next step to advance knowledge in this area.

## 8.6   Personal reflections

I started this project with a high level of personal commitment to answering a clinical question and seeking to answer this question required me to engage with a wide-range of different literatures. The answer to my question was something relatively simple and well-studied in other fields- the process of self-regulated learning. I have noticed during this research journey, a shift in the way I view the role of the physiotherapist in supporting change. Rather than seeing myself as an expert in walking problems, I have come to see that the most strategic way to optimise change processes is to see my role as a facilitator charged with creating the optimal conditions for change.

The second area of learning relates to the challenges encountered undertaking this project which I did not fully anticipate. In retrospect, I was somewhat naïve in underestimating the conceptual challenges entailed in this project. These included moving from the confines of a more conventional disciplinary based view of interventions to improve walking after stroke, toward a wider range of concepts outside my usual frame of reference. It also involved time to become familiar with new and challenging theories such as realist research philosophies and complexity theory. To manage these challenges within the constraints of the PhD, I had to trim back my early design plans to complete the project. Another area of difficulty was finding ways to communicate theoretical concepts without overwhelming the reader. I did notice the irony of reading about behavioural self-regulation while personally experiencing the cognitive and emotional challenges of completing this PhD. In motivating myself to keep on going with this research,

like many PhD students, I also had first-hand experience of self-regulated learning which provided personal insights. This project also provided me with greater empathy for the daily struggles faced by stroke survivors, inspiration from the courage they had and hope for the potential for physiotherapy to make a difference for them.

## 8.7 Conclusions

This thesis has attempted to identify the active ingredients needed to produce sustained change in walking after stroke. The *Walking for Wellbeing* intervention helped stroke survivors develop new daily walking routines; supported them to develop problem solving skills to overcome obstacles to goal striving and created opportunities to connect with other survivors through regular outdoor walking groups. It sought to encourage collaborative connections and context specific practice and to build confidence to promote the development of adaptive transfer. This thesis has offered a clear understanding of the processes behind adaptive transfer, but the findings of this doctoral work also show that this process is more complex than previously assumed and point to the integral role of self-regulated learning to changing walking habits and routines after stroke. The traditional approaches to improving walking in the real-world which typically involve one on one input and advice and skill training often in clinical settings fails to consider the role of the active learning mechanisms needed to promote long term change in walking behaviours. My hope is that a greater appreciation of these mechanisms will prompt a rethinking of rehabilitation interventions for stroke survivors and ultimately work to optimise the real-world impact of these interventions.

# Glossary

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| **Active ingredients** | Parts of an intervention necessary to produce change; includes context and mechanisms of action which interact to cause change in outcomes. |
| **Action control** | Processes necessary for initiation and execution of goal-directed behaviours; contributes to behavioural self-regulation. |
| **Adaptive transfer** | Learning gains that transfer across time (i.e. sustained change) and across different contexts. |
| **Automaticity** | Associative learning process where over time a behaviour become automatically enacted in response to contextual cues in the environment. |
| **Autonomy** | Individual capacity for self-determination. |
| **Autonomous motivation** | Type of motivation that a person perceives as coming from their own choice due to its inherent pleasure or consistency with personal values.[1] |
| **Autonomy-supportive environment** | A treatment atmosphere that encourages people to engage in health-conducive behaviours for their own reasons, facilitates success in dealing with barriers to change and conveys feelings of acceptance and respect.[2] |
| **Behaviour** | Activities a person does in response to internal or external events.[3] |
| **Behavioural self-regulation** | Learnt psychological skills that enable a person to exert control over themselves and direct their energy and attention towards goal setting and goal striving. |
| **Carryover** | Synonymous with adaptive transfer |
| **Competence** | The feeling of being effective in producing desired outcomes and exercising one's capacities.[4] |
| **Complexity** | Characteristics of an adaptive system (e.g. a human being) that responds to inputs in emergent and unpredictable ways and/or an intervention which has multiple interacting components. |

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[1] Deci & Ryan, 2008a

[2] Ng et al., 2012, p. 327

[3] Michie, Atkins, & West, 2014

[4] Ng et al., 2012, p. 327

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| **Context** | A set of characteristics and circumstances that surrounds an implementation effort. Context interacts, influences, modifies, facilitates or constrains the activation of mechanisms.[5] |
| **Context specific training** | Type of intervention that aims to enhance capability by encouraging repetitive practice in the real-world context where the behaviour will normally be executed. |
| **Contextual (motivational) transfer** | Process where gains in motivation following successful behaviour change creates expectancy of future success in a different context |
| **Collaboration** | Action of working with someone to produce something. |
| **Cognitive appraisal** | Process of evaluating and interpreting a situation to determine the personal significance. |
| **Emotional self-regulation** | Ability to effectively manage positive and negative feelings and flexibly respond to situational demands and in a socially appropriate manner |
| **Habit formation** | Process of incrementally strengthening the association between an action and a contextual cue until automaticity develops. |
| **Integration** | A complex person-environment interaction whereby new life experiences (i.e. illness) are assimilated into the self and activities of daily living, thereby contributing to overall life balance.[6] |
| **Mastery** | A sense of capability and control when performing a desired action. |
| **Mechanisms (of action)** | Underlying entities, processes or structures which operate in particular contexts to generate outcomes of interest.[7] At an individual level, can be viewed as how someone changes their reasoning in response to resources provided by an intervention.[8] |
| **Mid-range theory** | A broad grouping of theories that are positioned between grand theories and small (treatment) theories. A mid-range theory is specific enough that testable hypothesis can be generated, but general enough it can be applied to different contexts or populations. |
| **Motivation** | Brain processes that energise and direct behaviour. [9] |

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[5] Pfadenhauer et al., 2015
[6] Whittemore, 2005, p. 261
[7] Astbury & Leeuw, 2010, p. 3
[8] Pawson & Tilley, 1997
[9] Michie, van Stralen, & West, 2011, p. 7

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|---|---|
| **Motivational spill-over** | Situation where gains in confidence and/or commitment in one area positively influences motivation in a different area such as being more physically active leading to changes in eating patterns for example. |
| **Normalisation** | Process by which practices become embedded and integrated into their social contexts. [10] |
| **Physical integration** | Participating satisfactorily in desired activities that require movement of one's body. |
| **Real-world walking** | Actual walking in usual settings. |
| **Relatedness** | Feeling of being respected, understood and cared for by others (synonymous with social connections). |
| **Self-concept** | A person's perceptions of their behaviour, ability and unique characteristics, a mental picture of how a person views themselves. |
| **Self-confidence** | An estimation a person makes of their capability to accomplish something. |
| **Self-regulated learning** | Process by which a person learns to control their thoughts, feelings and actions to achieve a desired skill or perform a desired activity. |
| **Sense of coherence** | Process by which a person makes sense of their situation and responds in a way that is comprehensible, manageable and meaningful to them. |
| **Social connections** | Positive relationships with others in the social world. [11] |
| **Social integration** | Participating satisfactorily in a range of private and public interactions. |
| **Sustained (behaviour) change** | An alteration to an activity that continues to occur over time |
| **Treatment theory** | A specific type of theory that is abstract, describes what the intervention comprises and how it is expected to work. Also known as small or programme theory. |
| **Wellbeing** | Describes a life that is going well, and a person who feels good and functions effectively. |
| **Work** | Any activity that involves effort to achieve a result; can include physical, cognitive, emotional or interpersonal efforts. |

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[10] (C. May & Finch, 2009)

[11] Seppala, Rossomando, & Doty, 2013

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# Appendix A: Phase 1-Search strategy for Systematic Review

**Completed Feb 2013 and updated Nov 2015**

**Ebsco**

("free living" N8 walk*) OR ("free-living" N8 walk*) OR ("real-world" N8 walk*) OR ("real-world" N8 walk*) OR (usual N8 walk*) OR (functional N3 walk*) OR ("free living" N8 ambulat*) OR ("free-living" N8 ambulat*) OR ("real-world" N8 ambulat*) OR ("real-world" N8 ambulat*) OR (usual N8 ambulat*) OR (functional N3 ambulation*) OR ("free living" N8 gait) OR ("free-living" N8 gait) OR ("real-world" N8 gait) OR ("real-world" N8 gait) OR (usual N8 gait*) OR (functional N3 gait*)  OR ("free living" N8 locomotion) OR ("free-living" N8 locomotion) OR ("real-world" N8 locomotion) OR ("real-world" N8 locomotion) OR (usual N8 locomotion*) OR (functional N3 locomotion*) OR ("community ambulat*") OR (community N8 walk*) OR (community N8 pedometer) OR (community N8 accelerometer) OR (community N8 "activity monitor") OR (physical N8 pedometer) OR (physical N8 accelerometer) OR (physical N8 "activity monitor")

AND

RCT OR "random* control* trial*" OR "random allocation" OR "clinical trial*" OR "control* clinical trial*" OR "control group" OR "single-blind method" OR (controlled N5 trial*) OR (controlled N5 stud*) OR (clinical* N5 trial*) OR "quasi-random*" or "quasi random*" or "pseudo-random*" or "pseudo random*"

**Scopus**

("free living" W/8 walk*) OR ("free-living" W/8 walk*) OR ("real-world" W/8 walk*) OR ("real-world" W/8 walk*) OR (usual W/8 walk*) OR (functional W/3 walk*) OR ("free living" W/8 ambulat*) OR ("free-living" W/8 ambulat*) OR ("real-world" W/8 ambulat*)

OR

("real-world" W/8 ambulat*) OR (usual W/8 ambulat*) OR (functional W/3 ambulation*) OR ("free living" W/8 gait) OR ("free-living" W/8 gait) OR ("real-world" W/8 gait) OR ("real-world" W/8 gait) OR (usual W/8 gait*) OR (functional W/3 gait*)

 OR

("free living" W/8 locomotion) OR ("free-living" W/8 locomotion) OR ("real-world" W/8 locomotion) OR ("real-world" W/8 locomotion) OR (usual W/8 locomotion*) OR (functional W/3 locomotion*) OR "community ambulat*" OR (community W/8 walk*)

OR

(community W/8 pedometer) OR (community W/8 accelerometer) OR (community W/8 "activity monitor") OR (physical W/8 pedometer) OR (physical W/8 accelerometer) OR (physical W/8 "activity monitor")

AND

RCT OR "random* control* trial*" OR "random allocation" OR "control group" OR "single-blind method" OR (control* W/5 trial*) OR (control* W/5 stud*) OR (clinical* W/5 trial*) OR "quasi random*" OR "pseudo random*"

## AMED ( and Cochrane)

("free living" ADJ8 walk*) OR ("free-living" ADJ8 walk*) OR ("real-world" ADJ8 walk*) OR ("real-world" ADJ8 walk*) OR (usual ADJ8 walk*) OR (functional ADJ3 walk*) OR ("free living" ADJ8 ambulat*) OR ("free-living" ADJ8 ambulat*) OR ("real-world" ADJ8 ambulat*) OR ("real-world" ADJ8 ambulat*) OR (usual ADJ8 ambulat*) OR (functional ADJ3 ambulation*) OR ("free living" ADJ8 gait) OR ("free-living" ADJ8 gait) OR ("real-world" ADJ8 gait) OR ("real-world" ADJ8 gait) OR (usual ADJ8 gait*) OR (functional ADJ3 gait*)  OR ("free living" ADJ8 locomotion) OR ("free-living" ADJ8 locomotion) OR ("real-world" ADJ8 locomotion) OR ("real-world" ADJ8 locomotion) OR (usual ADJ8 locomotion*) OR (functional ADJ3 locomotion*) OR "community ambulat*" OR (community ADJ8 walk*) OR (community ADJ8 pedometer) OR (community ADJ8 accelerometer) OR (community ADJ8"activity monitor") OR (physical ADJ8 pedometer) OR (physical ADJ8 accelerometer) OR (physical ADJ8 "activity monitor")

AND

RCT OR "random* control* trial*" OR "random allocation" OR "clinical trial*" OR "control* clinical trial*" OR "control group" OR "single-blind method" OR (controlled ADJ5 trial*) OR (controlled ADJ5 stud*) OR (clinical* ADJ5 trial*) OR "quasi-random*" or "quasi random*" or "pseudo-random*" or "pseudo random*"

## PEDRO; OT Seeker: PsychBite

(Walk* AND Stroke)

(Gait AND Stroke)

# Appendix B: Early interactive design map of PhD

This interactive design map was informed guided by Maxwell (2013) and underwent multiple iterations during the early stages of my PhD which started in 2012. This one is version 7 and was created in January 2013.

**Title: Walking for life - A mixed methods approach using behavioural interventions to improve walking in the 'real world' for people with stroke**

**Goals:**

1. Understand what helps and hinders walking in the 'real world' for people with stroke

2. Identify which behavioural change strategies physiotherapists can incorporate into practice and how the strategies could facilitate carryover from improved walking capacity into improved walking in the real world.

3. Identify whether behavioural change strategies improve walking in the real world for people with stroke.

**Conceptual Framework?**

Behaviorism→ Behavioural change→ Beh Ch models; SR Theory; COMB/ ITHBC→ model for Physical activity

Life after stroke→ physical disability →Inactivity following stroke→ changes to usual walking

Life after stroke →Inactivity → social, cognitive, psychological consequences →biographical disruption

Physiotherapy-→ontology & epistemology→ changing professional practice

Rehabilitation →person centred care→ Patient centred goal setting

Complex intervention →intervention development →modelling processes using conceptual causal modelling)

Therapeutic relationship→ collaborative working alliance enabling & empathy

Mixed Methods

**Research Questions** -Overall objective:

To develop and evaluate a practice-friendly intervention which improves 'real world' walking using behavioural change techniques for people with stroke

1: How effective are current interventions at improving physical activity walking and walking in the real world following stroke?

2a: Who needs to do what, differently? 2b Using a theoretical framework what barriers and enablers need to be addressed.2c: Which intervention components (behaviour change techniques and mode(s) of delivery) could overcome the modifiable barriers and enhance the enablers? 3d: How can behaviour change be measured and understood?

3a: What does walking in the real world mean to people with stroke? 3b: How do people with stroke, their family members, and their physiotherapists believe walking in the real world can be enhanced and sustained?

4. What is the effectiveness of task-oriented exercise training and identified behavioural change techniques on improving the amount and rate of walking in the 'real world' for people with stroke?

**Methods:**

Multiphase Mixed Methods

- Fixed, sequential, each stage informs the next stage
  - Systematic Reviews→
  - Intervention development →
  - + Qualitative enquiry→
  - Evaluate effectiveness with single system design

17/01/2013

**Validity & Trustworthiness:**

- Systematic Review
  - Identification of bias in randomised controlled trials
- Intervention Development
  - Rigorous Reflexivity
  - Triangulation of evidence
- Qualitative enquiry
  - Strategies for trustworthiness
- Single system design
  - Blinded outcome assessment
  - Randomised intervention points
  - Multiple baseline

# Appendix C: Phase 1-Studies included in Systematic Review

| Study ID | Participants | Intervention | Control | Outcomes | Key Findings and Comments |
|---|---|---|---|---|---|
| Dean 2012 | People with chronic stroke (n= 151) who could attend exercise classes. Average age since stroke 5.9 years | 1x week exercise programme in a circuit delivered by physiotherapist. 2x week individual home exercise programme for 40 weeks; progressed regularly-focused on lower limb. | Attention control: Exercises for arms and cognitive activities 1x week and Home Ex. Prog. 2 x week for 40 weeks | Pedometer (steps/day) at 12 months follow up | Real-world walking measured using pedometer with positive point estimate but wide confidence intervals (SMD 0.30 [-0.5, 0.65]) Small increase in six-minute walk test (+34m ) and gait speed (0.07m/s) Pedometer not valid for people with slow walking speed of less than 0.8m/s- Intervention group baseline gait speed was 0.72m/s and control group mean 0.67 m/s Given Home Ex. Prog. + diary to record but no goals or plan to address individual barriers Intervention workbook available online lists adherence strategies but not clearly operationalised Recruitment was difficult, adherence to home exercise programme low especially as time went on |
| Duncan 2011a LTP | People with stroke- within 30 days – with gait speed <0.8m/s | 90 minutes, 3x week, progressive treadmill training and over ground walking in clinic; 30-36 sessions over 12-16 weeks | Usual care | StepWatch™ number steps per day at 6 months follow-up | No statistically significant difference between usual care and LTP on StepWatch™ Significant improvements in gait speed compared to control group and Home Exercise Programme (HEP) group presumably due to specificity of training. Real-world walking (number steps per day) SMD 0.19 [-0.10 to 0.49] |

| Study ID | Participants | Intervention | Control | Outcomes | Key Findings and Comments |
|----------|--------------|--------------|---------|----------|---------------------------|
| | | | | | Very intensive programme with 1-2 assistants and expensive equipment (treadmill) |
| | | | | | Participants in trial had low levels physical functioning |
| | | | | | Large, well-controlled study |
| Duncan 2011b HEP | People with stroke- within 30 days – with gait speed <0.8m/s | 90 minutes, 3x week, home-based low intensity exercises; 36 sessions over 12-16 weeks with goal oriented walking programme and encouragement to walk | Usual care | StepWatch™: Number steps per day at 6 months follow up | Statistically significant difference between usual care and Home Ex. Prog. group on StepWatch™ |
| | | | | | Originally intended as an attention control group with exercise intensity sufficiently low to not provide physiological overload |
| | | | | | Explicitly encouraged to walk in usual settings |
| | | | | | Similar results to LTP overall but more real-world walking SMD 0.30 [0.00,0.60] |
| | | | | | Exercise delivered in home setting |
| | | | | | Large well-controlled study |
| Galvin 2011 | People with acute stroke in hospital (within 2 weeks onset) (n=40) | Actively involved family in partnership with physiotherapist to increase exercise time over 8 week period during inpatient stay | Usual care | NEADL – mobility subscale (dichotomised at post intervention and 3 month follow-up) | Overall although small study with only 20 in each group, the intervention group showed statistically significant improvements in all outcomes and improvements in patient-reported outcomes persisted at the 3-month follow-up. |
| | | | | | NEADL at post-intervention (which reported activity preceding week) was administered while 23/40 participants still in hospital/inpatient rehabilitation so may explain negligible SMD at post assessment for |

| Study ID | Participants | Intervention | Control | Outcomes | Key Findings and Comments |
|---|---|---|---|---|---|
| | | Family-centred goal setting, progressive exercises and exercise diary | | | dichotomised mobility subscale. (SMD 0.08 [-0.57, 0.72]). Three month follow up had much higher point estimate but still wide CI  (SMD 0.44[-0.23,1.12]) |
| | | | | | Participants in the intervention group were also significantly more integrated into their community at follow-up. and overall results of other outcomes showed results sustained/increased even though intervention delivered during inpatient stay |
| | | | | | Family members in intervention group reported a significant decrease in their levels of caregiver strain at follow-up compared with control group despite increased time commitments for family |
| Logan 2004 | People with stroke at home within 3 years N= 168 | Goal setting by OT and home visits and practice in real-world settings to increase confidence | Informa-tion leaflets | NEADL-mobility subscale: at 4 and 12 months (dichotomised at both time points) | Information returned by post and blinded outcome assessors checked missing data (SMD 0.37 [0.06-0.69]) |
| Mansfield 2015 | People with stroke in inpatient rehabilitation N=60 | Daily activity recorded with activity monitors and results given to physiotherapist who gave feedback to the participants | Usual care | Accelerometer: Average number of daily steps in last three days of rehabilitation | Inpatient population. Feedback generated by accelerometer from Gulf Data Concepts with a custom-written step detection algorithm. Information provided to physiotherapist who chose to discuss it with participant in way they chose RMI used as outcome (SMD 0.21[-0.31-0.73]) |

| Study ID | Participants | Intervention | Control | Outcomes | Key Findings and Comments |
|---|---|---|---|---|---|
| Mudge 2009 | People with stroke >6months; residual gait problems but able walk independently<br><br>N= 58 | Group based circuit based exercise training, 1 hour, 3x week for 4 weeks= 12 sessions | Attention based control; social group | StepWatch™ (mean steps per day, peak activity index, Max 1, % time inactive):<br><br>Assessed post intervention and 3 months follow-up | No statistically significant difference in real-world walking (SMD 0.22[-0.30,0.73]) on StepWatch™ or self-report physical activity (PADS)<br><br>Quite short intervention 4 weeks<br><br>Significant change in 6 minute walk test post intervention but not sustained at 3 months |
| Pang 2005 | Community dwelling people with stroke<br><br>N=63 | Task oriented mobility programme 19 weeks, 3 x week i.e. Up to 57 sessions | Attention based control:<br><br>Seated upper extremity exercises | Physical activity scale for individuals with physical disabilities: post-intervention | Most intensive intervention in study in terms of number of session provided by health professionals but no home exercise programme provided<br><br>Lowest point estimate for activity<br><br>SMD -0.34[-0.85, 0.17]<br><br>Intervention group improved in 6MWT* cardiorespiratory fitness and bone density paretic leg<br><br>Did not included any behaviour change techniques |

| Study ID | Participants | Intervention | Control | Outcomes | Key Findings and Comments |
|---|---|---|---|---|---|
| Pohl 2007 | People with stroke in inpatient facility with stroke< 60 days who could not walk independently N=155 | Received 45 mins daily physiotherapy for 4 weeks which included 20 mins of repetitive locomotor therapy and 25 mins usual physiotherapy | 45 mins usual physiotherapy ( usual care) | RMI: post intervention and six months | Lower quality study

Very dependent population/ Inpatients

SMD 0.58 [0.24-0.91] |
| Van der Port 2012 | People with stroke recently discharged from hospital. N=250 | Attended task oriented circuit training for 12 weeks, 3x per week- worked in pairs | Usual care | RMI: post intervention and three month follow-up | High quality, well powered study

Range outcome measures but original trial showed no change in walking capacity and no change in self-report measures of ADL or participation

(SMD 0.39 [0.13, 0.64]) |

*SMD=Standardised Mean Difference, HEP= Home Exercise Programme, LTP= Locomotor Training Programme NEADL= Nottingham Extended Activities of Daily Living, RMI= Rivermead Mobility Index, 6MWT= 6 Minute Walk Test, ADL=Activities Daily Living

# Appendix D: Phase 1-Studies excluded with reasons

| Papers | Outcome not RWW* | Inadequate control | Mixed population | Unable calculate effect sizes | Additional comments |
|---|---|---|---|---|---|
| Ada 2003 | X | | | | |
| Ada 2013 | X | | | | |
| Batchelor 2012 | X | | | | |
| Boysen 2009 | | | | X | RMI but medians |
| Cooke 2010 | X | | | | Modified RMI |
| Cramp 2010 | | X | | | |
| Cumming 2011 | X | | | | |
| Dean 2011 | X | | | | |
| Desrosiers 2007 | X | | | | |
| Dickstein 2013 | | | | X | Authors contacted. No data |
| Dobkin 2010 ) | X | | | | |
| Elsworth 2011 | | | X | | |
| English 2014 | | | | X | |
| Gilham 2010 | X | | | | |
| Green 2002 | | | | X | RMI but medians |
| Harwood 2011 | X | | | | |
| Holmgren 2006 | X | | | | |
| Hwang 2010 | X | | | | |
| Johnston 2007 | X | | | | |
| Kirk 2013 | | | | X | |
| Kono 2013 | | X | | | |
| Kwakkel 2002 | | X | | | |
| Lennon 2008 | X | | | | |
| Lord 2007 | X | | | | |
| Lund 2012 | X | | | | |
| Michael 2009 | | X | | | |
| Moore 2010 | | | | X | |
| Olney 2006 | | X | | | |
| Park 2011 | X | | | | |
| Pundik 2012 | X | | | | |
| Smith 2004 | X | | | | |
| Teixeira-Salmela 1999 | X | | | | |
| Torres-Arreola 2009 | X | | | | |
| Van der Ploeg | | | X | | |
| Wade 1992 | X | | | | Early version RMI-not clear met criteria |
| Yang 2008 | X | | | | |
| Zedlitz 2012 | X | | | | |

*RMI=Rivermead Mobility Index *RWW= Real World Walking

# Appendix E: Phase 2-Design strategies to enhance validity for Qualitative Enquiry

The key features in this table were derived from several sources (Crotty, 1998; Maxwell, 2013; Nicholls, 2009b; Tracy, 2010)

| Key features | Rationale | Audit Trail |
|---|---|---|
| **Design features**: Worthy topic | Topic of research needs to be relevant, timely, significant and interesting to be considered worthy (Tracy, 2010). A significant contribution can extend current theoretical assumptions, develop curiosity in the reader and shed light on a contemporary problem (Tracy, 2010). | The topic is relevant and significant because it has emerged from disciplinary priorities of physiotherapists and people with stroke (End user consultation in Appendix L) |
| **Design features:** Careful consideration how key components interact and methodological congruence and coherence between components | Research design requires explicit and ongoing consideration of different design components and how they interrelate (Maxwell, 2013); needed to ensure methodological congruence and coherence and avoid 'method slurring' and other pitfalls associated with use of generic qualitative approaches (Kahlke, 2014) and mixed methods | Explicit design map developed at outset of the project which explicitly considered interaction of all components within Phase 2 and over whole project, design map regularly revisited and revised as project progressed- See Appendix B- (Maxwell, 2013).<br><br>Explicit overview of theoretical positioning of Phase 2 developed with multiple iterations. Engagement with methodological texts and consideration of alternatives (including pragmatism vs realism vs social constructionism; constuctivist vs intepretivist theoretical perspectives; interpretive vs qualitative descriptive methodologies; and content vs thematic analysis methods<br><br>Personal reflections on worldview; disciplinary perspectives; role of theory in different disciplines; prior experiences. personal and professional goals documented in research journal – see theoretical scaffolding in section 5.2.2 on page 81 (Thorne, 2008) |

| Key features | Rationale | Audit Trail |
|---|---|---|
| | | Selection of generic qualitative approaches (e.g. interpretive descriptive) and theory independent methods (e.g. thematic analysis) that can work with a realist philosophy and constuctivist lens (Braun & Clarke, 2006; Thorne, 2008; Kahlke, 2014). |
| **Strategies for rigour**: Data abundance | Rich rigor is present when there is adequate data to support significant claims, sample is appropriate for goals of the study, and appropriate procedures are used (Tracy, 2010). | Extensive supporting quotes for each theme contained in Chapter Five<br><br>Diverse sample of people with stroke included (See Table 6-for characteristics of participants) |
| **Strategies for rigour:** Sampling sufficiency | This refers to a situation where sufficient data has been collected so that in terms of developing an understanding of the phenomenon of interests additional data is essentially redundant (Carnevale, 2002; Hunt, 2009; Thorne, 2008) | After the first 6 interviews had been completed and analysed findings were discussed with the supervisory team. Two further participants were sought to a) increase the diversity of the sample (including one older male, and a young Pasifica woman) and b) increase geographical variation (additional participants recruited through different sources from different geographical locations). Analysis of these transcripts provided further illustrations of core findings and minimal additional new understandings |
| **Strategies for rigour:** Researcher reflexivity | Disciplinary perspectives can affect how the researcher can view issues so reflexivity important when seeking understand phenomenon of interest (Hunt, 2009b; Thorne, 2008) | Co-author on published auto-ethnography exploring disciplinary perspectives and enhancing reflexivity (Mudge et al., 2013)<br><br>I also undertook additional researcher training to enhance qualitative interviewing skills including role plays and peer discussion and reflective interview with experienced qualitative researcher |
| **Strategies for rigour:** Transparency | Transparent decision making trail enhance the dependability and confirmability of the findings (Tracy, 2010) | Audit trail of decision making documented in research journal –See Appendix I |

| Key features | Rationale | Audit Trail |
|---|---|---|
| **Strategies for rigour:** Researcher responsiveness | Sensitivity to participants means they are able to drive project within guidance of researcher (Nicholls, 2009a) | Open ended interview allows participants to direct interview as they wish |
| **Strategies for rigour:** Negative case analysis | Negative case analysis refers to a process of examining data in which the findings contrast with the major patterns that most of the accounts for (Thorne, 2008) | I re-reviewed transcripts and coding decisions for each case and identified any themes or categories that there was no coded data for. I wrote reflections on characteristics of the person or other contextual features that may influenced their perspectives to help clarify more in-depth understanding of the concept. |
| **Strategies for rigour** : Triangulation | Triangulation refers to the practice of drawing on "multiple sources of data, researcher viewpoints, theoretical frames and methods of analysis allows for different facets of the problem to be explored…. [to] deepen understanding " (Tracy, 2010, p. 843) | Presentation of findings to research team who have significant experience in stroke rehabilitation, engagement and physical activity after stroke. Findings resonated with researchers and after discussion we identified key aspects (e.g. role of cognitive impairments in recovery processes; motivation) which facilitated a return to the data to aid further understanding <br><br> Inductive data generated shows overlapping themes with Self-Determination Theory – a well-recognised framework for research into physical activity for healthy individuals. |
| **Analytic strategies:** Immersion in the data | Thorne (1997) encourages repeated immersion in the data particularly prior to commencement of coding to encourage deeper degree of synthesis and theorising | Transcripts read through multiple times before coding started <br><br> Extended immersion in data during an analysis retreat on two separate occasions |
| **Analytic strategies:** Memo Writing | Memo writing as particularly important strategy to chart, inform and detail the analytic journey informally (Charmaz, 2014, p. 162). | Reflective memos were developed from the beginning of the project.. (Charmaz, 2014, p. 169). Early memo related to assumptions about the project, and different methodological choices. Advanced memos focused on analytic decisions and were also used to park reflections for later consideration. See Appendix F. |

| Key features | Rationale | Audit Trail |
|---|---|---|
| | | A synopsis of each interview was also written after each interview to provide a summary of key contextual features for each individual. |
| **Analytic strategies:** Thematic analysis | Clear guidelines for the practice of thematic analysis are provided including the six stages and a 15 point check list (Braun & Clarke, 2006).<br><br>Six stages include:<br>1. Familiarising yourself with the data<br>2. Generating initial codes<br>3. Searching for themes<br>4. Reviewing themes<br>5. Defining and naming themes<br>6. Producing the report | Check list reviewed and process refined as needed<br><br>Data transcribed verbatim and checked against recording for accuracy<br><br>Inductive data driven coding with each item given equal attention; manual coding of data with development of code book for first four transcripts. See Appendix H.<br><br>All relevant extracts for each theme collated in a table<br><br>Themes checked against each other and back to the original data set<br><br>Developing themes reviewed on multiple occasions by supervisory team.<br><br>Feedback provided about the match between data and analysis<br><br>Iterative thematic map developed (See Figure 10) |
| **Analytic strategies:** Axial Coding questions | Axial coding is a strategy developed in grounded theory which seeks understand interaction between codes | During the development of the thematic map, it became clear that rather than discrete categories, several of the themes were directly linked to each other, appearing to represent two different points on a continuum For example forced to be dependent vs freedom; hope of recovery vs feeling helpless and hopeless;<br><br>The thematic map was modified to include bidirectional arrows to represent process of moving from one state to another and back again depending on various factors |

| Key features | Rationale | Audit Trail |
|---|---|---|
| | | Coded transcripts were revisited and examined using the questions from axial coding ( *what context is embedded in here, what conditions give rise to this process in this story, what are the action/interaction strategies by which it is handled, managed, carried out?, What are the consequences of these strategies?*)( Straus and Corbin cited in Maxwell & Miller, 2008) |
| | | Comparison across cases using a matrix allowed for greater insights into similar emotional responses that occurred- e.g. elation or joy following success in a walking related activity. |
| **Analytic strategies:** Connecting strategies (Maxwell & Miller, 2008) | Coding strategies that focus on similarities in the data such as thematic analysis can lead to the loss of contextual detail. | I returned to the un-coded individual transcripts and created a narrative summary for each participant (Maxwell & Miller, 2008). A narrative summary retains the contextual features, but is also analytic summary of the narratives told by the participants. |
| | | Set up narrative stories to gather further contextual detail to determine specifically how though could be better. Each summary contained around 4-5 stories told by participants (e.g. the first walk in hospital, a positive experience waking etc.) |
| | | I closely examined each story on its own (which contained extensive quotes) using axial coding questions (as described above). See Appendix K |
| **Confirmability**: Member checking | Returning findings to participants allows for feedback regarding confirmability of findings. | Study findings were shared with participants and their thoughts on the findings elicited. |

| Key features | Rationale | Audit Trail |
|---|---|---|
|  |  | There was a broad consensus from all end user members, although one man disputed the value of walking itself as providing source of autonomy. For him, moving into a rest home was the key to giving him autonomy over his life rather than the act of walking. This lead to modification of the claims acknowledging that walking was just one way of providing autonomy and for different people and different times had greater or less significance. |

# Appendix F: Reflective writing in preparation for pre-understanding interview

**Pre-understanding interview- written 17th October 2014**

I am preparing a brief reflection to help guide my meeting with Jo. There are two main 'bits' I think. The first bit comes from ID book which talks about clarifying the theoretical fore structure by locating the theoretical allegiances ( e.g. paradigms or methodologies); locating the discipline ( e.g. physio/rehab) and positioning the researcher within these ideas ( surface, acknowledge and reflect up ideas we hold that may be influencing us in the design and interpretation). This will essentially help me to understand my "consequent angle of interpretive enquiry".

Secondly Jo has asked me to consider (several weeks ago now) – how holding a perspective of pragmatism will influence what is considered knowledge and how knowledge is created. She asked me to specifically thing about what I would do if the research 'evidence' conflicts the comments from qualitative participants- what would I do with that? How will I justify or reconcile these differences? What if my clinical perspective is in tension with either one or both of these sources?

Firstly the theoretical allegiance. I have done quite a bit of work in this area through the autoethnography and working through the framework of the study. So I feel reasonably confident that I am aware of my underlying paradigms as a clinician, researcher, and probably as a person having completed a series of critical reflections. From what I understand as a neurological physiotherapist by profession my primary paradigm of practices has been reasonably unconsciously influenced by a biomechanical discourse where the body is seen much like a machine. This means that I tend to take a reductionist, normal vs. abnormal view of human movement and walking. For example I think about what is happening when walking at each of the joints…heel strike….swing phase…and I think about how much strength is needed in legs that have to walk to a site 300m or so away from home. I have in my brain what a 'normal range of movement at a joint is'- and have been trained to recognise when something is not normal and estimate the possible implications on 'function'. A focus on the physical and function characterise my practice as a neurological physiotherapist and I assume that the physical/functional focus is also of absolute priority to the people with stroke I meet. This assumption of the priority of these aspects; the narrow glasses with magnified lens coupled with a sense of unconscious expectation that to do my job properly I need to be an expert- leads to a sense of unease….as though I a missing something…there is something outside my view…behind or beside me that naggingly is more important.

As a person I value relationships, interactions with people, caring for people and personally I recognise that I really have no idea what it is like to live with a disability such as stroke. I think I was drawn to a rehabilitation field because of its espoused commitment to patient-centred practice which is more consistent with my personal values- which also drive my academic interest in collaborative practice.

In terms of research paradigms- I am mostly comfortable to describe myself as a post-positivist but I like flirting with other paradigms- mainly interpretivist approaches.

I have just had a break for morning tea and was reflecting on why I chose the world 'flirting'. I think it is because flirting suggests pleasurable engagement without any sense of constraining commitment.  I guess I see myself as a 'mid-point' if there is such a place, or one who hedges/fence sits. I like the view from where I am. Maybe I am drawn my newly discovered pragmatist orientation as it allows me to stay with a foot in both camps- doing mixed methods as it avoids too much intellectual wrestling. To be honest a part of me does wonder if all this philosophical musings is really all that important. At the end of the day, one can't get past the basics of human thinking and interaction. Respect, listening, caring, trying to understand where someone is coming from.

Jo always talks about what something constrains or enables which is a really useful concept. I think my methodological positioning enables me to wander around a variety of perspectives, it avoids too much intellectual energy which can side track me from my desire to move forward, to make progress, to come up with workable solutions……

What does it constrain? I think at the simplest level there are two main problems with trying to have a foot in two camps. Firstly it is actually emotionally demanding, dividing ones attention, reorienting from one to the other. Moving from trying to do my systematic review and painstakingly documenting the minutiae…  to my qualitative enquiry where thinking in a different way. It is kind of like multi-tasking with kids in one ear and trying to talk to my mother on the phone. Sometimes/ often is doesn't really work that well. The second problem is that you are not really considered an expert or part of either group. Trying to do too many things and ending up doing nothing very well. Jack of all trades and master of none. Always going to be a novice or run the risk of thinking you know more than you do; or the reverse of undervaluing what you do know.

Jo asked about how I would resolve a tension in findings-This has particular relevance for the intervention development phase. My instinctive response was that qualitative data would take priority over the 'evidence' but that is a bit shallow. I chose that instinctively because I don't really trust' evidence- knowing how limited it can be. But I think that is a bit naive about qualitative data as I haven't really done a lot and I hear Felicity in my head… wondering if she is making up some of her findings…especially when there is so much interpretation. So I think the proper answer is that it is context specific. So for each issue of tension, the differences need to be resolved on a case by case basis. Recognise that there are limitations to each perspective (clinical, qualitative, quantitative etc) and that (much like the picture of the wave and the beach- what I think depends on where I sit).

So my general plan is to look carefully, consider carefully, make a call and document what has been done and why. I think that is the beauty of this process that I am wanting to provide a trail of the journey so that my findings can be followed. I have often felt like an explorer of unchartered territory; at times trail blazing with not much to show for it. Using other people's resources, pulling from here and there and resusing for my purposes. Trying to do something really really simple (e.g. provide carryover) but discovering both everything is trickier than you think, but also for most of the challenges there is someone that has done something that provides a small part of the answer.

# Appendix G: Phase 2-Information sheet for qualitative enquiry

**Participant Information Sheet**

Person Centred Research Centre
www.aut.ac.nz/pcrc

## Exploring perspectives of walking after stroke

**Main Investigator**



| | | |
|---|---|---|
| | Caroline Stretton | PhD Candidate |
| | | AUT University |
| | | Phone: 921 9999 x 7697 |
| | | Email: caroline.stretton@aut.ac.nz |
| **Other Investigators** | Dr. Suzie Mudge | Post-Doctoral Research Fellow, AUT University |
| | Dr. Nicola Kayes | Senior Lecturer, AUT University |
| | Prof Kath McPherson | Professor of Rehabilitation, AUT University |

### An invitation

You are invited to take part in a study exploring perspectives of walking following stroke. You are invited to take part because you have had a stroke

This study is being carried out by Caroline Stretton. I am based at the Person Centred Research Centre at AUT University. This study is a part of my PhD project. My PhD aims to discover how physiotherapists can better help people with stroke get out and about and walk more often.

- You can choose if you want to take part in the research. If you decide not to take part, this will not affect your rehabilitation.

- If you do take part, you can change your mind at any time and withdraw from the study. You do not have to give a reason. You can withdraw you participation and your interview data at any stage without consequences up until the end of data collection.

- This information sheet gives you information about this study. You do not have to decide now about taking part in the study. Please talk with family or whānau first if you wish.

### What is the research about?

The aim of this study is to explore the perspectives of people with stroke about walking. We know that walking difficulties are common following stroke. There are several reasons for this. Research has shown that exercises on their own can help improve walking but often there is no change to usual walking habits. This is especially true once rehabilitation has finished. We would like to understand what walking means to people after stroke. Secondly, we want to know how you think your walking could be better.

### How will this study help?

Your views and perspectives will help us understand what is most important in rehabilitation of walking following stroke.

We are also interviewing family/whānau members and physiotherapists with experience retraining walking following stroke. We will also be asking them how they think walking could be better after stroke. Taken together these insights will influence the development of a new intervention. At a later stage this new intervention will be evaluated to see if is effective at helping people with stroke get out and about and walk more often.

### How are people chosen to be part of this study?

You have been identified because you are receiving or have previously received rehabilitation from a locality who has agreed to support recruitment for this study. We want to get a range of views on this topic and so wish to speak with people from different backgrounds, different levels of physical ability, and time since the stroke.

### Who can take part?

You are able to take part in this research if you have had a stroke and :

- Are over 18 years of age

- Are able to participate in a conversation and describe your perspective

- Live in the greater Auckland area

We would also like someone from your family/whānau , or a carer to take part. We will ask you if you can nominate someone. We will arrange a separate interview with them. Alternatively if you prefer they can take part in the interview with you or you can sit in on their interview

If you do not wish to nominate family/whānau to take part, you can still take part in the study

## What happens if I decide to take part?

You and your family/whānau will be asked to take part in a face to face interview. The interview will take about an hour. I will arrange a time and place that suits you to complete the interview. This can be in your own home or at another agreed place if this is better for you

We would like to audio record the interviews to make sure we don't miss important details.

At the end of the study we will send you a summary of our findings. We will also invite you to tell us if the findings are consistent with your experiences of walking after stroke.

## What are the risks of this study?

Taking part in the study will take some of your time and require you to talk about your experiences of walking. There is no guarantee you will benefit directly from being involved nor are there any known risks.

It is possible you may find talking about your experiences difficult or you may find it helpful. If during the interview you find a question or topic distressing, you do not have to answer it. You can stop the interview at any point.

If sensitive or distressing issues do arise during the interview and you would like to discuss these with someone after the interview please let us know so we can connect you with some support.

## How will my privacy be protected?

What you say is confidential. Only the investigators will know what you say. You will not be identified in research findings. Your information will be safely stored at AUT University. Computer files will be password protected.

Your information will be stored for at least 10 years. Future use of the information will be strictly controlled and is bound by the Privacy Act. Any information used in the write up of the study will be anonymised and any information that might identify you will be removed.

## What are the costs of participating in this project?

There will not be any cost to you other than your time. You will receive a small gift card as a token of appreciation for your time

## What will happen with the findings?

The findings from this study will be used to help develop an intervention that can be used by physiotherapists in rehabilitation. In addition the findings may be used to develop training tools in the future. Findings will also be communicated to rehabilitation service providers and physiotherapy groups. They will also be presented at conferences and through publication in peer-reviewed journals.

### How do I agree to participate in this research?

You will be asked to fill out a consent form to show that you are willing to take part in this study.

### Will I be able to have a copy of the findings?

If you would like to receive a summary of the findings you can say so on the consent form and they will be sent to you at the end of the study. The findings should be available approximately 6 months after you take part.

### What do I do if I have concerns about this research?

If you want some more information please feel free to contact one of the researchers

| | | |
|---|---|---|
| Caroline Stretton | 09 921 9999 ext 7697 | caroline.stretton@aut.ac.nz |
| Dr. Suzie Mudge | 09 921 9999 ext 7096 | suzie.mudge@aut.ac.nz |

Concerns regarding the conduct of the research should be notified to the executive Secretary, AUTEC, Kate O'Connor 09 921 999 ext 8860

Approved by the Auckland University of Technology Ethics Committee on 22/10/2013
AUTEC Reference number 13/274

# Appendix H: Phase 2- Example of code book

## Codebook for EPW 29.10.14 v1

| Name | Description | Hierarchical Name | Number Of Sources Coded |
|---|---|---|---|
| Helps walking | Includes codes that are developed in response to question about what helps make walking better | Nodes\\Helps walking | 2 |
| Before I used to | Describes previous walking activities that used to have meaning | Nodes\\Helps walking\Before I used to | 3 |
| Being told helpful information | Describes information provided by a health professional that helps understand aspects of walking or the impact of the stroke on walking related activities | Nodes\\Helps walking\Being told helpful information | 2 |
| Experiencing I can do this confidence | The time when a person has a successful walking related experience, particularly powerful if long desired and uncertain of abilities | Nodes\\Helps walking\Experiencing I can do this confidence | 1 |
| Feeling good | Positive emotions during or after walking | Nodes\\Helps walking\Feeling good | 2 |
| Friends taking us out to | Describes others who use their resources ( time, car etc) to help person achieve goal getting out of the house in order to achieve something | Nodes\\Helps walking\Friends taking us out to | 1 |
| It is easier for me in here | Describes places where it is easy to do walking related activities because the way the built environment is stuctured | Nodes\\Helps walking\It is easier for me in here | 3 |
| Knowing how far or fast I can walk | Describing having the knowledge about their own walking capability which influences perception of future capabilities. I have done that so I could do that. | Nodes\\Helps walking\Knowing how far or fast I can walk | 2 |

# Appendix I: Phase 2- Example of audit trail

This excerpt is taken form the audit trail noted for the first steps of thematic analysis (Braun & Clarke, 2013)

Audit Trail of Data Analysis (as described by Braun & Clarke, 2013)

| Stage | Thematic Analysis | What done and evidence |
|---|---|---|
| 1. | Transcription | Audio recorded and transcribed, set up with page numbers<br>On I drive |
| 2. | 2a Reading and familiarisation taking note of terms of potential interest- completed for four transcripts then set aside | John √<br>Brownie√<br>K √<br>Lottie√<br>Did less dense transcripts Mary √, Jiawai √<br><br>Completed final two interviews Steve √ Maria √<br>Notes on transcripts |
| 3. | Coding-complete; across entire dataset in response to key questions<br>-systematic<br>-staying close to the data so trying to avoid interpretation<br>-coding meaningful units<br>-using participants words<br>-using memo's to park reflection<br><br>-Did two scripts first so inductive for Brownie and John<br>-Set up script so two columns, one for meaning purpose/ one for help hinder<br>Made note of descriptions of emerging codes in code book as went along | Coded in two readings, one for meaning , one for help and hinder<br>Memo used to process thinking or park thinking<br>Tried to stay close to data and answer two questions<br>   1. What does real world walking mean to this person<br>   2. What helps or hinders walking here<br><br>Occasionally thought about what are people saying silent about, what are they saying or trying to say; used memo to record what I see happening in individual data, also to park interpretation, aim stay close to the data<br><br>Compared next two transcripts and modified<br>Just coded final two less dense scripts- no adaptations necessary but not dense<br><br>Coded final two transcripts; revisited transcripts as categorising. Similar themes as from preliminary analysis so felt that any additional data collection would not provide additional new relevant information so stop data collection. Had diverse sample<br><br>Early Memos as described by Braun & Clarke |

# Appendix J: Phase 2- Example of memo

I have included two excerpts from my journal to illustrate the use of memos; the first example shows how memos were used in the early stages to aid coding and the second case to park reflections during data analysis

**Memo during initial data analysis: 26<sup>th</sup> October 2014**

What does real world walking mean?

Sometimes walking is part of going to the supermarket and this usually involves someone helping out. Other times the walking is about a more abstract goal like John's plans to do the shore to shore or just get better. I have a means to build up to a goal and a means to achieve something adn I think that they are related- I guess they are both ways to achieve a goal, one a walking abtract futrue goal, the other a daily, concrete survival goals, get food so can eat. Different types of walking achieve both, is it just future orientated vs survival- not sure here

Also there is something in all three transcripts around the issue of noticing new things as being so important to counter boredom and negative thinking. I don't have a code for that yet

What helps?

There are several related codes, largely from Brownie, doing it with a different attitude, overcome, give it a go, which seem to refer to having a fighting, do or die, non-passive approach, not giving up but overcoming. Overcoming what? Overcoming the tendency to give up, to stop fighting, to give in, to becoming helpless and hopeless really. Helping people to see themselves as not helpless and not hopeless, not as victims but as active progressing participants but then I am leaping ahead here.

It reminds me a bit of athletes, it is not about the skill although that is important but it is more about the mental game isn't it.

What hinders:

Weather, invisible things like fatigue, being stuck others worries, limitations, previous lifestyles, fear of others, lack of information, emotional problems stuff going on in your head, feeling hopeless and helpless

John talks about everyday being a battle- and maybe this is the new code. Real world walking means a battle

He is talking about managing fatigue and finding something worthwhile to do

A way to win a battle- what is the battle? to have a worthwhile life, to be normal again,

There is quite a strong them of battling in all three transcripts- Lottie talks about being pushed down (into what?), John talks about everyday being a battle, Brownie talks about overcome

There is something very important here ...

## Preparing to write my next memo for thematic analysis

So I am going to write another memo as part of my understanding of my developing themes. The issues that I want to discuss in this memo include

1. The use of metaphor- fight, active, fighting or not?
2. Related to this the symbolic value of walking. What is going on here in terms of symbols and metaphors?
3. Am I right in thinking that the progress associated with walking based on the feedback about how far and fast one has walked based on landmarks is particularly helpful because it is something that is more tangible.
4. Is it as simple as progress= hope or is there something else going on?
5. Occupational adaption is now written about extensively. Do I really find examples of this in my participants?
6. Are there examples of place attachment namely where are they talking about when they are talking about walking?
7. I am defining my theme of adaptation as this "This is this renegotiation of new bodies and interactions with changed spaces interaction with built and social environments" Is this okay?
8. How do my participants understand their body, their movement and their relationship to the environment?

Three themes

- Fighting for freedom
    - This is about a proactive stance. There is a sense that there is an opponent that is unpredictable so the outcome is not certain no matter what you do. It appears to be about controllability and perhaps 'agency' if I understand this concept right. It involves exerting effort over the situation. Perhaps it is related to the 'means' aspect of controllability
- Step by step
    - This is about the tangibility of walking providing feedback about progress that is a metaphor for life as a whole and a means of hope or despair depending on how much desired progress is perceived as satisfactory or not. It is linked to the experience of "I can do' this which appears to be a type of mastery perhaps or successful skill completion which brings confidence that is directly linked to hope. This is linked to outcomes or the ends aspect of control.
    - Gaining/opportunity hope step by step refers to the progressive nature of seeing change, the positive emotions with change in skill, the crushing frustration when there is no progress

# Appendix K: Phase 2- Example of narrative strategy

This is an excerpt from Lottie's interview. I went through the interview and took out the stories she told. This excerpt includes the story of walking at the rest home and the first walk in hospital. The story was colour coded to reflect the different themes and analysed using axial coding questions which sought to understand the context, the conditions which lead to the action, the action and interactions strategies and the consequences (Maxwell & Miller, 2008; Strauss & Corbin, 1998)

**Walking at the rest home**

Caroline: So being in a secure environment where you are feeling generally more confident. You have mentioned a lot of examples of getting out and about. You have talked about trying to build up your confidence to get on the bus, walk in the mall, do a loop around...can you maybe tell me a little bit about a usual day, how much walking you would usually do?

Lottie: Well I try to walk around, 5 or 10 minutes. There is four suites here...so it's good. They have got beautiful gardens and that is another reason you walk slow you are looking at the gardens. They have just planted some new vege gardens and there is one out there and everybody has brought in their own plants and everything and they already have so you are noticing different plants all the time and you meet the other ones...it is like meeting a neighbor up the shops....as you are going around so whoever planned this place has planned it well. And you don't have to be in each other's company all the time that was what worried me. I don't want to get too close and feel that they feel I am clinging to them because I like my own space but I like people. So and this is the old deal like I am in my room here and there is 9 other people out there in my suite and I can have morning and afternoon tea with them and I can go to other suites for exercises and when we go to the dining room, the whole four suites have their meals together at different tables, so I am not at the table with the people from here. It is marvelous the thing, so you are not in the same. And I have actually got a lady in here who has got the same surname as my sister in law so that has been a bit confusing too but it is well planned out because even the walking you know even to begin with like I walked around the building...my sisters walked me up to Royal Oak mall, so I have done that a few times and that is not a problem but to do it on me own and now I know there is a seat half way up there. I am going to go up with one of the ladies from here one day so we both know where the seat is before we cross to go to the mall. So that is all we need. And I will always have my phone on me so that if collapse or anything, someone can feel my pockets for a phone. As I say (name) street. Well my brother found the seat. He took me for a walk around to (name) street. And he found this seat there which I didn't even know was there so that has now given me the confidence to do that walk on my own because I know I will get there but I didn't know if I could walk that far and walk back without having a rest.

**Walking in hospital:**

. But even for me to get out of the bed at the hospital and be taken to the toilet that was a miracle really. Because they had to bring the pan into me to begin with. So that was the first walk in the hospital...to be taken to.. no that's right. They put me on the pan, they bought the commode to me, that's right. Then as I got stronger, I just walked across the hallway and that was a lovely walk. That was a good feeling

Caroline: Can you tell me some more about how it felt?

Lottie: Well you got hope back again, hope, you know, you knew you were sick but there was hope. Everything I did at the gym, everything that I did at that rehab just gave me hope and it was a bit like I called it like getting school cert like you had to pass this exam, you had to pass that exam, before you went home. You know before you got to be... I was in there 5 weeks, so every time I achieved something I either marked it with a kid in primers in my head or that I was at the high schools getting the school cert and all that and getting close to go home so the day that I went home was the day that I went home was the day that I passed school C! (laughter).

tstretto
The context here is that Lottie is describing a usual day, in relation to walking. She has recently moved into the rest home from her own home. She is describing her new experiences of walking around the suites in the village. the process I think is the need for variety, by noticing different plants. The conditions are being able to walk and view nice gardens, slow enough, the action is to notice and the consequences seem to be her attention is on something other than walking so she walks slow

tstretto
This part seems to be describing relatedness as walking around meant that she meets people 'like meeting neighbor up the shops' the action is that she has social connectedness and the consequences are people who she can sit with having meals together

tstretto
So this is about planning to ensure she is safe and not needing help so have coded it as autonomy. The context is talking about progressing her ability to do it on her own in future by careful planning such as taking phone, having it in her pocket by preparing for possible collapse, knowing where the seats are. The consequence is that she feels more confident and more likely to do that activity on her own.

tstretto
The context of this is the first time being able to walk to the toilet while in hospital. The conditions ws that someone helped . the action was walking across the hallway with help to toilet and the consequence as a good feeling;

tstretto
The context of the story is being in rehabilitation following stroke and having specific tasks to complete before being able to go home. The conditions that give rise is having a person to set the 'test'; the ability to achieve the tasks. The actions were doing things in rehab and the consequence was hope of recovery

## Appendix L: Phase 3a- Definitions of expected mechanisms of action

Key: K= Knowledge; P=Planning; Ma=Mastery; Mo=Motivation; HF=Habit formation; SC= Social connections

|  | Mechanism of action | Description | Rationale and Key References | Related intervention components | Supported by data? Yes= ✔ No= X |
|---|---|---|---|---|---|
| K1 | Knowledge (K1)-Knowledge of recommended activity behaviour | An awareness of the content of physical activity recommendations after stroke | The provision of relevant information about expert recommendations regarding type and amount of physical activity after stroke provides informational resources to prepare for goal setting by promoting shared focus and understanding (Cane et al., 2012). | **Family meeting:** Explanation of activity pyramid and activity recommendations **Group meeting:** Repeat of explanation and provision of activity pyramid as take home hand outs | ✔ |
| K2 | Awareness (K2)- Self-awareness about own behaviour | An awareness of current behaviour | Individualised feedback regarding current capability and self-reflection on habitual daily activities provides information that can enhance self-awareness (Cane et al., 2012; William M. M. Levack et al., 2006) | **Family meeting**: Individual feedback about assessment findings in relation to physical activity guidelines; **Everyday interview:** specific questions about usual daily activities e.g. 'tell me about your usual day' to elicit description of daily routines | x |

| | Mechanism of action | Description | Rationale and Key References | Related intervention components | Supported by data? Yes= ✓ No= X |
|---|---|---|---|---|---|
| P1 | Intention | A conscious decision to act in a certain way | Holding an intention to change behaviour such as walking more is an act of the will, which is generally considered a necessary (although not sufficient mechanism for behaviour change (Rhodes & de Bruijn, 2013). | **<u>Goal setting</u>**<br>Individuals were invited to select an area on which they wanted to focus goal setting efforts | ✓ |
| P2 | Goals Setting | A goal is a mental representations of outcomes or end states that an individual is committed to | The process of goal setting creates a discrepancy between what one wants to be like and what one is currently like and creating this discrepancy is what sets self-control in motion (Inzlicht, Legault, & Teper, 2014). Setting concrete goals  allows for better monitoring because it generates feedback about degree to which  standards are being met (Cane et al., 2012; Gollwitzer & Oettingen, 2011). | **<u>Family meeting</u>**<br>Collaborative goal setting process to select meaningful goals for the person with stroke | ✓ |

| | Mechanism of action | Description | Rationale and Key References | Related intervention components | Supported by data? Yes= ✓ No= X |
|---|---|---|---|---|---|
| P3 | Feedback on behaviour (through self-monitoring) | Monitoring and recording behaviour in response to behavioural intention | By comparing actual behaviour to desired intention/goal this provides feedback which can be used sustain attention during goal striving (Michie, Abraham, Whittington, McAteer, & Gupta, 2009). | **<u>Self-monitoring</u>** <br> Participants were provided with sheets and asked to record when they completed exercises or other goal related activity | x |
| Mo 1 | Autonomy | Human autonomy includes the combination of volition (free will) and personal relevance and is experienced as a sense of psychological freedom | Acting autonomously without feeling constrained increases self-regulatory skills (Legault & Inzlicht, 2013), leads to positive emotional experiences and enhances autonomous motivation. Environments that support autonomy offer choice, enhance interest and support intrinsic motivation. (Vansteenkiste, Williams, & Resnicow, 2012). | **<u>Autonomy-supportive environment</u>** <br> Provision of autonomy-supportive environment through conversational behaviours that encourage choice personal control, and promote shared expertise. | ✓ |

| | Mechanism of action | Description | Rationale and Key References | Related intervention components | Supported by data? Yes= ✓ No= X |
|---|---|---|---|---|---|
| Mo 2 | Internalisation of motivation | A process of personal endorsement of externally offered norms values and regulations | If basic psychological needs are satisfied then the reason for change can become internalised which enhances autonomous motivation which in turn can energises goal setting and striving (Vansteenkiste, Williams, & Resnicow, 2012). | **Autonomy-supportive environment** Provision of autonomy-supportive environment through conversational behaviours and provision of autonomy supportive materials helps to help satisfy basic psychological needs which enhances internalisation of benefits of physical activity | x |
| Ma1 | Cognitive reappraisal of capability for walking | Greater confidence and trust in capability of one's own body to meet the situational demands of walking in the real-world | Experiencing a stroke can lead to feeling unsure of physical capabilities. Through experiencing success in physical challenges, faith in one's body is restored through reappraisal of beliefs in response to successful experiences which leads to greater sense of trust and confidence in one's body and its capabilities (Clark, Whelan, Barbour, & MacIntyre, 2005). | **Home-based exercise programme** Encouragement of repeated practice, recording of success and emphasis on positive features of experience **Escorted Community Walking** Taking the PWS out on a more challenging walk can extend personally imposed limitations and create opportunities to re-evaluate walking capability in different settings **Group meeting** Encouragement of 'growth' mindset at group meeting and phone follow up **Outdoor walking group** Walking routes that were perceived as being safe were provided | ✓ |

| | Mechanism of action | Description | Rationale and Key References | Related intervention components | Supported by data? Yes= ✔ No= X |
|---|---|---|---|---|---|
| Ma2 | Greater Perceptions of safety in unfamiliar settings | Judgement made by person around how safe physical environment is for them. Often made in relation to their own capabilities. | Realist review examining how features of built environment affected reasoning showed that all relevant features (including aesthetics, connectivity, use of building) contributed to perceptions of safety that affected their decision to walk or not (Yen, Flood, Thompson, Andersen, & Wong, 2014) | **<u>Escorted community walking</u>**<br>Support to walk in outdoor settings was offered as a way to reduce anxiety and increase confidence in real world settings.<br>**<u>Barrier identification:</u>**<br>Coping planning used to identify barriers in environment and develop plan to overcome barriers as needed | ✔ |
| Ma3 | Contextual (Motivational) transfer | The practice of applying skills learnt to a different context | The process of transferring learnings across different contexts is cognitively challenging and can be adversely affected by emotions such as fear, but helped with active learning interventions that encourage exploratory learning and error encouragement.<br>(Bell & Kozlowski, 2008; Kaminski, Foley, & Kaiser, 2013). Exact mechanisms not yet clear but contextual transfer likely requires | **<u>Barrier identification</u>**<br>Development of coping plans provide strategy to overcome fearful situations<br>**<u>Group Meetings;</u>**<br>Focus on 'trial and error' approach, which encourages experimentation mind-set<br>**<u>Outdoor walking</u>**<br>Careful selection of new and pleasurable outdoor routes which are appropriately challenging to provide opportunities for walking in new situations | ✔ |

| | Mechanism of action | Description | Rationale and Key References | Related intervention components | Supported by data? Yes= ✓ No= X |
|---|---|---|---|---|---|
| | | | different neural structures (e.g. greater cerebellar input) to make sensorimotor adaptations needed in response to changeable environmental demands encountered during walking (Seidler, 2010). High levels of autonomous motivation and perceptions of autonomy support in one context (i.e. physical activity at school ) can transfer to other contexts (i.e. physical activity at home) for school students (Hagger et al., 2009; Hagger & Chatzisarantis, 2016, 2007) | | |
| HF1 | Situation specific automaticity | Describes process where the initiation of goal directed responses are automatised to pre-selected cues | A behavioural plan which links anticipated situations with specified behaviours means control of behaviour pass from conscious attention to anticipated cues (Orbell & Verplanken, 2010); having if-then plan means recognition | **If then planning** Participants asked to create If-then plan, write it out in own words, put it in visible place to act as reminder and regularly asked about attainment of plans | ✓ |

| | Mechanism of action | Description | Rationale and Key References | Related intervention components | Supported by data? Yes= ✔ No= X |
|---|---|---|---|---|---|
| | | | of cues is more accessible and salient which can overcome the limitations of limited working memory (Gollwitzer & Oettingen, 2011). | | |
| HF2 | Goal dependent automaticity | Phenomenon whereby behaviour is prompted automatically by contextual cues. Involves efficiency in both motor and cognitive processes. May require intention to engage in behaviour but once initiated activity operates very well with minimal attentional guidance | Strategies that promote repeated practice of desired behaviour will lead to new habits and routines that can be integrated into daily live and sustained without conscious effort (Bargh, Schwader, Hailey, Dyer, & Boothby, 2012; Orbell & Verplanken, 2010) | **If-then planning**<br>Selection of goals that could be integrated into regular routines<br>**Barrier identification**<br>Ongoing discussions about overcoming barriers to implementing plans<br>**Coaching calls**<br>Phone calls to support goal striving and habit formation during second month of programme | ✔ |

| | Mechanism of action | Description | Rationale and Key References | Related intervention components | Supported by data? Yes= ✔ No= X |
|---|---|---|---|---|---|
| SC1 | Trust & synergy | Sense of teamwork by two or more people based on a trusting bond and agreement to collaborate and work toward shared goals – results in impacts greater than can occur by separate individuals. Also known as therapeutic alliance or working alliance. | A sense of synergy can occur when there is a shared focus and relationship that is trusting and this leads to a sharing or insights perspectives and resources which results in new ways of viewing problems and solutions and energises action (Lasker, Weis, & Miller, 2001; Hall, Ferreira, Maher, Latimer, & Ferreira, 2010; Martin, Garske, & Davis, 2000) | **<u>Autonomy-supportive environment</u>** created using interactional strategies taken from health coaching to promote collaboration and connection | ✔ |
| SC2 | Warm caring and concern | Demonstrations of positive regard that provides a type of emotional support | Positive emotional support provided by significant others and possibly health professionals acts as a stress buffer and reduces negative physiological arousal (Thoits, 2011) | **<u>Autonomy-supportive environment</u>** Communication style employed that promoted autonomy and creative positive and supportive atmosphere | ✔ |
| SC3 | Empathetic understanding (Including acceptance of ventilation and validation of | Describes an interaction that is marked by empathy which is the ability to understand where another person is | Due to in-depth understanding situation similar others can provide validation of emotions. Having been there similar others can tolerate expressions of | **<u>Group based meeting and walking group</u>** Creating opportunities for spontaneous social interactions between peers during and after group based activities can provide opportunities for emotional support and sharing where both ventilation and validation can be experienced | ✔ |

| | Mechanism of action | Description | Rationale and Key References | Related intervention components | Supported by data? Yes= ✓ No= X |
|---|---|---|---|---|---|
| | feelings and concerns) | coming from. May also include the experience of feeling understood or validated by others, and the opportunity for emotional ventilation through the expression of pent up feelings. | emotional distress (i.e. ventilation) so are naturally empathetic which reduces physiological arousal, and provides sense of emotional support and affirmative support that boosts self-regard. (Thoits, 2011; Reynolds, 2005) | | |

| | Mechanism of action | Description | Rationale and Key References | Related intervention components | Supported by data? Yes= ✔ No= X |
|---|---|---|---|---|---|
| SC4 | Belonging mattering and self-worth | Affirmative or esteem support provides sense of belonging to a caring group of people, a sense of mattering which promotes self-regard | People with stroke can often become socially isolated and existing social networks strained.<br><br>Experiencing sense of mattering and belonging can provide forms of emotional sustenance that reduce the impact of adversity. By engaging family/whanau in goal setting meetings, the person will stroke will experience sense of belonging; and by participating in peer based groups this can be further enhanced and new social connections can established (Eisenberger & Cole, 2012; Thoits, 2011). | **Autonomy-supportive atmosphere:** Modelling positive autonomy-supportive interactions to facilitate positive social connections<br>**Family Meeting:**<br>Involvement of selected family members in goals planning meeting ( as identified by participant)<br>**Routine-based intervention**: Identification of existing social networks using eco map<br>**Group meetings**: designed in part to create sense of belonging and connection<br>**Outdoor walking group:** Selection of participants live geographically close create opportunities for future social connection; | ✔ |
| SC5 | Coping & informational support | Includes all kinds of informational assistance, such as provision of facts or information that may help a person solve problems, reappraisal | Multiple opportunities for ideas and encouragement from range of sources is likely to provide different opportunities to meet varied needs and support coping strategies (Thoits, 2011) | **Barrier Identification**<br>Development of coping plans during family meeting to help identify plans to overcome barriers<br>**Group Meetings:**<br>sharing selected stories of coping examples | ✔ |

| | Mechanism of action | Description | Rationale and Key References | Related intervention components | Supported by data? Yes= ✔ No= X |
|---|---|---|---|---|---|
| | | support, feedback about interpretation of situation | | **Outdoor group walking:** creating opportunities for discussion after walk | |
| SC6 | Instrumental assistance | Offering or supplying assistance with practical needs | Practical support works to reduce the burdens of the problematic situation decreasing the degree of perceived threat and physiological and emotional impact of the stressful aspect of the situation (Gottlieb & Bergen, 2010; Thoits, 2011) | **Family Meeting** Involvement family in goals setting meeting to identify if assistance needed **Home based Exercise Programme** Provision of equipment needed to complete exercises. | ✔ |
| SC7 | Social influence and control | Social influence and control refers to attempts by people in social network to monitor, encourage, persuade, remind, person to adhere to health behaviours | Engaging family members in meeting enhances their awareness of both recommendations and plans so can use social influence to support goal attainment.(Thoits, 2011). | **Family Meeting:** Encouraging select family member involvement in goal setting meeting | **X** |

| | Mechanism of action | Description | Rationale and Key References | Related intervention components | Supported by data? Yes= ✓ No= X |
|---|---|---|---|---|---|
| SC8 | Social comparison | The process of evaluating oneself in comparison to another | People gain normative and behavioural guidance through comparisons with others in their reference group. Can involve upward or downward comparison and lead to sense of achievement or re-evaluation of own abilities or possibly creates hope of a possible self (Thoits, 2011; Reynolds, 2005). | **Group based meeting and walking group** Provision of peer based group activities within own geographical location (education group and group based walking) to provide opportunities for social mechanisms | x |

## Appendix M: Phase 3a- End user consultation

| Group and Date | Purpose for consultation & stage of project | Key Recommendations and Discussion points | Action taken |
|---|---|---|---|
| Mātauranga Committee<br><br>2013 | Preparation for Qual Enquiry:<br><br>Meet ethical obligations under health legislation to ensure project meets "special needs of Māori" | Commended on consultation with local stakeholders<br><br>Suggested discuss project with Kaitiaki (LK) for additional Māori physio perspective<br><br>Be prepared interviews take longer and establish time to connect<br><br>Reciprocity-provide vouchers/summary findings | Interviewed Kaitiaki as recommended<br>Scheduled interviews to allow plenty of time<br>Provide vouchers and copy of results to ensure reciprocity |
| Key informant interview<br><br>2013 | Treatment theory development:<br><br>Kaitiaki/ Māori Neurological Physiotherapist with extensive experience with Māori clients | Reinforced significant difficulties related to severity for Māori stroke survivors, lack of understanding, but warmth of support<br><br>Benefits of exercise buddy and walked to letterboxes daily and then a little more, had nurse praise and give feedback fortnightly,<br><br>Benefits from group support for those lacking confidence | Included group support in intervention<br>Attempted to identify potential exercise buddies during goal setting meeting<br>Ongoing consideration of how to optimally engage whānau |

| Group and Date | Purpose for consultation & stage of project | Key Recommendations and Discussion points | Action taken |
|---|---|---|---|
| Physiotherapy academics and expert physiotherapy clinicians<br><br>2014 | Treatment theory development: Focusing scope project<br><br>Articulate mental models | Priority on <u>how</u> interventions work<br><br>Importance of carryover to neurological physiotherapy<br><br>Discussion of what carryover means | Focus on *how* intervention works as key primary component.<br>Focused literature review and concept evaluation exploring carryover completed<br>Exploration of mechanisms of change |
| Focus group and individual interviews for follow up<br><br>2014 | Maximise end user relevance<br><br>Identify features likely effect implementation | Implementation issues:<br><br>Timing of intervention in terms of readiness- at what point are they most ready?<br><br>Variability- need for variability to support motor learning<br><br>Concern about over simplifying<br><br>Resources ( able to be delivered regardless funding constraints)<br><br>How to educate students given difficulty new ideas<br><br>Cognitive impairments ( self-awareness and other cognitive impairments limiting interventions) | Issue timing discussed with Stroke Advisory Group. Clear that optimal time once discharged and when other services starting to be removed. Need take into account fatigue and adjustment process<br>Cognitive impairments significant challenge to goal setting, striving and gaining feedback. Use supported planning to account for this<br>Variability needed for cognitive stimulation and challenge. Variety of venues included in group walking<br>Resources- need to ensure sustainability of programme |

| Group and Date | Purpose for consultation & stage of project | Key Recommendations and Discussion points | Action taken |
|---|---|---|---|
| Expert physiotherapy clinicians<br><br>May 2015<br><br>Focus groups and individual interviews | Treatment theory development:<br><br>Articulate mental models | Key activities of physiotherapists include:<br><br>Observation to:<br><br>-identify problems<br><br>- Comparison to normal,<br><br>-Identify what constrains, motivation/cognition, informing, explaining, coaching, suggesting, adjusting<br><br>Problem solving with them<br>In order to enable choice and achievement of things they desire | Similar perspectives as<br><br>Enabling worth exploring as potential goal physiotherapy practice |
| Expert physiotherapy clinicians<br><br>July 2015 | Treatment theory development:<br><br>Identify features that affect implementation | Need specific target<br><br>Need provide help in breaking goals down,<br><br>Could use group sessions to work on If-then plans<br><br>Value walking buddy<br><br>Suggestions walking venues and wet weather options<br><br>Exercise leader to keep rounding people up, hoped this role would emerge from group | Make sure include specific targets in intervention<br><br>Discussion of if then plans in education group<br><br>Ensure walking buddy encouraged<br><br>Watch out and support emerging leader; look opportunities to encourage |

| Group and Date | Purpose for consultation & stage of project | Key Recommendations and Discussion points | Action taken |
|---|---|---|---|
| Advisory group: People with stroke<br><br>June 2015<br><br>Individual interviews and member checking of QE findings | Action theory development:<br><br>Identify features that affect implementation | Difficulty with sustained attention limiting him from reading a book | Included dealing with setbacks in education group |
| | | Dealing with setbacks particularly challenging. | Clarification of degree repetition needed before 'automatic' but how context specific and vulnerable to set backs |
| | | Good advice: Go for a walk, one house per day, pace yourself, give yourself some rewards | |
| | | Automaticity; started eyes on feet, 4-5 months could look around, lift stick off ground, sudden, but lost with stroke extension | |
| | | Timing- very intense once initially home | |
| | | Disruption of habits once home | |
| | | Need for rest, demands of the intervention, demands of meeting and socialising, one thing per week! | |
| Advisory group- Stroke June 2015 | Reduce respondent burden for case evaluation | Formatting on questionnaires could be improved to make easier | Reformat questionnaires |
| | | | Keep 4 of questionnaires |
| | | Most questionnaires captured important and relevant concepts | Removed 5th questionnaire as possibly superfluous |
| | | Took around 30 minutes to complete | |

| Advisory Group- Stroke June 2015 | Action theory development: Identify features that affect implementation | Agreed walking important/makes you feel good | Adapt walking group so not walking together but focus on the coffee and walk before or after |
|---|---|---|---|
| | | Confidence boosting from being with similar others, improved physicality boosted confidence, positive social input boosted, comparing self favourably to others | Include bigger and smaller routes so able tailor group walking to individual needs |
| | | Difficulty carers dealing with concerns about falling and hurting themselves. Over protectiveness can add to anxiety | Ensure explicit discussion about multi-tasking and fatigue |
| | | Love and support of others and having a plan, social aspects give a reason to go | Ensure education provided for caregivers around fatigue and other 'invisible impairments' |
| | | Coffee can be a good reason | Consider how to help family members provide autonomy-supportive environment? |
| | | Encouragement from others | |
| | | Lack knowledge for caregivers challenging | |
| | | Bit of a challenge to get balance right, | |
| | | Leaving me to it best for some | |
| | | Struggling with fatigue related to having to concentrate, look the same but not giving the usual cues | |
| | | Walking and talking can be fatiguing | |
| | | Walking with wife is fatiguing because having to concentrate on making sure she is okay | |
| | | Smaller and larger walk and meet up for coffee | |
| | | Walking can be an outlet for carers | |
| | | 3-4 wks after discharge, someone come in to summarise where at, where you are going, and what you are doing next | |

# Appendix N: Verification of consultation with the Mātauranga Māori Committee

**School of Rehabilitation and Occupation Studies**

**Verification of Māori Consultation Processes**

AUT
UNIVERSITY
TE WĀNANGA ARONUI O TĀMAKI MAKAU RAU

This document provides verification that the research project named below was discussed with the School of Rehabilitation and Occupation Studies Mātauranga Māori Committee, AUT University. Specific comments and recommendations are indicated below.

| Research Title: Walking for life following stroke: a qualitative study | | |
|---|---|---|
| **Researcher(s):** Caroline Stretton, Suzie Mudge, Nicola Kayes, Kathryn McPherson | | **Date:** 9/10/13 |
| **Discussion Areas** | **Addressed** | **Comments/ Recommendations** |
| **Whakapapa: Relationships** | | |
| Researcher experience in field | x | |
| Consultation with local stakeholders | x | C1 |
| Consenting process | | |
| Clarity of data usage | x | |
| Dissemination of findings | x | R8 |
| Benefits to participants | x | R8 |
| **Tika: Validity of the research** | | |
| Clear purpose of project | x | |
| Relevance to Māori | x | C3,4 |
| Likely outcome for participants, communities, other stakeholders | x | |
| Participant recruitment methods | x | C4,5 |
| Māori involvement in project (participants, researchers, etc) | x | C4 |
| **Manaakitanga: Responsibility and respect** | | |
| Participants' access to appropriate advice | | |
| Participants treated with dignity and respect | x | |
| Privacy and confidentiality | | |
| Whānau support | x | |
| Transparency of research process | x | |
| **Mana tangata: Power & Authority** | | |
| Reciprocity (acknowledgements, compensation, gifts) | x | R8 |
| Risks of participation identified | x | |
| Ownership of outcomes | | |
| Informed consent process | | |
| | | |

**Comments**

1. The researchers are commended for a well thought out project that has had extensive consultation already.
2. There was discussion on whether Western psychology approaches are appropriate or acceptable for Māori.
3. The importance of walking for Māori was raised. Caroline justified the focus on walking in that it is the most popular form of activity for older adults and that it is free & accessible.
4. For Māori, it should be considered that an individual's mana may be reduced if they are unable to walk. Whānau may compensate for this to provide support ("wraparound"). These factors are likely to influence of meaning and importance of walking for individuals.
5. There was some discussion of the level of impairment of participants and how well they would be able to walk. Caroline clarified that participants need to be able to ambulate but will range from those requiring an assistive device to those capable of independent walking in the community. Caroline will attempt to recruit Maori with a range vef walking abilities.
6. The patient's location (urban, rural) and their built environment may influence the meaning/importance

| |
|---|
| of walking. This may need to be taken into consideration. |
| 7. Caroline indicated that the interviews will be undertaken at a location of participant's choice. |

**Recommendations**

1. Provide a definition of "walking" as it serves different purposes, e.g. exercise, transport, recreation. Consider that the meaning of walking may be influenced by socioeconomic status. Suggest looking at the Physical Activity Questionnaire to see examples of walking-based activity/exercise.
2. Define the "real world", e.g. home, marae, community.
3. Determine if there are any previous NZ studies investigating the acceptance of similar psychological approaches to Māori.
4. May be useful to discuss the therapist's perspective with Lynda Kirkman (physiotherapist, Ngā Pou Mana, Laura Fergusson Trust Wellington).
5. Consider recruitment of patient and therapist participants through Maori Primary Health Organisations, National Hauora Coalition, Melissa Evans (OT department).
6. Check to see if Laura Fergusson Trust has ethnicity data for clients to determine if this is a suitable venue for recruiting different ethnicities.
7. It will be important to establish a relationship with Māori participants and their whānau. During interviews, it may take some time before participants are ready to discuss and talk about the questions of interest, so be prepared for interviews to take longer than expected. This should be taken into consideration when designing safety protocols.
8. There should be some form of reciprocity with participants – providing vouchers and a copy of the results of study will be useful.

Feedback on these comments and recommendations is to be provided by: 1/10/2014

Signature:                                                          Date:   15/10/13

Dr Gwyn Lewis, Representative, Mātauranga Māori Committee

# Appendix O: References for carryover review

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# Appendix P: Phase 3b-TiDieR* Worksheets for intervention components

Template for Intervention Description and Replication from Hoffmann et al. (2014)

### Intervention component: 1- Autonomy-supportive environment

| Item | Description | Location |
|------|-------------|----------|
| 1. BRIEF NAME<br>Provide name or a phrase that describes the intervention component | Autonomy-supportive environment | All locations |
| 2. WHY<br>Describe any rationale, theory of goal of the elements essential to the intervention | An autonomy-supportive environment describes a treatment atmosphere that encourages people to engage in health conducive behaviours for their own reasons, facilitates success in dealing with barriers to change and conveys feelings of acceptance and respect (Ng et al., 2012). Based on Self-Determination Theory (Deci & Flaste, 1995; Deci & Ryan, 2008b); it works to satisfy basic psychological needs by supporting autonomy, enhancing competence and fostering social connections to support development of autonomous motivation and promote sustained behavioural change | |
| 3. WHAT<br>Materials: Describe an physical or information materials used in the intervention and where materials can be accessed | Health coaching materials to support autonomy-supportive environment are contained in Appendix R,S and T | |
| 4. PROCEDURES<br>Describe each procedures, activities, and/or processes used in the intervention including any enabling or support activities | Distinctive social context facilitated by therapist or educator through interaction style, conversational behaviours, selection of learning activities and other activities designed to create contextual conditions for change. See Table 17 for examples of enabling conversational strategies. | |
| 5. WHO PROVIDED<br>For each category of intervention provider (e.g. psychologist, nursing assistant) describer their expertise, background and any specific training given | Physiotherapist trained in health coaching | |

| | | |
|---|---|---|
| **6. HOW**<br>Describe the modes of delivery and whether provided individually or in a group | Facilitation of autonomy-supportive environment during individual and group sessions | |
| **7. WHERE**<br>Describe location where intervention occurred, including necessary infrastructure or relevant features | Autonomy-supportive principles applied during home-based and group-based sessions. See section 7.2.1.2.1 on page 162. | |
| **8. WHEN and HOW MUCH**<br>Describe the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule, and their duration, intensity or dose | Primarily delivered during family meeting to support collaborative goal planning, during escorted community walking to enhance enjoyment and group-based sessions to build problem solving skills | |
| **9. TAILORING**<br>If the intervention was planned to be personalised, titrated, or adapted, then describe what, why, when and how | Personalised interactions in relation to individual goals, barriers and social context | |
| **10. MODIFICATIONS**<br>IF the intervention was modified during the course of the study, describe the changes ( what, why, when and how) | | |
| **11. HOW WELL**<br>Planned: if intervention fidelity was assessed describe how and by whom and what strategies were used to maintain or improve fidelity | Not assessed | |
| **12. HOW WELL**<br>Actual: If fidelity assessed, describe extent to which intervention was delivered as planning | Fidelity not assessed but see discussion on section 7.4.2 on page 188 | |

## Intervention component 2- Family Meeting: Involvement with family

| Item | Description | Location |
|------|-------------|----------|
| 1. BRIEF NAME<br>Provide name or a phrase that describes the intervention component | Family meeting: Involvement with family | Participant's home |
| 2. WHY<br>Describe any rationale, theory of goal of the elements essential to the intervention | Engaging family in a collaborative goal setting meeting is likely to have several advantages such as providing greater perceptions of emotional support, additional insights into practical and social context and help create sense of synergy so that family members can add support to the process of behaviour change | |
| 3. WHAT<br>Materials: Describe an physical or information materials used in the intervention and where materials can be accessed | Provision of information: about physical activity recommendations ( as shown in Appendix Q), individualised feedback regarding number daily steps and physical performance capability to inform discussion | |
| 4. PROCEDURES<br>Describe each procedures, activities, and/or processes used in the intervention including any enabling or support activities | Participant asked to identify key family members to be invited to meeting<br>Meeting scheduled at place selected by participant ( usually their own home) and at time that all family members can make<br>Collaborative interactions modelled to family to keep needs of participant central to process<br>Family encouraged to be actively involved | |
| 5. WHO PROVIDED<br>For each category of intervention provider (e.g. psychologist, nursing assistant) describer their expertise, background and any specific training given | Organised by research physiotherapist | |
| 6. HOW<br>Describe the modes of delivery and whether provided individually or in a group | Delivered to family as a whole | |
| 7. WHERE<br>Describe location where intervention occurred, including | Location chosen by participant and in all cases was in own home | |

| | | |
|---|---|---|
| necessary infrastructure or relevant features | | |
| 8.   WHEN and HOW MUCH<br><br>Describe the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule, and their duration, intensity or dose | One meeting per participant at the start of the intervention. Three out of the five participants selected an evening so that family member who worked could attend. | |
| 9.   TAILORING<br><br>If the intervention was planned to be personalised, titrated, or adapted, then describe what, why, when and how | Personalised to meet needs of participant and family. Invited family members included spouses, children, aunties, and grandchildren | |
| 10. MODIFICATIONS<br><br>IF the intervention was modified during the course of the study, describe the changes ( what, why, when and how) | | |
| 11. HOW WELL<br><br>Planned: if intervention fidelity was assessed describe how and by whom and what strategies were used to maintain or improve fidelity | | |
| 12. HOW WELL<br><br>Actual: If fidelity assessed, describe extent to which intervention was delivered as planning | All participants completed a family meeting and field data collected | |

## Intervention component 3-Family Meeting: Interview about everyday routines

| Item | Description | Location |
|---|---|---|
| 1. BRIEF NAME<br>Provide name or a phrase that describes the intervention component | Interview about everyday routines | Participant's home |
| 2. WHY<br>Describe any rationale, theory of goal of the elements essential to the intervention | Understanding the practical and social way that people organise their days can help identify key moments in the day where new behaviours can be implemented. Linking these new behaviours with a contextual cue due to location or time of day, or emotional feeling; means  the rehearsed behaviour is more salient and accessible and more likely to effectively cue or prompt the desired behaviours. | |
| 3. WHAT<br>Materials: Describe an physical or information materials used in the intervention and where materials can be accessed | Daily schedule with slots for each hour (empty), pen and paper | |
| 4. PROCEDURES<br>Describe each procedures, activities, and/or processes used in the intervention including any enabling or support activities | Open ended question as part of semi-structured interview; "*tell me about your usual day*"?<br>Completion of a hand-drawn eco map where person lists their social connections and the degree of support provided which provides guidance about broader social context in which they live their lives. See sample eco map below | |
| 5. WHO PROVIDED<br>For each category of intervention provider (e.g. psychologist, nursing assistant) describer their expertise, background and any specific training given | Research physiotherapist | |
| 6. HOW<br>Describe the modes of delivery and whether provided individually or in a group | Delivered as part of family-based meeting | |
| 7. WHERE<br>Describe location where intervention occurred, including | At participants own home with family members he/she has asked personally to participate | |

| | | |
|---|---|---|
| necessary infrastructure or relevant features | | |
| 8.   WHEN and HOW MUCH<br><br>Describe the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule, and their duration, intensity or dose | Once | |
| 9.   TAILORING<br><br>If the intervention was planned to be personalised, titrated, or adapted, then describe what, why, when and how | Personalised according to needs of participant and family | |
| 10. MODIFICATIONS<br><br>IF the intervention was modified during the course of the study, describe the changes ( what, why, when and how) | | |
| 11. HOW WELL<br><br>Planned: if intervention fidelity was assessed describe how and by whom and what strategies were used to maintain or improve fidelity | | |
| 12. HOW WELL<br><br>Actual: If fidelity assessed, describe extent to which intervention was delivered as planning | Record kept of daily routine and ecomaps | |
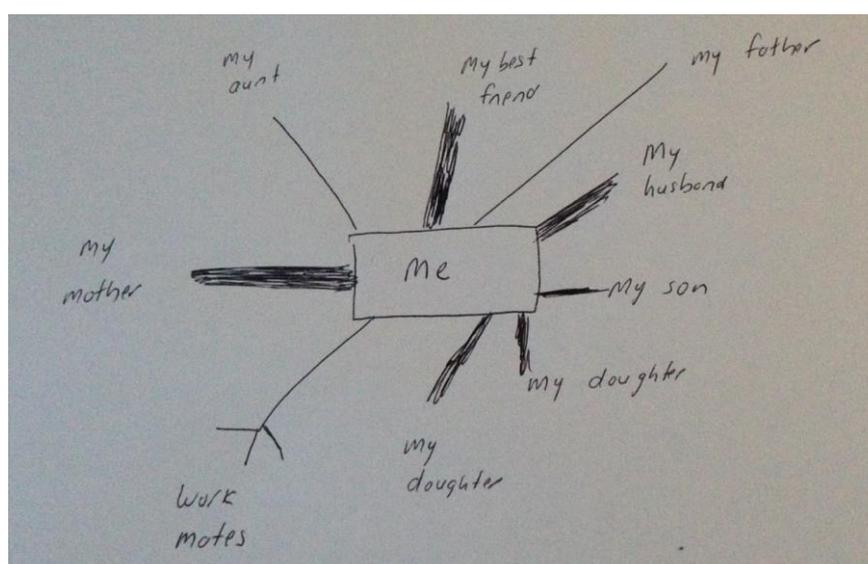


Figure 34. Sample of ecomap

## Intervention component 4 - Family Meeting: If-then planning

| Item | Description | Location |
|---|---|---|
| 1. BRIEF NAME<br>Provide name or a phrase that describes the intervention component | Goal setting and barrier identification with if-then planning | |
| 2. WHY<br>Describe any rationale, theory of goal of the elements essential to the intervention | Setting concrete specific goals supports goal monitoring because it generates feedback about degree to which standards are being met (Cane et al., 2012; Gollwitzer & Oettingen, 2011). Goals that are personally meaningful are monitored more urgently (Legault & Inzlicht, 2013), and potentially achievable goals are likely to energise expectations of positive outcomes which increases confidence and motivation to support goal attainment.<br><br>A behavioural plan which links anticipated situations with specified behaviours means control of behaviour passes from conscious attention to anticipated cues (Orbell & Verplanken, 2010). Having if-then plan promotes more accessible recognition of cues and salient overcomes help overcome the limitations of limited working memory (Gollwitzer & Oettingen, 2011). Such a plan may be particularly helpful for people with cognitive loss and reduced executive functioning (Allan, Sniehotta, & Johnston, 2013) | |
| 3. WHAT<br>Materials: Describe an physical or information materials used in the intervention and where materials can be accessed | Information provided about physical activity recommendations provided basis for discussion and goal planning (see Appendix Q) | |
| 4. PROCEDURES<br>Describe each procedures, activities, and/or processes used in the intervention including any enabling or support activities | Collaborative goal planning occurred in family meeting, following the interview about daily routines.<br><br>Once explanations were given, the person was encouraged to brainstorm areas where they wished to improve their health and wellbeing (see worksheet in Appendix S). Participants asked to select an area to focus on and given support to develop If-then statements that they wrote down in their own writing. | |

| | Barrier identification was then used to identify potential barriers to goal striving using the questions: What might get in the way of you doing these things? What could you say to yourself that would give you the most chance of success?" Further if-then plans were developed in response | |
|---|---|---|
| 5. WHO PROVIDED<br><br>For each category of intervention provider (e.g. psychologist, nursing assistant) describer their expertise, background and any specific training given | Research physiotherapist | |
| 6. HOW<br>Describe the modes of delivery and whether provided individually or in a group | As part of family meeting with participant and research physiotherapist | |
| 7. WHERE<br>Describe location where intervention occurred, including necessary infrastructure or relevant features | In participants own home | |
| 8. WHEN and HOW MUCH<br>Describe the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule, and their duration, intensity or dose | Once at the start of the programme during family meeting, but revisited regularly and participant encouraged to use problem solving strategies in other areas of their life as needed | |
| 9. TAILORING<br>If the intervention was planned to be personalised, titrated, or adapted, then describe what, why, when and how | Specifics of If-then plan varied according to needs and desires of participant | |
| 10. MODIFICATIONS<br>IF the intervention was modified during the course of the study, describe the changes ( what, why, when and how) | | |
| 11. HOW WELL<br>Planned: if intervention fidelity was assessed describe how and by whom and what strategies were used to maintain or improve fidelity | | |
| 12. HOW WELL<br>Actual: If fidelity assessed, describe extent to which | If then plans written out, put in public place and reviewed during coaching calls during second month of the intervention | |

| | | |
|---|---|---|
| intervention was delivered as planning | | |

## Intervention component 5- Self-monitoring

| Item | Description | Location |
|---|---|---|
| 1. BRIEF NAME<br>Provide name or a phrase that describes the intervention component | Self-monitoring | Participants home |
| 2. WHY<br>Describe any rationale, theory of goal of the elements essential to the intervention | Recording in an exercise diary is postulated to provide a way of self-monitoring behaviour and providing feedback that can support goal striving because it shows progress toward attainment | |
| 3. WHAT<br>Materials: Describe an physical or information materials used in the intervention and where materials can be accessed | Paper based exercise record and habit change diary ( see Appendix T) with space for day, date, amount exercise completed, walks completed and whether If-then plan implemented | |
| 4. PROCEDURES<br>Describe each procedures, activities, and/or processes used in the intervention including any enabling or support activities | Demonstrated use of daily record and checked record at each visit; asked if it could be placed in prominent place; asked about record at coaching sessions. | |
| 5. WHO PROVIDED<br>For each category of intervention provider (e.g. psychologist, nursing assistant) describer their expertise, background and any specific training given | Research physiotherapist | |
| 6. HOW<br>Describe the modes of delivery and whether provided individually or in a group | Discussed exercise recording during home visit | |
| 7. WHERE<br>Describe location where intervention occurred, including necessary infrastructure or relevant features | In own home | |
| 8. WHEN and HOW MUCH<br>Describe the number of times the intervention was delivered and over what period of time including the number of sessions, | Participant encouraged to complete form daily | |

| | | |
|---|---|---|
| their schedule, and their duration, intensity or dose | | |
| 9.   TAILORING<br><br>If the intervention was planned to be personalised, titrated, or adapted, then describe what, why, when and how | Participant encouraged to fill it in in own writing | |
| 10. MODIFICATIONS<br><br>IF the intervention was modified during the course of the study, describe the changes ( what, why, when and how) | | |
| 11. HOW WELL<br><br>Planned: if intervention fidelity was assessed describe how and by whom and what strategies were used to maintain or improve fidelity | | |
| 12. HOW WELL<br><br>Actual: If fidelity assessed, describe extent to which intervention was delivered as planning | Poor adherence to this behaviour over time and this was unrelated to success of intervention as a whole; particularly difficult for behaviour being automatized; practical difficulties finding paper, finding pen, wife tidied away; weakness in arm recording; programme differed for all participants | |

## Intervention component 6- Home-based exercise programme

| Item | Description | Location |
|---|---|---|
| 1.  BRIEF NAME<br>Provide name or a phrase that describes the intervention component | Home-based exercise programme | Participants home and local environs |
| 2.  WHY<br>Describe any rationale, theory of goal of the elements essential to the intervention | People with stroke are deconditioned physically as a result of physically inactive lifestyle. Gradually increasing exercise challenge produces physiological overload which produces adaptive biological changes that can improve walking capability. Improved walking capability could potentially increase perceptions of competence  for real world walking | |
| 3.  WHAT<br>Materials: Describe an physical or information materials used in the intervention and where materials can be accessed | WEBB programme was planned to be provided; used successfully as home based programme for people with stroke ( see http://www.webb.org.au/)<br>In practice existing programmes tailored to optimise overload or address specific needs instead.<br>During group education principle progressive overload taught 'just right challenge' | |
| 4.  PROCEDURES<br>Describe each procedures, activities, and/or processes used in the intervention including any enabling or support activities | Emerging from goal setting meetings and ongoing conversations; existing programmes extended or progressed, self-monitoring encouraged through daily exercise record | |
| 5.  WHO PROVIDED<br>For each category of intervention provider (e.g. psychologist, nursing assistant) describer their expertise, background and any specific training given | Physiotherapist | |
| 6.  HOW<br>Describe the modes of delivery and whether provided individually or in a group | Individually tailored exercise programme built on existing exercise practices or previously provided programmes | |
| 7.  WHERE<br>Describe location where intervention occurred, including necessary infrastructure or relevant features | At home setting, inside or outside | |

| | | |
|---|---|---|
| 8.   WHEN and HOW MUCH<br><br>Describe the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule, and their duration, intensity or dose | 3 x week; aiming for between 10 and 30 reps; in 2-3 sets as able to provide progressive overload | |
| 9.   TAILORING<br><br>If the intervention was planned to be personalised, titrated, or adapted, then describe what, why, when and how | Personalised by adapting and extending existing home based exercise programmes to reduce cognitive burden of learning new exercises.<br><br>Individualised support to encourage self-monitoring via exercise diary | |
| 10. MODIFICATIONS<br><br>IF the intervention was modified during the course of the study, describe the changes ( what, why, when and how) | Not given WEBB as all participants already had own programme they were familiar with. Decided to adapt existing programmes.<br><br>Cognitive-motor interference exercises also planned but not delivered as this not a problem for any of the participants | |
| 11. HOW WELL<br><br>Planned: if intervention fidelity was assessed describe how and by whom and what strategies were used to maintain or improve fidelity | | |
| 12. HOW WELL<br><br>Actual: If fidelity assessed, describe extent to which intervention was delivered as planning | | |

**Intervention Component 7- Escorted community walking**

| Item | Description | Location |
|---|---|---|
| 1. BRIEF NAME<br>Provide name or a phrase that describes the intervention component | Escorted community walking | Outdoor locations |
| 2. WHY<br>Describe any rationale, theory of goal of the elements essential to the intervention | Loss of confidence major barrier to getting out to desired locations. Escorted community walking refers to real world walking practice that occurs in desired community settings such as catching buses, walking in shopping malls etc. Limited explicit discussion of rationale in literature but it is believed that support of a therapist can help overcome anxiety related to loss of confidence. Most plausible explanation comes from stress buffering hypothesis which proposes that social support can provided emotional support that can reduced physiological arousal and anxiety and provide a type of coping strategy so that walking skill mastery can develop. | |
| 3. WHAT<br>Materials: Describe an physical or information materials used in the intervention and where materials can be accessed | The availability and emotional support of a physiotherapist | |
| 4. PROCEDURES<br>Describe each procedures, activities, and/or processes used in the intervention including any enabling or support activities | During goal setting meetings, potential venues for escorted community walking were flagged. Venues included: an accessible walking route 'around the block', any potential visit to a friend or family member, or any other desired venue. During escorted walking the physiotherapist provided encouragement to extend distance, opportunities to develop walking skill and suggested other new venues of interest that might promote physical integration or social integration or create opportunities to master walking skills | |
| 5. WHO PROVIDED<br>For each category of intervention provider (e.g. psychologist, nursing assistant) describer their expertise, background and any specific training given | Physiotherapist with experience in stroke rehabilitation who has participated in collaborative goal setting with recipient | |
| 6. HOW | Provided individually one on one during home based escorted walking sessions; | |

| | | |
|---|---|---|
| Describe the modes of delivery and whether provided individually or in a group | and indirectly through group based walking group | |
| 7. WHERE<br>Describe location where intervention occurred, including necessary infrastructure or relevant features | Outdoor walking routes close to participants home | |
| 8. WHEN and HOW MUCH<br>Describe the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule, and their duration, intensity or dose | Between 20- 60 minutes; during first month of the programme in weeks 2,3,4; as part of home visits | |
| 9. TAILORING<br>If the intervention was planned to be personalised, titrated, or adapted, then describe what, why, when and how | Location depended on desire of participant, drove to walking route for one participant, suggested additional routes based on needs; tried to extend existing routes if possible to provide additional challenge and create opportunities for mastery | |
| 10. MODIFICATIONS<br>IF the intervention was modified during the course of the study, describe the changes ( what, why, when and how) | Offer provided but not taken up if no desirable venue or need apparent | |
| 11. HOW WELL<br>Planned: if intervention fidelity was assessed describe how and by whom and what strategies were used to maintain or improve fidelity | N/A | |
| 12. HOW WELL<br>Actual: If fidelity assessed, describe extent to which intervention was delivered as planning | Less sessions delivered that planned. Relatively low uptake with most participants having 1-2 sessions only | |

## Intervention Component 8- Group Education sessions

| Item | Description | Location |
|---|---|---|
| 1. BRIEF NAME<br>Provide name or a phrase that describes | Group Education session | |

| | | |
|---|---|---|
| the intervention component | | |
| 2. WHY<br><br>Describe any rationale, theory of goal of the elements essential to the intervention | During the first month participants met weekly as a group. Purpose of the group was to develop positive attitudes toward physical activity, develop planning and problem solving skills and to develop sense of cohesion as a group. | |
| 3. WHAT<br><br>Materials: Describe an physical or information materials used in the intervention and where materials can be accessed | Health coaching resources Appendix Q , R, S and T were provided as resources from Health Change Australia: http://www.healthchange.com/resource_optinal_tools_for_clients and five ways to wellbeing from https://www.mentalhealth.org.nz | |
| 4. PROCEDURES<br><br>Describe each procedures, activities, and/or processes used in the intervention including any enabling or support activities | Learning outcomes for the three sessions were:<br>Benefits of walking<br>1. Explain the benefits of physical activity<br>2. Describe the use of If-then plan and self-monitoring<br>3. Make a social connection with at least one other person in the group<br>Motivating self to keep on going<br>1. Explain different type of motivation<br>2. identify some new strategies to help motivate themselves to keep active<br>3. Explain progressive overload and apply it to walking<br>Ways to wellbeing<br>1. Describe the 5 ways to wellbeing<br>2. Reflect on current involvement with some of the ways of wellbeing<br>3. identify new possibilities to enhance personal wellbeing<br>A range of adult learning strategies were used including brainstorming, story crafting from phase 2 data to support points, reflective activities, sharing experiences and other interactive strategies<br>Simple refreshments were provided | |
| 5. WHO PROVIDED<br><br>For each category of intervention provider (e.g. psychologist, nursing assistant) describer their expertise, background and any specific training given | Research physiotherapist with experience in adult learning | |

| | | |
|---|---|---|
| **6. HOW**<br>Describe the modes of delivery and whether provided individually or in a group | Group based session | |
| **7. WHERE**<br>Describe location where intervention occurred, including necessary infrastructure or relevant features | At local community facility | |
| **8. WHEN and HOW MUCH**<br>Describe the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule, and their duration, intensity or dose | Initially planned for 4 sessions, but needed to cancel one due to lack of attendance so delivered 3 sessions only | |
| **9. TAILORING**<br>If the intervention was planned to be personalised, titrated, or adapted, then describe what, why, when and how | Some tailoring of content to reflect individual needs ( e.g. selection of relevant stories) | |
| **10. MODIFICATIONS**<br>IF the intervention was modified during the course of the study, describe the changes ( what, why, when and how) | Four session intended but only three delivered<br>Venue changed to local community hall to assist access for participants after first session | |
| **11. HOW WELL**<br>Planned: if intervention fidelity was assessed describe how and by whom and what strategies were used to maintain or improve fidelity | | |

| | | |
|---|---|---|
| 12. HOW WELL<br><br>Actual: If fidelity assessed, describe extent to which intervention was delivered as planning | | |

**Intervention Component 9- Weekly coaching phone calls**

| Item | Description | Location |
|---|---|---|
| 1.  BRIEF NAME<br>Provide name or a phrase that describes the intervention component | Weekly coaching phone calls | |
| 2.  WHY<br>Describe any rationale, theory of goal of the elements essential to the intervention | Coaching phone calls have been shown to be able to provide support for behaviour change. Used to support with goal striving and help problem solve any barriers to achieving goals | |
| 3.  WHAT<br>Materials: Describe an physical or information materials used in the intervention and where materials can be accessed | Phone | |
| 4.  PROCEDURES<br>Describe each procedures, activities, and/or processes used in the intervention including any enabling or support activities | Phoned participant at predetermined time each week during month 2 | |
| 5.  WHO PROVIDED<br>For each category of intervention provider (e.g. psychologist, nursing assistant) describer their expertise, background and any specific training given | Research physiotherapist with training in health coaching | |
| 6.  HOW<br>Describe the modes of delivery and whether provided individually or in a group | Provided individually | |
| 7.  WHERE<br>Describe location where intervention occurred, including necessary infrastructure or relevant features | Over phone in participants own home | |
| 8.  WHEN and HOW MUCH<br>Describe the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule, and their duration, intensity or dose | 2-3x, in second month of intervention | |

| | | |
|---|---|---|
| 9. TAILORING<br><br>If the intervention was planned to be personalised, titrated, or adapted, then describe what, why, when and how | Personalised according to individual's goals | |
| 10. MODIFICATIONS<br><br>IF the intervention was modified during the course of the study, describe the changes ( what, why, when and how) | | |
| 11. HOW WELL<br><br>Planned: if intervention fidelity was assessed describe how and by whom and what strategies were used to maintain or improve fidelity | Records taken of sessions; relatively short and limited social interaction by participants. No new goals identified | |
| 12. HOW WELL<br><br>Actual: If fidelity assessed, describe extent to which intervention was delivered as planning | | |

**Intervention Component 10- Outdoor Walking Group**

| Item | Description | Location |
|---|---|---|
| 1. BRIEF NAME<br>Provide name or a phrase that describes the intervention component | Outdoor Walking Group | |
| 2. WHY<br>Describe any rationale, theory of goal of the elements essential to the intervention | Walking in a group with other stroke survivors in attractive natural settings around a pre-selected course has potential to increase positive emotion through task mastery and context specific practice; enhance social connections and sense of belonging by providing opportunities for emotional support and ventilating negative emotions with other stroke survivors, gaining information help coping. It may also help to manage negative emotions due to the restorative qualities of natural settings | |
| 3. WHAT<br>Materials: Describe an physical or information materials used in the intervention and where materials can be accessed | Local outdoor park setting with pre-specified course 800- 1200m ( measured about ahead of time with a measuring wheel) | |
| 4. PROCEDURES<br>Describe each procedures, activities, and/or processes used in the intervention including any enabling or support activities | Screening for safety prior to start. Risk assessment process undertaken. See Figure 21<br>Once weekly meeting at central location in one of four pre-specified settings. Supported by at least one physiotherapist and able family members. Followed by time sitting and talking | |
| 5. WHO PROVIDED<br>For each category of intervention provider (e.g. psychologist, nursing assistant) describer their expertise, background and any specific training given | Walking for wellbeing study participants and others who have expressed interest during screening process. All participants screened for falls history and medical risk using PAR-Q. See Figure 21 | |
| 6. HOW<br>Describe the modes of delivery and whether provided individually or in a group | Two walking routes provided at each location to allow tailoring to individual level. Information provided ahead of time. Routes chosen for safety, suitability, accessibility. Two routes to allow tailoring to individual needs; e.g. Long loop ( around 1200m) and short loop around (800m); | |

| 7.   WHERE<br>Describe location where intervention occurred, including necessary infrastructure or relevant features | Public setting in local park, maintained grounds, with flat terrain, parking, café or place to sit and talk, disabled toilets | |
|---|---|---|
| 8.   WHEN and HOW MUCH<br>Describe the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule, and their duration, intensity or dose | Once week on Wednesday mornings at 10am, for 4 weeks at 4 venues. Walk for around 20-30 minutes at self-selected intensity.  3 x outdoor venues (parks) and 1x indoor setting (Large Indoor Hardware store) for rainy day option. | |
| 9.   TAILORING<br>If the intervention was planned to be personalised, titrated, or adapted, then describe what, why, when and how | Two marked routes recommended of different lengths to adapt to individual needs. Encouraged walk at own pace | |
| 10. MODIFICATIONS<br>IF the intervention was modified during the course of the study, describe the changes ( what, why, when and how) | Group continued independently after programme finished for several months. Additional friends attended at invitation of participants from the local Stroke Club- not screened after intervention phase | |
| 11. HOW WELL<br>Planned: if intervention fidelity was assessed describe how and by whom and what strategies were used to maintain or improve fidelity | Toward the end of the intervention participants tended to do same route so added additional challenge for more disabled participants | |
| 12. HOW WELL<br>Actual: If fidelity assessed, describe extent to which intervention was delivered as planning | Largely delivered as planned. Variable support from family members | |

**Appendix Q: Phase 3b-Health Change Australia resource- The Activity Pyramid**

Taken from Health Change Australia:   http://www.healthchange.com/resource_optinal_tools_for_clients

# THE ACTIVITY PYRAMID

**Cut down on**

TV
SITTING FOR
LONG PERIODS

**Sporadic**
(weekly or monthly)

DAY OF SPORT
(eg golf)

LARGE SOCIAL EVENTS
PLAY WITH CHILDREN / GRANDKIDS

**2 - 5 times / week**

STRENGTH TRAINING
DANCING
GARDENING
GENTLE EXERCISE GROUP        BOWLING
YOGA CLASS                VACUUMING

**Daily / Most days**
(30 minutes)

WALK
SWIM
YOGA           CHAIR EXERCISES
WALK THE DOG
SHOPPING
CYCLING

**Incidental**

TAKE EXTRA STEPS IN YOUR DAY          PARK YOUR CAR FURTHER AWAY
HELP WITH HOUSEHOLD CHORES / COOKING    TAKE STAIRS INSTEAD
TAKE A WALK IN A SHOPPING CENTRE       WALK TO STORE OR MAILBOX
                                       WORK IN GARDEN

## Appendix R: Phase 3b-Health Change Australia resource- Agenda setting worksheet

Taken from Health Change Australia:   http://www.healthchange.com/resource_optinal_tools_for_clients

**What can you do to be healthier?**

## Appendix S: Phase 3b-Daily record of habit change

Taken from Health Change Australia:   http://www.healthchange.com/resource_optinal_tools_for_clients

## My Habit Change Diary

Date: _____

| Week | Positive Actions | Mon | Tue | Wed | Thur | Fri | Sat | Sun | Total days Actions Taken | Comments |
|------|-----------------|-----|-----|-----|------|-----|-----|-----|--------------------------|----------|
| 1 | | | | | | | | | | |
| 2 | | | | | | | | | | |
| 3 | | | | | | | | | | |
| 4 | | | | | | | | | | |
| 5 | | | | | | | | | | |
| 6 | | | | | | | | | | |

Track the actions that will move you closer to achieving your health aims. For example, tick the days when you meet a chocolate minimisation goal (say, 4 squares of chocolate only per day), or tick your alcohol free days. Alternatively, tick the days that you do something positive for your health, such as being physically active. Aim to increase the number of ticks that you give yourself over time. But, *don't* record the times when you don't do so well. If you do, you will only focus on your perceived failures, not your successes. Total up your achievements and make comments in the last two columns. Don't stress if you don't get many ticks in the first few weeks. Habits take time to change! With persistence, you can watch your daily actions turn into healthy habits over time.

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Behaviour Change Methodology

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## Appendix T: Phase 3b-Health Change Australia resources to promote growth mind-set

Taken from Health Change Australia:  http://www.healthchange.com/resource_optinal_tools_for_clients

**One Step at a Time, Adding up over Time**



HealthChange® One Step at a Time, Adding up over Time
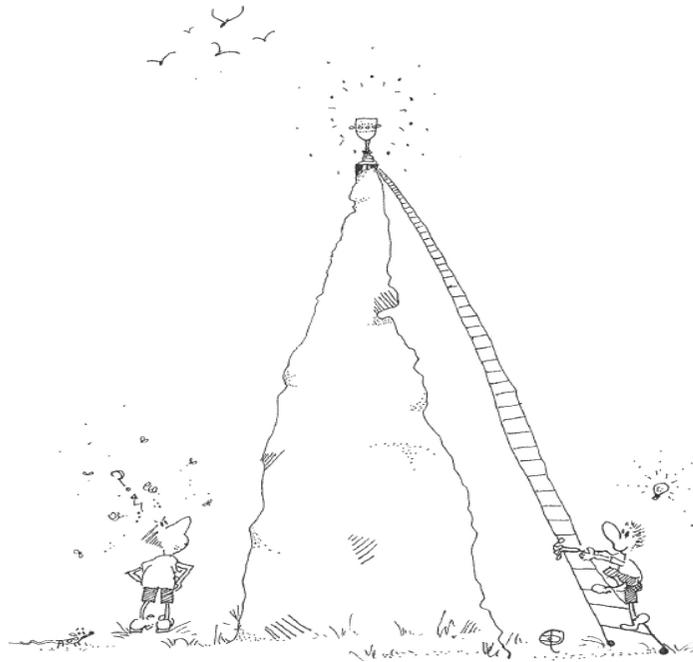
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## Trial and Error approach

| Instead of... | Try thinking |
|---|---|
| I am not good at this | What am I missing? |
| I give up | I'll use some of the strategies we've talked about |
| This is too hard | This may take some time and effort |
| I can't make this any better | I can always keep trying to improve |
| I just can't do _____ | I am going to train my brain and body to do ___ |
| I made a mistake | Mistakes help me to learn better |

# HealthChange® Trial and Error
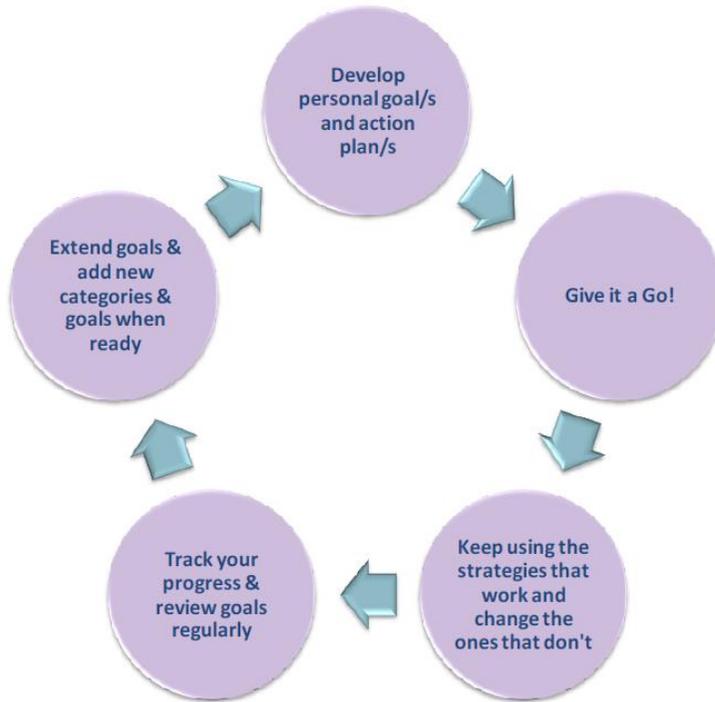
**Appendix U: Phase 3b-Research protocol for *Walking for Wellbeing after Stroke* Evaluation**

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HEALTH AND REHABILITATION RESEARCH INSTITUTE

# Walking for Wellbeing after Stroke: Research Protocol

Version 2, August 2015

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## Contents

# Walking for Wellbeing after Stroke

## 1. List of amendments

| Protocol Number | Amendment dates | Changes by | Summary of changes |
|---|---|---|---|
| Version 2 | August | Caroline | 4 assessment points not 5 6 people included |
| | | | |

## 2. The research team

Caroline Stretton (PhD candidate)
Suzie Mudge (Primary supervisor)
Nicola Kayes (Supervisor)
Kath McPherson (Supervisor)

## 3. Advisory group

Three groups of end users are involved in advising this project.

Group One: People with stroke (n = 4) and Family Members (n=2)
Group Two: Expert Physiotherapy clinicians from Laura Fergusson Trust (n=3)
Group Three: Academics in Rehabilitation from the Health and Rehabilitation Research Institute (HRRI) at AUT University

## 4. Overview of project

### 4.1 Background

Problems with walking are a common area of difficulty following stroke and lead to difficulty walking confidently and effectively outdoors (Barnsley, McCluskey, & Middleton, 2012). For example, surveys of long term survivors of stroke identify that problems with mobility remain their single largest unmet need (McKevitt et al., 2011) and 75% of people living with stroke describe it as important or essential to be able to 'get out and about' (Lord, McPherson, McNaughton, Rochester, & Weatherall, 2004). A systematic review completed as the first phase of this project (Stretton, Mudge, Kayes, & McPherson, 2014) demonstrated that improvements in real world walking after stroke were possible but that certain types of interventions were more effective than others. For example interventions that included behaviour change techniques from health psychology were more effective than exercise alone. The second phase which involved qualitative interviews of stroke survivors showed that walking in the real world enabled people with stroke to meet psychological needs for wellbeing by providing an opportunity for freedom from forced dependence and a sense of hope for future recovery. Providing interventions that improve the ability to walk in the real world and sustain this ability would address physical as well as psychological needs for stroke survivors.

The term 'real world walking' describes actual walking that occurs in usual settings such as in the home as well as walking in the community (World Health Organisation, 2002). Usual settings in the community that are essential to people with stroke include shopping venues and other public venues (Lord et al., 2004). However clinical audits from New Zealand, Australia and the USA reveal little clinical time is devoted to improving community walking and the vast majority of people (93%) are discharged from rehabilitation with inadequate walking speed and endurance to access these essential community settings (Hill, Ellis, Bernhardt, Maggs, & Hull, 1996; Latham et al., 2005; McNaughton, DeJong, Smout, Melvin, & Brandstater, 2005).

The reasons for this inadequate ability stem from the direct effects of the stroke as well as the deleterious effects of a lifestyle of physical inactivity, both common following stroke (Billinger, Coughenour, Mackay-Lyons, & Ivey, 2012). Regular structured exercise can provide physical gains and lead to improvements in the ability to walk further and faster when measured in the clinical setting but there is minimal knowledge of how to translate these improvements into a change in walking habits that would lead to a more physically active lifestyle for people with stroke (Ada, Dean, & Lindley, 2013; English & Hillier, 2010; Mudge, Barber, & Stott, 2009). This translation is necessary before any potential health benefits from activity can be realised.

Studies which examine the actual number of steps taken per day by people with stroke reveal that they are they are one of the most inactive of all clinical populations (Rand, Eng, Tang, Jeng, & Hung, 2009; Roos, Rudolph, & Reisman, 2012; Tudor-Locke et al., 2011). Walking more often has been described as providing the optimal preventative medicine (Tudor-Locke, 2012) to counter the significant functional and health risks of physical inactivity but there are a number of barriers for people with stroke. Behaviour change techniques that encourage active involvement in changing walking behaviour have been shown to be effective in people without health conditions (Bird et al., 2013). However there are at least 40 different behaviour change techniques that have been used in the literature to assist with changing physical activity (Michie, Ashford, et al., 2011) and few have been evaluated for use for people with stroke. The use of social support has also been mentioned repeatedly in qualitative reports of stroke survivors as providing an important facilitator to recovery following stroke (e.g. Reed, Wood, Harrington, & Paterson, 2012). Therefore my intention is to draw on these findings to help people with stroke walk more often and to develop a clinical intervention that is easily incorporated into current physiotherapy practice.

## 4.2 Development process

The *Walking for Wellbeing after Stroke* intervention has been developed through a systematic multiphase process informed by the guidelines published by the Medical Research Council (MRC) in the UK on the development of complex interventions (Campbell et al., 2000) and the evaluation of such interventions (Moore et al., 2015).

During 2013-2015 the following steps were completed in line with the MRC recommendations (Medical Research Council, 2006). These steps include the completion of a systematic review (Phase 1), a qualitative enquiry of perspectives of people with stroke (Phase 2), and a realist synthesis (Phase 3) (Pawson & Tilley, 1997; Rycroft-Malone et al., 2012). The purpose of the realist synthesis is to synthesise the findings on the first two phases and other relevant published literature to develop a programme theory. A programme theory for the intervention is a working model of how the components of an intervention aim to address the problem and links the components with the mechanisms of change. The relationship between the MRC framework and the project as a whole is outlined below in Figure One.

Figure One: Overview of Research Structure for Project

| MRC Framework | Development Phase | | | Feasibility/Pilot |
|---|---|---|---|---|
| | Identify evidence base | Identify theory | Model process and outcomes | Test procedure (Understand causal processes) |
| Mixed Methods approach | QUANT | QUAL | QUANT/QUAL | QUANT/QUAL |
| Research methods | Design, Implementation, Analysis | | | |
| | Systematic Review ( Phase 1) | Qualitative Enquiry (Phase 2) | Realist Synthesis (Phase 3a) | Process Evaluation (Phase 3b) |
| Purpose | Determine effectiveness current interventions | Build theory | Develop programme theory | Test programme theory |

(Diagram adapted with permission from MacBain, 2015)

One of the key findings from the realist synthesis was that there are four possible families of change mechanisms (Pawson, 2002) that together are likely to result in changing walking behaviour after stroke. These change mechanisms are 'planning for change', 'self-confidence', 'social influences' and 'habit formation'. It is hypothesised that delivering intervention components that are able to activate these change mechanisms is likely to optimise the effectiveness of any interventions which aims to lead to sustained change walking habits for this population (Astbury & Leeuw, 2010; Dalkin, Greenhalgh, Jones, Cunningham, & Lhussier, 2015).

Recently a manual which aims to assist intervention developers to work through the stages needed to systematically develop a theoretically informed behaviour change interventions has been published (Michie, Atkins, & West, 2014; Michie, van Stralen, & West, 2011). This manual provides step by step guidance for developers based on a behaviour change framework known as the 'Behaviour Change Wheel' which was developed through an extensive international consensus process. This framework was used to operationalise an intervention that aimed to activate the identified mechanism and thus has the following four goals.

1. Support planning for change,
2. Build confidence for walking
3. Create social connections
4. Establish new habits & routines

Figures 2a and 2b provides a summary of the key findings of each phase and provides background information charting the conceptual development of the intervention and the intervention components selected. The remainder of this research protocol outlines in more detail the intervention which will be delivered and the process evaluation of the intervention which is in two parts; a) evaluating the process of implementation and b) evaluating the impact of the intervention (Moore et al., 2015).

## 5. Objectives

The overarching research question for this process evaluation is: What is the impact of the *Walking for Wellbeing after Stroke* and if it works, how and why does it work?

Three subsidiary questions are (Westhorp, 2014):

- When it works, how (i.e. by what mechanisms) does it work?
    - Did the expected mechanisms operate? For whom?
    - Were there any unexpected mechanisms?
- When it doesn't work, why doesn't it work?
    - For whom did expected mechanisms not operate?
    - What features of context prevented anticipated mechanisms from being activated?
- What matters about how it is done, in order for it to work?
    - What were the critical aspects of implementation, or context that influenced how the programme operated?

**Figure 2a: Flow chart of conceptual development of an intervention to improve real world walking after stroke**

**Phase 1: Systematic review**
- Improvement in real world walking is possible after stroke; but only some interventions effective
- Clinic-based exercises are not effective on their own
- Both *context specific practice* AND *collaborative work* are needed to change real world walking
- Support from family may assist with sustained change

(Context specific practice includes home-based exercise or escorted community walking. Collaborative work includes change techniques such as goal setting, barrier identification in collaborative interaction style)

**Phase 2: Qualitative Enquiry**
- Walking in the real world was profoundly important to participants and could contribute to *psychological wellbeing*
- Walking in the real world requires *constant attention* for most participants
- Stroke participants used *planning* skills, *confidence* building experiences, changes to their thinking, everyday *routines*, and drew on *social* resources to *motivate themselves to overcome* the significant challenges they faced.

**Relevant published literature (See Figure 2b)**

**Phase 3: Realist Synthesis**
Four key groups of change mechanisms for stroke survivor
- Planning for change
- Self-confidence for walking
- Social influences
- Habit formation

Intervention goals:
1. Support planning for change
2. Build confidence for walking
3. Create social connections
4. Establish new habits & routines

**Intervention components**

Planning support
- Goal setting with If-then plans
- Barrier identification
- Exercise diary for self-monitoring
- Autonomy-supportive interaction style

Confidence building
- Home-based exercise programme to improve physical capability
- Escorted community walking to build confidence through successful mastery

Social connections
- Family engagement in goal setting
- Group based activities with other stroke survivors including outdoor walking group

Developing new habits and routines
- Routines based interview (plus above activities)

**Figure 2b: Summary of relevant published literature to realist synthesis**

**Relevant published literature**

For healthy adults:

- Changing physical activity behaviours requires self-regulatory (or planning) skills (Sniehotta, 2006). Change techniques that support self-regulation (e.g. goal setting, self monitoring) are most effective techniques for changing physical activity behaviours (Michie 2009) including walking (Bird 2013)
- Maintaining changes in physical activity behaviour may requires additional processes including the development of intrinsic motivation to support sustained behaviour change ( Teixera 2012). An autonomy-supportive social environment (which can be provided by a collaborative interaction style) can help develop this (Fortier 2007, 2011)

Walking specific research:

- Effective interventions that lead to sustained change in walking behaviours include both motivational and planning components (Draker 2010, French, 2012)
- Walking is often a largely habitual activity (Eves 2007) and 'automaticity' is key ingredient behind formation new habits (Gardner 2012)
- Walking groups are particularly effective at promoting sustained change in walking habits (Kassavou 2013, Hanson 2015)

For people with stroke:

- Many stroke survivors have cognitive difficulties which affect psychological capability for managing attention, decision making and planning processes    ( Cumming 2013)
- Perceptions of reduced capability (i.e. self-confidence) limit engagement in walking activities (Horne 2014)
- Social influences (especially attitudes of physiotherapists and family members) can play a 'gate keeping role' which restricts walking opportunities (Barnsley 2012)
- Reengaging in desired activities like walking more is one part of a difficult and complex process of psychosocial adaptation (Kubina 2013; Kirkevold 2012)

**Phase 3: Realist Synthesis**

Four key groups of change mechanisms for stroke survivor

- Planning for change
- Self-confidence for walking
- Social influences
- Habit formation

Intervention goals:

1. Support planning for change
2. Build confidence for walking
3. Create social connections
4. Establish new habits & routines

**Intervention components**

Planning support

- Goal setting with If-then plans
- Barrier identification
- Exercise diary for self-monitoring
- Autonomy-supportive interaction style

Confidence building

- Home-based exercise programme to improve physical capability
- Escorted community walking to build confidence through successful mastery

Social connections

- Family engagement in goal setting
- Group based activities with other stroke survivors including outdoor walking group

Developing new habits and routines

- Routines based interview (plus above activities)

## 6. Intervention- *Walking for Wellbeing after Stroke*

*Walking for wellbeing after stroke* is an 8 week programme based on self-determination theory (Deci & Ryan, 2000, 2008). The intervention includes individual, family and group based activities designed to support planning for change, build confidence for walking, create social connections and establish new routines and habits. It will do this by providing opportunities for context-specific practice, the use of behavioural change interventions and social support. By providing an autonomy-supportive environment (Fortier et al., 2011), successful experiences of walking that enhance personal competence and multiple opportunities for social connection the intervention aims to enhance wellbeing, and hopefully lead to sustained change in walking habits.

**Figure 3: Overview of the 8 week 'Walking for wellbeing After Stroke' intervention**
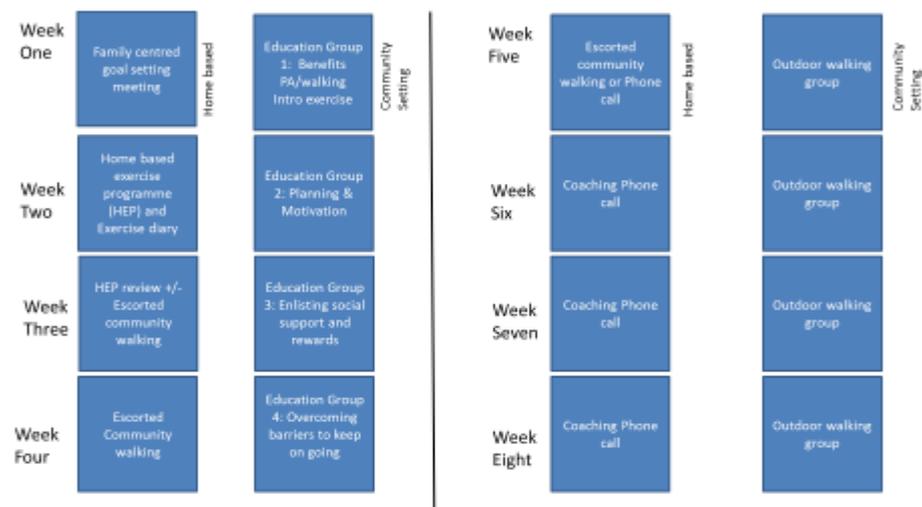


## 6.1 Self-determination theory (SDT)

Self-determination theory (Deci & Ryan, 2000, 2008) is a well-established theory that has been used successfully to promote health related behaviour change a number of different populations (Murray et al., 2015; Ng et al., 2012) but is yet to be used in stroke. There is particularly good evidence of its effectiveness in promoting sustained change in levels of physical activity (Fortier, Sweet, O'Sullivan, & Williams, 2007; Teixeira, Carraça, Markland, Silva, & Ryan, 2012; Wilson, Mack, & Grattan, 2008). SDT argues that people are actively involved in their lives with a natural tendency toward growth and development but that the social context can act to support or thwart this process. It hypothesises that psychological wellbeing and optimal functioning can only occur when three basic psychological needs are met: autonomy, competence and relatedness. Autonomy describes a sense of freedom, choice and control through having the perception of being the origin of one's own behaviour. Competence refers to the feeling of being effective in one's abilities. Relatedness is a feeling of being cared for and understood by others (Deci & Ryan, 2000; Ng et al., 2012). Support and satisfaction of these needs leads to a sense of vitality and energy.

An individual may choose to not be physically active either because they perceive they do not have the competence or because they do not feel the activity is sufficiently important to them (Teixeira et al., 2012). SDT also distinguishes between different types of motivation; contrasting *amotivation, controlled motivation* and *autonomous motivation*. The first two types include the experience of lacking motivation, or being physically active because of a sense of having to. Autonomous motivation is characterised as motivation that the individual perceives as coming from their own sense of volition due to its inherent pleasure or consistency with their identified values ( (Deci & Ryan, 2000; Teixeira et al., 2012). This type of motivation has been consistently shown to be linked to sustained behaviour change in physical activity for healthy people (Fortier et al., 2011; Teixeira et al., 2012). Social contexts which support autonomy by providing an patient centred autonomy supportive counselling style (Fortier et al., 2011; Patrick & Williams, 2012; Ryan, Lynch, Vansteenkiste, & Deci, 2011) lead to greater autonomous motivation for change. The intervention components of the programme have been selected in part because of their potential to a) enhance perceptions of competence, or b) strengthen social connections (i.e. relatedness) and/or c) promote autonomy via creating an autonomy supportive environment which can potentially assist with motivation for sustained change. Table 1 below summarises the relationship between the qualitative enquiry, SDT and the intervention.

Table 1: Findings from the qualitative enquiry, SDT constructs and interventions goals

| Themes from Qual. Enquiry | Constructs from Self Determination Theory | Intervention Goals |
|---|---|---|
| 1. Freedom from forced dependence | Needs satisfaction: Autonomy | Collaborative goal setting process that supports autonomy and choice |
| 2. Step by step progress brings hope | Needs satisfaction: Competence | Context-specific practice that enhances perceptions competence |
| 3. Opportunity for a different place and space | Fostering awareness and mindfulness | Supportive social environments that fosters awareness |
| 4. Motivating self to overcome | Participation motives ( e.g. autonomous vs controlled motivation) | Autonomy supportive interaction style that aims facilitate autonomous motivations |
| 5. Make it social | Needs satisfaction: Relatedness | Create social connections and foster social integration |

## 6.2 Behaviour Change Wheel

The Behaviour Change Wheel (Michie, van Stralen, et al., 2011) is framework for understanding behaviour and behaviour change that integrates 19 different behaviour change frameworks. It was developed through a consensus process with international experts in behaviour change. This framework is centred on three key aspects of behaviour: capability, opportunity and motivation and argues these are all essential requirements for behaviour change. In terms of capability; adequate physical skills and psychological capability for decision, memory and attention processes are required. Secondly the physical and social environment needs to provide opportunities for this change to occur. Both of these factors can affect the motivation for change. Motivation is described as " all those brain processes that energize and direct behaviour" (Michie, van Stralen, et al., 2011, p. 4). These brain processes include reflective cognitive processes (such as having a plan, or perceptions of capability) or non-reflective processes (which are below conscious awareness) such as fear or other habitual responses. The Behaviour Change Wheel (COM-B)has been further developed into a comprehensive and systematic process for linking identified behavioural targets with intervention components which can work to address identified barriers (Michie et al., 2014). The

table below summarises findings from earlier phases of this project into walking after stroke. It illustrates how difficulties in any of these areas can lead to barriers that affect the change process. The primary behaviour change target desired for group participants is increasing the number of daily steps. The table below provides the rationale for the inclusion of intervention components to address the identified barriers in the *Walking for wellbeing after stroke* programme

Table 2: Worksheet to identify barriers to achieving increase in daily steps

1 Target Behaviour: Take more steps per day

| COM-B Components | What needs to happen for the target behaviour to occur? | Is there a need for change? |
|---|---|---|
| Capability- Physical | Physical skill training to ensure adequate leg muscle strength, balance and reduction in cognitive-motor interference | Yes |
| Capability-Psychological | Support to identify opportunities and turn intention into opportunities with self-regulatory skills | Yes |
| Opportunity-Physical | Can depend on access issues such as stairs, slopes, weather | Maybe |
| Opportunity-Social | Caregivers significant others and therapist can facilitate/inhibit  so need involve and educate | Yes |
| Motivation -Reflective | Likely need support to focus efforts and feel more confident abilities | Yes |
| Motivation- Subconscious | Change unconscious sedentary habits, reduce fear of falling or fear of second stroke or other restrictive beliefs and negative emotions; lack of purpose | Yes |
| Behavioural diagnosis of the relevant COM-B components | All areas likely to need support and attention to aid change | |

## 6.3 Planning for change with a family centred goal setting meeting

Collaborative goal setting meetings are an important feature of the rehabilitation process (Sugavanam, Mead, Bulley, Donaghy, & van Wijck, 2013). In this intervention, family will be specifically encouraged to attend and contribute to the meetings which will be the first point of contact with the physiotherapist. The research physiotherapist will schedule the meeting around the needs of the family/whānau to ensure that as many members of the family are able to attend as wish to. Similar to a 'take charge' meeting developed by Harwood and colleagues (Harwood et al., 2012) the family will be encouraged to be actively involved in the rehabilitation journey, thus contributing to an autonomy supportive environment (McNaughton, Thompson, Stinear, Harwood, & McPherson, 2014).

### Autonomy supportive environment
The key principles of an autonomy supportive approach include a) taking the perspective of the person/whānau into consideration b) acknowledging their feelings and thoughts c) providing relevant

information d) effective opportunities for choice and e) minimising therapist control (Fortier et al., 2011). These principles have been applied to neurological physiotherapy using an 'activity coaching' model (Stretton, Mudge, Kayes, Taylor, & McPherson, 2013) which was acceptable to neurological patients who wanted to improve walking. Techniques from activity coaching will be used to support patient autonomy and create a collaborative interaction style.

### Routines-based interview

Habits are relatively automatic actions that a person does repeatedly. In contrast routines are a "type of higher order habit that involves sequencing and combining process, procedures or steps" (Clark, 2000, p. 1285). Most walking occurs as part of routines that are initiated largely below conscious awareness (Eves, Scott, Hoppé, & French, 2007). In order to identify daily activity routines a routine-based interview will be used to determine how a usual day is spent by asking the stroke survivor and primary care giver to 'tell me about a typical day for you?' Developed from family-based interventions in education this approach has been created for use in natural settings and focuses on understanding daily routines before identifying key areas to focus on changing behaviour (McWilliam, Casey, & Sims, 2009). By working systematically through the day, possible areas of focus can be highlighted and prioritised for later planning stages thus providing opportunities to 'piggyback' changes into existing daily routines.

### Goal setting with If-then plans

The process of behavioural self-regulation involves the process of setting goals and striving to achieve them. This can be particularly challenging for people who experience problems with executive functioning as is common following stroke (Poulin, Korner-Bitensky, Dawson, & Bherer, 2012). The use of 'If-then plans have a robust theoretical basis (Gollwitzer, 1999; Gollwitzer & Sheeran, 2006) and proven feasibility for use with neurological patients such as multiple sclerosis and stroke to promote walking (Kersten, McPherson, Kayes, Theadom, & McCambridge, 2015). Three to four 'If then plans' will be developed as part of the family-centred goal setting meeting as a result of the interview that focus around walking and exercise related goals. Each goal and If-then plan will be written on a piece of paper as a visual reminder and placed in in a carefully selected place in the home to act as an environmental prompt.

### Barrier identification

A process of barrier identification that aims to identify what may get in the way of achieving the goals will be prompted during the goal setting meeting and continued during other sessions. For example after the goals have been identified, the therapist may ask "What might get in the way of you doing these things? What could you say to yourself that would give you the most chance of success?" A further if-then plan in response to this question will be documented and discussed with the family. As the participant's skills progress during the intervention and during follow-up sessions the therapist may also ask "what is limiting you from achieving your goal relative to walking? The purpose is to develop confidence to address barriers that may be limiting desired activities and to provide an opportunity for self-reflection.

### Exercise diary for self-monitoring

The process of self- monitoring one's own behaviour has been demonstrated to be the single most effective change technique at improving physical activity behaviour for healthy people (Michie, Abraham, Whittington, McAteer, & Gupta, 2009). It is likely that self-monitoring provides a form of feedback and reminders about desired goals. An exercise diary will be provided and the person encouraged to fill it in on a daily basis. They will record whether or not they completed the if-then plans identified earlier, the amount of exercises completed as part of the home exercise programme and the amount of daily waking that is able to be recalled.

## 6.4 Building confidence using context specific practice

*Home based exercise programme*

Exercises based in the home setting have been shown to be effective at improving physical capabilities following rehabilitation after hip fracture (Latham et al., 2014) and following stroke (Duncan et al., 2011). The Weight-bearing Exercise for Better Balance (WEBB) exercise programme (Sherrington, Canning, Dean, Allen, & Blackman, 2008) includes a progressive series of strengthening exercises, and balance activities with increasing challenge and encourages regular walking practice. This programme has been used successfully in both home and community settings for people with stroke (Dean et al., 2012). In addition to the home based activities shown in the WEBB programme, participants will also practice dual tasking activities that challenge cognitive and motor activities such as walking while talking, or walking while carrying an object. Experiencing difficulties with cognitive-motor interference during walking is a common area of difficulty after stroke (Plummer et al., 2013) and can adversely affect walking in the real world (Lord & Rochester, 2007).

*One on one Escorted Community Walking*

A loss of confidence is often the major barrier to getting out to desired locations after stroke and this can be overcome with the support of a therapist (McCluskey & Middleton, 2010). Multiple escorted outings and training with a therapist enable people to get out more following stroke (Logan, Ahern, Gladman, & Lincoln, 1997; McCluskey et al., 2013). Escorted community walking refers to real world walking practice that occurs in desired community venues such as shopping malls or catching buses etc. accompanied by a therapist. Following the goal setting meeting, at least two desired venues will be selected and 2-3 outdoor journeys will be undertaken.

## 6.5. Create social connections

*Background*

Social integration refers to "the extent to which an individual participates in private and public social interactions" (Gottlieb & Bergen, 2010a, p. 512) and the greater the number and diversity of social ties the greater the social integration (Gottlieb & Bergen, 2010b). There is compelling evidence that stronger social ties and support is a significant causal factor in both physical and mental health and wellbeing (Tay, Tan, Diener, & Gonzalez, 2013; Thoits, 2011). Specifically in relation to physical activity behaviour, social influences can enhance adherence and social isolation predicts decreased physical activity (Tay et al., 2013). Social psychological mechanisms underpinning social support are varied but can be usefully grouped into mechanisms that provide emotional sustenance (such as emotional validation or ventilation) and those that provide active coping assistance (Thoits, 1995). Social support can be provided by those who can be considered 'significant others' (such as family); those who can be considered as 'similar others' (such as fellow stroke survivors) or 'knowledgeable others' (such as health professionals). Each provide different but complementary sources of support (Thoits, 1995). Several qualitative studies of stroke survivors describe the importance of social support to their functioning, (Morris, Oliver, Kroll, & MacGillivray, 2012; Sumathipala, Radcliffe, Sadler, Wolfe, & McKevitt, 2012) the increasing social isolation they experience following a stroke, and the value of social connections to help them regain desired activities such as walking after stroke (Kubina, Dubouloz, Davis, Kessler, & Egan, 2013). By explicitly providing multiple opportunities to meet as a group, to develop social connections with 'similar others' this programme hopes to increase social integration for programme recipients that hopefully will continue to occur once the group finishes.

### Group based sessions

During the first month the participant's will meet as a group to complete four sessions in a community setting at the Laura Fergusson Trust facilities. The purpose of these sessions are threefold: 1) to develop positive attitudes and beliefs towards physical activity; 2) to support planning and problem solving skills for keeping active; and 3) to develop a sense of cohesion as group. Family members will also be encouraged to join in the group and a separate time and space will be provided for them to talk with other family members to discuss relevant issues to living with a stroke survivor. The opportunity for group members to develop social connections with other 'similar others' is expected to provide three benefits. Firstly it aims to provide an opportunity for emotional support as being able to talk to others in a similar situation allows the opportunity to 'ventilate' and have their experience validated by other who understand (Thoits, 2011). Secondly, members are likely to gain some active coping assistance through the exchange of knowledge and ideas. Finally the development of social relationships between all group members means the family members may be more likely to actively support future opportunities for social interactions enhancing ongoing opportunities for social integration. During the second month the focus will shift to group-based outdoor walking.

#### Outdoor walking group

Walking groups have demonstrated effectiveness at improving levels of physical activity (Kassavou, Turner, & French, 2013; Kassavou, Turner, Hamborg, & French, 2014) and provide important physical health benefits (Hanson & Jones, 2015). While walking groups have been evaluated in a range of populations such as sedentary individuals and people with Parkinson's Disease(Hanson & Jones, 2015) they are yet to be evaluated for use in stroke. A careful risk management plan has been developed to minimise potential risks. A preselected course with a range of routes based on different levels of ability will be provided. The purpose is to walk outdoors in a natural setting, to provide a sense of personal satisfaction, social connectedness, task mastery as well as visual variety. In addition group participants will be encouraged to bring a support person who can act as an 'exercise buddy' along with them.

## 6.6 Establish new habits and routines

Several of the interventions mentioned in previous sections aim to help establish new habits and routines. Four target behaviours have been selected. They are 1) take more steps per day; 2) do a daily home-exercise programme; 3) record exercises and walking daily in an exercise diary and 4) participate in weekly outdoor walking with one or more people. The intervention components explained earlier to support this include; identifying current daily routines with the routines based interview; setting meaningful goals and plans to support new habits; providing self-monitoring opportunities via the exercise diary and the provision of environmental cues to act as reminders. It is hoped that these components will prompt the regular repetitive practice needed to develop new habits and routines. By involving members of participants existing social network as well as developing wider social networks through the *walking for wellbeing* support group it is hoped this will provide greater social connections and positive experiences that will increase motivation and opportunities to enact the desired behaviours.

## 7. Process Evaluation

The process evaluation has two components; a measure of impact of the intervention on the desired outcomes and an evaluation of the implementation process

## 7.1 Inclusion and exclusion criteria

*Inclusion Criteria*

4-6 participants will be recruited to participate who have experienced a stroke and have a desire to improve their walking in the real world. In addition they need to have

- a walking speed of at least 0.8m/s
- Have adequate communication and comprehension abilities so that that they can adequately express their perspective

*Exclusion criteria*

Potential participants will be excluded if:

- They reside more than 45 minute commute from LFT facilities in Greenlane because the group sessions will initially be held at this facility
- They are considered to be at moderate or high risk of falling as assessed with a standardised Fall Risk Screen (Stapleton et al., 2009)
- They have absolute contraindications to exercise including; a history of recent myocardial infarction, uncontrolled cardiac conditions such as arrhythmias, heart failure or severe aortic stenosis, uncontrolled hypertension, uncontrolled metabolic disorders, significant musculoskeletal plain in the lower limbs made worse by walking, major depression or psychiatric illness or acute infection (Jones & Rose, 2005). The questions from the PAR-Q ( Physical activity readiness questionnaire) (Thomas, Reading, & Shephard, 1992) will be used to clarify if there are issues that need to be discussed.

    a. Has your doctor ever said you have a heart conditions AND you should only do physical activity recommended by a doctor?

    b. Do you feel pain in your chest when you do physical activity?

    c. In the past month, have you had chest pain when you were not doing physical activity?

    d. Do you lose your balance because of dizziness or do you ever lose consciousness?

    e. Do you have bone or joint problems that could be made worse by a change in your physical activity?

    f. Do you know of any other reason why you should not do physical activity?

If any of the questions are answered positively, the research physiotherapist will ask further questions to clarify if there is any contraindications to exercise (which would mean exclusion from the programme) and recommendation to see a doctor as soon as possible; or if they would require closer monitoring/supervision or any specific modifications to the exercise programme. Similar to the approach taken in clinical practice, the research physiotherapist will ask if they can contact the person's GP to clarify their medical conditions if in their professional opinion this would be helpful for them or the research participant.

## 7.2 Recruitment

Recruitment will primarily be through the Stroke Programme that currently occurs at Laura Fergusson Trust facilities in Greenlane. This programme provides an 8 week course and stroke survivors are referred to the Stroke Programme through a variety of sources including self-referral, or by community physiotherapists or GP's. About 3-4 Stroke Programmes are offered each year (over an 8 week period) with between 20-40 people on each group and funding for this programme is through a philanthropic donor. People are only able to attend the course once. People who have either received the programme previously or who are on the waiting list will receive a letter of invitation to be involved in the research.

If not enough participants are recruited the researcher will approach the Stroke Foundation and ask them if they could circulate details amongst their field workers in the Greater Auckland area. Personal and professional networks of the research team or the staff at AUT may be also used to identify potential participants if needed.

## 7.3 Screening

All potentially interested participants will be asked to attend a screening session at LFT to determine eligibility. Transport may be able to be provided for attending this session if they are not able to organise their own transport. At the screening session the individual will be assessed on the following

- The 10 metre walk test (time to walk 10 m) (Perera, Mody, Woodman, & Studenski, 2006a)
- Serial subtraction during walking (a test of cognitive motor interference that involves subtracting while counting down from 100 e.g. 'count backwards in 3 from 100' and the number of errors recorded and time to complete)(Patel & Bhatt, 2014)
- Fall Risk Assessment Test ( a carefully developed screening tool commonly used to determine risk of falling ) (Stapleton et al., 2009)
- Readiness for physical activity using the PAR-Q ( Physical Activity Readiness Questionnaire) (Thomas et al., 1992)

They will also be asked if they are currently involved in any other research that involves an active intervention. Regardless of whether they are identified to be eligible to take part, they will complete a consent form covering usage of their outcome data collected during screening.

If the potential participant does not meet the inclusion criteria – they will be provided with a summary of their assessment findings, an information sheet about keeping physically active after stroke and any areas of potential concern identified in the screening assessment will be discussed with them. They will also be encouraged to explore alternative activity options such as the existing Stroke Programme at LFT if they haven't already completed it; or other community programmes. Finally, they will be asked if they would be interested in being contacted for future related research studies they may be eligible for at AUT University.

If the potential participant does meets the inclusion criteria the project will be explained to them and they will be given an information sheet about the project. The assessment process for the research and the distinctive features of the intervention will be explained in general terms at this stage including the fact that once the first assessment takes place that they will be unable to participate in any other interventions until data collection for this study has been completed. The selection process (which involves purposeful selection of group participants who live as close geographically as possible and with a mix of genders will also be explained to them. They will be told that they will be phoned by the researcher to let them know as soon as possible if they will be invited participate in the study. They will also be provided with a copy of their individualised screening information provided in a

16

similar way to those who do not meet the criteria. If appropriate they will also be asked for permission to contact their GP to clarify their medical suitability for the programme and contact details for the GP requested if they have a Yes on the PAR-Q or are aged over 69 and are not used to being active.

## 7.4. Informed consent and family engagement

If the person is selected for the study and agrees over the phone in principle to participate- the researcher will make an appointment to visit them in their own home probably within a few days after the phone call. At this visit they will go through the study information in more detail and answer any questions. When the researcher organises the appointment she will encourage the potential participant to invite any significant others to be part of this visit and to discuss the project with them. If they need extra time to talk over the project with their family/whānau that will be arranged with the researcher.

During the home visit the researcher will explain in more detail what will be involved, and complete the process of informed consent. If they do not have a 'significant other' at this visit, they will be asked if they are happy to nominate a family or friend who would act as an additional contact person and be able to support them in their desire to improve their real world walking. If this person is not present at the interview (and after permission from the stroke survivor) the research physiotherapist will follow up with a phone call to explain the study and discuss it with them. Issues related to transport, time management, and desire to be actively involved in the process will be explored to ascertain the level of support to the process that they may be able to contribute. Qualitative research involving family members 'mediating' rehabilitation interventions has consistently shown that families value the opportunity to be involved and measures of caregiver strain are usually reduced not increased by the opportunity to support rehabilitation for their family member (Galvin, Cusack, & Stokes, 2009; Galvin, Stokes, & Cusack, 2014). However this will not be presumed and a spirit of teamwork and open discussion will be encouraged by the researcher when working with the stroke survivor and any family members that they wish to be involved.

## 7.5 Ethics

Ethical approval is being sought for this study through AUTEC

## 7.6 Data collection

This project is a mixed methods project. A mixed methods data collection procedure will be used involving both quantitative and qualitative data collection. Data will be collected at 4 different time points, pre-intervention, mid-intervention, post-intervention and three months after completion of the programme.

## 7.7 Measuring the impact of the intervention

The first part of the process evaluation focuses on the effect of the intervention on the desired outcomes and measures this with quantitative outcome measures. For this stage, four self-report measures, two performance based quantitative measures of the impact of the intervention will be collected by an independent assessor at all four times points. Each measure has been selected to reflect the key causal mechanism and desired outcomes identified and Table 3 below summarises this link.

**Table 3: Link between outcome measures and causal mechanisms**

| Outcome measure | Causal mechanism/ Desired outcome |
|---|---|
| Completion of selected If-then plans | Planning for change (behavioural self-regulation) |
| Ambulatory Self-confidence Questionnaire (ASCQ) | Self-confidence for walking |
| Subjective Index of Physical and Social Outcome (SIPSO) | Social connections and integration |
| Behavioural Regulation of Exercise Questionnaire (BREQv2) | Reasons underlying decision to engage in exercise ( motivational factors) |
| Automaticity subscale of the Self Report Habit Index | Automaticity (Habit formation) |
| Step watch Activity Monitor- Mean steps per day | Habit formation |
| Six minute walk test (6MWT) | Improved physical capability |

*Self-report indicators of outcome: (Independent Assessor)*

Completion of If-then plans for selected goals

Each participant will be given a check sheet with each of the days of the week for each 'If-then' plan that has been agreed upon and encouraged to complete a tick for days completed. 1 or 2 goals will be selected and the check list used to determine how often the goal was completed per week (Trigg & Wood, 2003; Trigg, Wood, & Hewer, 1999).

Ambulatory Self Confidence Questionnaire- ASCQ

This outcome measure of self-confidence during walking has 22 items and has been developed for use in community dwelling older adults and is reliable with good concurrent validity with other measures of balance self-efficacy (Asano, Miller, & Eng, 2007).

Subjective Index of Physical and Social Outcome-SIPSO

This 10 item measure of social and physical integration after stroke (Trigg & Wood, 2003; Trigg et al., 1999; Kersten, Ashburn, George, & Low, 2010) provides an indicator of reintegration following stroke and is brief and sensitive to change. Rasch analysis of the measure has shown that using the two subscales (physical integration and social integration) is better than one overall total score (Kersten et al., 2010).

Self-report Behavioural Automaticity Index -SRBAI

This four item subscale measures the degree of automaticity (Gardner, Abraham, Lally, & de Bruijn, 2012) that occurs for a selected behaviour. It has been used repeatedly in healthy populations but is yet to be evaluated for use in stroke. It is taken from the 'Self-report Habit Index' (Verplanken & Orbell, 2003).

Behavioural Regulation of Exercise Questionnaire v2 (BREQv2)

This outcome measure will be used to evaluate whether the intervention has any effect on the degree of autonomous motivation experienced as a result of the intervention. This 19 item questionnaire evaluates types of motivation (e.g. autonomous vs controlled motivation) towards exercise on a 7 point Likert scale based on self-determination theory (Markland & Tobin, 2004). It has been used extensively in healthy populations but has not been validated for use following stroke.

18

*Performance-based indicators*

### Step watch Activity Monitor (SAM)

Each participant will wear a StepWatch Activity Monitor for three consecutive days as a measure of the amount and rate of usual walking performance. Outputs used will be total steps/day and peak activity index, highest stepping rate in one minute and percentage of time inactive, which have been shown to be the most reliable outputs for people with stroke (Mudge & Stott, 2008). The StepWatch Activity Monitor has been shown to be a valid and measure of real world walking for people with stroke (Mudge, Stott, & Walt, 2007).

### Six minute walk test (6MWT)

As part of the goal to improve walking related confidence, the home based exercise programme will aim to improve physical capability. The Six minute walk test- 6MWT (Perera, Mody, Woodman, & Studenski, 2006) is a measure of walking-related physical capability and will be used to determine the effectiveness of the exercise programme and will also provide data regarding any changes in walking ability that occurs from the programme.

## 7.8     Evaluating the implementation process

*Data sources*

### Activity diary

Including a record of walking and other activities and any barriers experienced

### Participant interviews:

Intervention participants will be interviewed at their home using an open ended semi-structured interview and prompt sheet at 3 time points. The time points will be mid-intervention, post-intervention and at the three month follow up period. An independent assessor who has not delivered the intervention will complete the outcome measures as well as the qualitative interview. The purpose of the interviews are to provide information about the process of implementation, to help understand the participants reasoning in response to the intervention and to provide additional contextual insights. The prompt sheet will focus on questions that aim to elicit reflective insights exploring the perspectives of participants taking part in the intervention about what aspects were useful or not. Secondly the prompt sheet will include questions aimed to elicit the underlying thinking that has occurred. The previous self-report measures may be used as a prompt.

### Research Journal and field notes

Thoughts and reflections will be captured through field notes and a reflexive research journal by the research physiotherapist delivering the intervention

## 8. Data analysis

Data analysis will involve three stages. The first stage will be analysis of standardised outcome data drawing on system design approaches. The second stage will be content analysis of the qualitative data. In the final stage the two data sources will be integrated in order to answer the research questions more comprehensively and develop a more nuanced interpretation of the data.

## 8.1 Quantitative data analysis

Quantitative data from self-report and performance based measures will be analysed first, separately for each of the measures. The single yield data for each of the outcome measures will be graphed against time for each participant across the five assessment points. Visual inspection will be used

initially to look for any changes in data patterns (e.g. trend, level or variability) (Nourbakhsh & Ottenbacher, 1994).

## 8.2 Qualitative data analysis

Qualitative data from participant interviews will be audio taped, transcribed and also be entered into NVivo which is a qualitative data management software package. It will then be deductively analysed using content analysis (Elo & Kyngäs, 2008) and qualitative descriptive methodology (Sandelowski, 2000, 2009). Data from field notes, activity diaries and the researcher journal will also be entered into NVivo and along with reflective research memos will be available for analysis.

## 8.3 Integration of quantitative and qualitative data

The purpose of integrating the qualitative and quantitative is to compare findings in order to provide triangulation which leads to greater understanding of how the change process occurred (Bazeley, 2009; Onwuegbuzie & Combs, 2010) As a result the two data sources will be analysed separately but concurrently (Onwuegbuzie & Combs, 2010, p. 411). For the quantitative data after the statistical analysis has been completed, the quantitative data will then be as "qualitised' i.e –'transformed into narrative data that can be analysed qualitatively" (Onwuegbuzie & Combs, 2010, p. 414) and entered in NVivo for integration with other qualitative data. Through a process of comparison, identification of areas of congruence and difference in the data will be made. These findings will then be compared to the initial programme theory developed during the realist synthesis and used to further refine the programme theory and answer the research questions previously outlined.

## 9. Budget

| Item | | Units | Unit cost | Cost | |
|------|---|-------|-----------|------|---|
| 1- End User Consultation | | | | | |
| | People with stroke ( Acknowledgement contribution 2 hour $40 total x 5 ) | 5 | $40 | $200 | |
| | Academic End Users ( Lunch for 10-12 people) | 1 | $80 | $80 | |
| | LFT Clinicians ( Afternooon tea & Coffee) 2 x $30 | 2 | $30 | $60 | |
| 2. Mileage & Transport costs | | | | | |
| | Assessments (20 X 40km) | 800 | $ 0.79 | $ 632.00 | |
| | Researcher Visits ( 20 x 40km) 5 per person x4 | 800 | $ 0.79 | $ 632.00 | |
| | | | | | |
| 3. Resources for participants | | | | | |
| | Measuring Wheel Model 4500 | | | $160 | |
| | Portable Seat ( Walk stool 55X-Large Folding Stool) | | | $150 | |
| | Environmental triggers ( Printing and Laminating) | | | $20 | |
| | First Aid Kit and portable BP cuff | | | $160 | |
| | Exercise Diaries | | | $10 | |
| | Hand outs & Binders | | | $24 | |
| | Heavy Duty cructch tips $5 per participant | | | $20 | |
| | Therabands for exercises ( 2 per person @ $15 each) | | | $120 | |
| | | | | | |
| 3. Resources: Generic | | | | | |
| | Scrivner- Writing Tool | | | $130 | |
| 4. Professional Resources | | | | | |
| | NZSP Fees 2016 | 1 | $ 400.00 | $ 400.00 | |
| | APC 2016 | 1 | $300 | $ 300.00 | |
| 7. Mixed mthods Indepdent Assessor ( RA ) | | | | | |
| | Assessments HTRA 08 ( 8 per person x 4 participants) | 32 | $ 28.53 | $ 912.96 | |
| | Training time | 4 | $ 28.53 | $ 114.12 | |
| | Travel time | 20 | $ 28.53 | $ 570.60 | |
| | Holiday pay at 8% | | | $ 127.77 | |
| 8 | Dissemination | | | $ 180.00 | |
| | | | | | |
| 9. Transport | | | | | |
| | Screeening Participants 10 x 40 km (400km) to LFT | 400 | 0.79 | $316.00 | |
| | Support Attendence to Group Sessions 8 x 60 km( 480km) | 480 | 0.79 | $379.20 | |
| 10 Conference travel and expenses | | | | | |
| | Poster printing for Rehab conference | | | $ 60.00 | |
| | Return flights Wellington for Rehab Conference | | | $250 | |
| | Rehab Conference Fees | | | $ 575.00 | |
| | Approx return air fare | | | $ 2,500.00 | |
| | Accomodation 4 nights at $150 | | | $600 | |
| | Per diem at overseas conference 4 days at $75 | | | $ 300.00 | |
| | Conference Fee | | | $ 500.00 | |
| | | | | | |
| TOTAL | | | | $ 10,483.65 | |
| | | | | | |
| | | | | | |
| | | | | | |
| PCR | 500 | | | | |
| PNZ | $1,200 | | | | |
| FHES | $3,353 | | | | |
| LFT | $5,444 | | | | |
| Total | $10,497 | | | | |

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# Walking for Wellbeing after Stroke

## 1. List of amendments

| Protocol Number | Amendment dates | Changes by | Summary of changes |
|---|---|---|---|
| Version 2 | August | Caroline | 4 assessment points not 5<br>6 people included |
| | | | |

## 2. The research team

Caroline Stretton (PhD candidate)
Suzie Mudge (Primary supervisor)
Nicola Kayes (Supervisor)
Kath McPherson (Supervisor)

## 3. Advisory group

Three groups of end users are involved in advising this project.

Group One: People with stroke (n = 4) and Family Members (n=2)
Group Two: Expert Physiotherapy clinicians from Laura Fergusson Trust (n=3)
Group Three: Academics in Rehabilitation from the Health and Rehabilitation Research Institute (HRRI) at AUT University

## 4. Overview of project

### 4.1 Background

Problems with walking are a common area of difficulty following stroke and lead to difficulty walking confidently and effectively outdoors (Barnsley, McCluskey, & Middleton, 2012). For example, surveys of long term survivors of stroke identify that problems with mobility remain their single largest unmet need (McKevitt et al., 2011) and 75% of people living with stroke describe it as important or essential to be able to 'get out and about' (Lord, McPherson, McNaughton, Rochester, & Weatherall, 2004). A systematic review completed as the first phase of this project (Stretton, Mudge, Kayes, & McPherson, 2014) demonstrated that improvements in real world walking after stroke were possible but that certain types of interventions were more effective than others. For example interventions that included behaviour change techniques from health psychology were more effective than exercise alone. The second phase which involved qualitative interviews of stroke survivors showed that walking in the real world enabled people with stroke to meet psychological needs for wellbeing by providing an opportunity for freedom from forced dependence and a sense of hope for future recovery. Providing interventions that improve the ability to walk in the real world and sustain this ability would address physical as well as psychological needs for stroke survivors.

The term 'real world walking' describes actual walking that occurs in usual settings such as in the home as well as walking in the community (World Health Organisation, 2002). Usual settings in the community that are essential to people with stroke include shopping venues and other public venues (Lord et al., 2004). However clinical audits from New Zealand, Australia and the USA reveal little clinical time is devoted to improving community walking and the vast majority of people (93%) are discharged from rehabilitation with inadequate walking speed and endurance to access these essential community settings (Hill, Ellis, Bernhardt, Maggs, & Hull, 1996; Latham et al., 2005; McNaughton, DeJong, Smout, Melvin, & Brandstater, 2005).

# Appendix V: Phase 3b-Participant information sheet for - *Walking for Wellbeing after Stroke*

CENTRE FOR
**PERSON CENTRED RESEARCH**
HEALTH AND REHABILITATION RESEARCH INSTITUTE

AUT
AUCKLAND UNIVERSITY OF TECHNOLOGY
TE WĀNANGA ARONUI O TĀMAKI MAKAU RAU

## Participant Information Sheet

## Walking for Wellbeing after Stroke

**Main Investigator**

| | | |
|---|---|---|
| | Caroline Stretton | PhD Candidate |
| | | AUT University |
| | | Phone: 921 9999 x 7697 |
| | | Email: caroline.stretton@aut.ac.nz |

| **Other Investigators** | Dr. Suzie Mudge | Post-Doctoral Research Fellow, AUT University |
|---|---|---|
| | Dr. Nicola Kayes | Senior Lecturer, AUT University |
| | Prof Kath McPherson | Professor of Rehabilitation, AUT University |

### An invitation

**You are invited** to take part in **a new programme** which aims to help people with stroke **walk more in the real world.** You are invited to take part because you have had a stroke.

This study is being carried out by Caroline Stretton. I am based at the Person Centred Research Centre at AUT University. This study is a part of my PhD project. My PhD aims to discover how physiotherapists can better help people with stroke get out and about and walk more often.

- **You can choose if you want to take part in the research.**

- If you do take part, you can **change your mind** and withdraw from the study at any point up until the end of the programme. You do not have to give a reason.

- This information sheet gives you information about this study. You **do not have to decide now** about taking part in the study. **Please talk with family or whanau** first if you wish.

### What is the research about?

The purpose of this study is to evaluate a new physiotherapy programme that aims to help people **get out more** often and **more confidently** in the real world. *Walking for Wellbeing After Stroke* is a lifestyle programme that hopes to help stroke survivors become more active by taking charge of their life and by making small changes to **daily walking habits**. It will try to do this by

helping to build walking related confidence, provide help with motivation, and encourage the development of stronger social support networks to help in the recovery journey.

### How will this study help?

*Walking for Wellbeing After Stroke* has been developed through a careful process that includes talking to stroke survivors and experts in rehabilitation. But it has not yet been **tested** in the real world to see **how well it really works**. Your views of how helpful or not the programme is will help us improve and refine our understanding of how to help people with stroke get and out and about and walk more often.

### How are people chosen to be part of this study?

We are looking for a **small group of 4-5 people** who live **reasonably close to each other** to participate in trialling the programme and contributing to the evaluation of the programme. To be a part of the study you need to have met the study criteria for inclusion and live reasonably close to the other group members. This is because we hope that group members are able to continue supporting each other once the study finishes so we need to ensure that you live close enough for this to be possible.

### Who can take part?

You are able to take part in this research if you have had a stroke and have a goal to walk more or be more active and you:

- Have successfully completed the initial assessment and are considered at **low risk of falls** ( based on the falls risk screening tool)

- Have a walking speed of greater **than 0.8m/s**

- Have no contraindications to taking part in an exercise programme

- Live within reasonable commuting distance of the other group participants

We would also like to work closely with **support people** from your social network. For example partners, family/whanau and friends. We would like you to think about **who you would like to have involved in this process as a support person/people for you**. For example, we encourage you to invite family members to attend the first goal setting meeting. Also your support people will be invited to attend the group sessions and community walking group if you wish.

If you **do not wish to nominate family/whānau** to take part, you can still take part in the study

### What happens if I decide to take part?

Once the group has been finalised the researcher **will phone** you to let you know if you have been selected and arrange a time to come and visit you in your home and talk with you about the programme in more detail.

*Walking for Wellbeing after Stroke* is an **8 week** programme. It will involve home based activities, walking practice with a physiotherapist at locations that are important to you, and group sessions. The home based activities will included a **goal setting meeting in your home** that your family is encouraged to attend and home based exercises that the physiotherapist will show you how to do.  The meeting will be organised at a time to suit you and your family. The walking practice will involve walking with the physiotherapist in a place that you would like to be more confident in going to such as a shopping mall or catching a bus for example.

The group sessions will be held once a week for each of the 8 weeks. The first four session will be at Laura Fergusson Trust in Greenlane. They will focus on getting to know the other group members as well as information sessions designed to equip and motivate you to be able to make lifestyle changes that will help you be more active. The final four sessions will be at a local park as part of an outdoor walking group. You will be encouraged to invite a support person with you who could act as your exercise buddy if you wish to these sessions. If you do not yet drive we will arrange assistance to ensure you can attend this sessions.

For the group members, who will be participating in the evaluation of the programme, there will also be a **regular assessment process**. This assessment process will take place at five different times over a five month period. The researcher will visit you **in your own home** and measure your walking, help you complete 4 questionnaires and spend about 30 minutes interviewing you about your experience of participating in the programme. It is expected it will take no **more than one and half hours** in total. You will also need to wear an activity monitor on your ankle to keep track of the number of steps you take for the 3 days before or after the visit.

### What are the risks of this study?

Taking part in the *Walking for Wellbeing after Stroke* programme will involve completing a daily exercise programme of about 30-45 minutes per day and setting aside time for regular walking practice. As part of the programme, participants will be encouraged to attend the group sessions. There is a small risk of falling or other adverse events occurring when people are active and undertaking activities that may challenge their balance. The research physiotherapist will discuss these issues with you.

### What compensation is available for injury or negligence?

In the unlikely event of a physical injury as a result of your participation in this study, rehabilitation and compensation for injury by accident may be available from the Accident Compensation Corporation, providing the incident details satisfy the requirements of the law and the Corporation's regulations.

**How will my privacy be protected?**

What you say during the evaluation of the programme is confidential. Only the investigators will know what you say. You will not be identified in research findings. Your information will be safely stored at AUT University. Computer files will be password protected.

Your information will be stored for at least 10 years. Future use of the information will be strictly controlled and is bound by the Privacy Act. Any information used in the write up of the study will be anonymised and any information that might identify you will be removed.

**What are the costs of participating in this project?**

There will not be any cost to you other than your time. Transport for group members will shared among group members and their support people. There may also be some support available through the Laura Fergusson Trust to assist with attendance. If you or your support person cannot drive we will make other arrangements to ensure you can attend the group sessions.

**What will happen with the findings?**

The findings from this study will be used to further refine the programme for future use in rehabilitation. In addition the findings may be used to develop training tools in the future. Findings will also be communicated to rehabilitation service providers and physiotherapy groups. They will also be presented at conferences and through publication in peer-reviewed journals.

**How do I agree to participate in this research?**

You will be asked to fill out a consent form to show that you are willing to take part in this study.

**Will I be able to have a copy of the findings?**

If you would like to receive a summary of the findings you can say so on the consent form and they will be sent to you at the end of the study. The findings should be available approximately 6 months after you take part.

**What do I do if I have concerns about this research?**

If you want some more information please feel free to contact one of the researchers

| | | |
|---|---|---|
| Caroline Stretton | 09 921 9999 ext 7697 | caroline.stretton@aut.ac.nz |
| Dr. Suzie Mudge | 09 921 9999 ext 7096 | suzie.mudge@aut.ac.nz |

Concerns regarding the conduct of the research should be notified to the executive Secretary, AUTEC, Kate O'Connor 09 921 999 ext 6038

## Appendix W: Phase 3b- Raw quantitative outcome data

Note: sig. change between two time points in hypothesised direction highlighted in green, unexpected in red; no sig. change not shaded

| | P1_Eva | | | | P2_Lily | | | | P3_Joy | | | | P4_Robert | | | | P5_Sione | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Time | T0 | T1 | T2 | T3 | T0 | T1 | T2 | T3 | T0 | # | # | T3 | T0 | T1# | T2 | T3 | T0 | T1 | T2 | T3 |
| ASCQ Mean 10 questions Total/10 | 8.6 | 8 | 8.3 | 7.8 | 9.6 | 9.7 | 10 | 10 | 5.5 | | | 4.2 | 2.6 | | 7.2 | 7.6 | 3.6 | 6.0 | 6.8 | 7.6 |
| BREQ Amotivation /16 | 0 | 0 | 0 | 0 | 13 | 11 | 14 | 12 | 2 | | | 3 | 1 | | 0 | 0 | 4 | 0 | 0 | 0 |
| BREQv2 CM /32 | 4 | 0 | 0 | 0 | 18 | 14 | 21 | 23 | 12 | | | 10 | 6 | | 12 | 16 | 17 | 21 | 16 | 22 |
| BREQv2 AM /32 | 32 | 32 | 28 | 22 | 24 | 26 | 19 | 19 | 27 | | | 31 | 25 | | 31 | 32 | 32 | 32 | 32 | 32 |
| % SRHBAI | 14 | 100 | 93* | 78* | 100 | 90 | 96 | 100 | 60 | | | 82 | 42 | | 86 | 93 | 75 | 75 | 82 | 71 |
| StepWatch Mean Step/day | 4859 | 5047 | 4850 | 4283 | 2319 | 2147 | 2019 | 2560 | 2342 | | | 3464 | 3008 | 4599 | 3445 | 3464 | 2674 | 3948 | 2551 | 3526 |
| SIPSO-P /20 | 19 | 17 | 19 | 19 | 20 | 20 | 20 | 20 | 11 | | | 12 | 14 | | 18 | 20 | 16 | 10 | 14 | 14 |
| SIPSO-S /20 | 12 | 15 | 12 | 15 | 16 | 15 | 17 | 19 | 15 | | | 17 | 12 | | 15 | 14 | 11 | 13 | 15 | 10 |
| SIPSO- Total /40 | 31 | 32 | 31 | 34 | 36 | 35 | 37 | 39 | 26 | | | 29 | 26 | | 33 | 34 | 27 | 24 | 29 | 24 |

TO Baseline, T1 Mid-intervention, T2:Post-intervention, T3 3 month follow up *Activity changed from walking daily (T0, T1) to doing exercises (T2,T3) #Quant outcomes not assessed at this time point

# Appendix X: Figures plotting change for each participant over time in relation to MDC*

*MDC (Minimal Detectable Change) displayed by dashed orange lines – 'true' change needs be outside MDC

## Participant 1: Eva



P1: Walking self-regulation- SAM — **No change**

P1: Walking Self Confidence — **No change**

P1: Integration- SIPSO Total — **Positive change at T3**

## Participant 2: Lily



P2: Walking self-regulation- SAM — **No change**

P2: Walking Self Confidence — **No change**

P2: Integration- SIPSO Total — **Positive change at T3**

# Participant 3: Joy



P3: Walking self-regulation- SAM

Positive change at T3



P3: Walking Self Confidence

Negative change at T3



P3: Integration- SIPSO Total

Positive change at T3

# Participant 4: Robert



P4: Walking self-regulation- SAM

Positive change at T1



P4: Walking Self Confidence

Positive change at T2,T3



P4: Integration- SIPSO Total

Positive change at T2,T3

## Participant 5: Sione



**P5: Walking self-regulation- SAM**
Positive change at T1, T3

**P5: Walking Self Confidence**
Positive change at T1, T2,T3

**P5: Integration- SIPSO Total**
Negative change at T1, ,T3

## Appendix Y: Phase 3b- Outcome Matrix 1

*SO (source of data) Divergent outcomes from theory and between quant. and qual. data italicised

| Expected Outcomes | Eva | Lily | Joy | Robert | Sione |
|---|---|---|---|---|---|
| **1. Was a meaningful plan developed?** | Yes<br><br>Plan to walk at 9:00 with family member (*SO: field data, interview) | Yes<br><br>Plan to walk when sore; walk to library once week (SO: field data, interview) | Yes<br><br>Plan to take sleeping medication at set time; when visitors come ask to join her in walk (SO: field data, interview) | Yes<br><br>Plan to walk the dog each day and return to swimming. (SO: field data, interview) | Yes<br><br>Plan to walk outside more; distract negative thoughts when in public (SO: field notes, interview) |
| **2. Was new walking behaviour enacted?** | Yes, for first few weeks only (SO: field data, interview) | Yes (SO: field data, interview) | Yes (SO: interview) | Yes, started walking dog and return to water walking in pools (SO: interview) | Yes, walking am and pm and going into public settings alone (SO: interview) |
| **3. Was a supportive and collaborative social environment created?** | *Partly, describes appreciation of family articulating their support to an outsider during family meeting*<br><br>*Did feel 'intrusive' having someone come into house (SO: interview)* | *Unclear ( SO: interview)* | Yes, found family meeting valuable (SO: interview) | Yes, especially describes answers from education programme was what he was looking for (SO: interview) | Yes, some increase in engagement evident during family meeting, (SO: interview, reflective field notes)<br><br>Expressed appreciation for opportunity to discuss one on one and problem solve barriers (SO: interview) |

| Expected Outcomes | Eva | Lily | Joy | Robert | Sione |
|---|---|---|---|---|---|
| **4. Did self-monitoring of activity levels take place?** | *Minimal (SO: field data, T3 interview)* | No (SO: field data) | *Unclear but unlikely (SO: interview)* | No (SO: field data) | *Minimal (SO: field data, interview)* |
| **5. Were gains in walking self-regulation evident? I.e. did participant walk more?** | *No clinically significant change average daily steps at any time points ( SO; outcome)* *Does not consider intervention helped be more active and disengaged from walking goal to focus on home exercise programme due to fear of abduction and lack of control over companion's schedule (SO: T3 interview)* | *No clinically significant change in average daily steps at any time point. (SO: outcome data)* *Does not feel intervention helped her walk more. (SO: interview data)* | Yes, large clinically significant positive change in daily steps at follow-up. (SO: Outcome) Attributes intervention as reason why (SO: Interview) | Yes, small clinically significant change in steps at mid-intervention *but not at end intervention or follow up time points.(SO: outcome data). Does report more daily activity including dog walking, water walking and incidental walking. (SO: Interview)* *Did not use StepWatch™ in water so likely improved as expected (SO: reflective field notes)* | Yes Clinically significant increase in average daily steps at mid-intervention and follow-up. (SO: Outcome data) Describes how overcomes fear when out walking to keep on going when walking in various settings. Attributes intervention to providing ability to do this. (SO: interview) |

| Expected Outcomes | Eva | Lily | Joy | Robert | Sione |
|---|---|---|---|---|---|
| **6. Did autonomous motivation for walking-related activities increase?** | *No, Very high level autonomous motivation at baseline and mid-intervention. Some reduction post-intervention and follow-up. (SO: Outcome data) Describes self as very motivated and denies intervention helped motivation ( SO: Interview data)* | *No, autonomous motivation decreased at post intervention and follow-up. Controlled motivation increased at same points (SO: Outcome data) Not able to describe any benefits of programme (SO: Interview data)* | Yes, increase in autonomous motivation at follow-up (SO: outcome data) Describes how important walking is to her now after intervention (SO: Interview) | Large increase in both autonomous and controlled motivation over time; autonomous motivation higher (SO: outcome data). Describes pleasure in walking and satisfaction at achieving walking related goals. (SO: interview) | *No change. (High levels at baseline) Slight increase in controlled motivation over programme. (SO: outcome data). Describes great pleasure in walking and appreciation of benefits such as better energy. Attributes practice of walking to helping motivate himself not intervention per se. (SO: interview)* |
| **7.Was greater confidence and mastery of walking-related skills evident?** | *No change over time. High baseline levels, (SO: outcome data)* | *No change over time. High baseline levels (SO: outcome data)* | *Small significant reduction at follow-up/?clinically significant (SO: outcome data).* | Yes, large clinically significant gains increasing over time to nearly normal levels. Attributes intervention (SO: outcome, interview data) | Yes, large clinically significant gains increasing over time to nearly normal levels. Attributes intervention. Describes confidence walking in variety settings. (SO: outcome, interview data) |

| Expected Outcomes | Eva | Lily | Joy | Robert | Sione |
|---|---|---|---|---|---|
| **8. Did new walking behaviours become automatic and were new routines established?** | *No, abandoned walking goal and replaced with daily exercise programme*<br>*(SO: field data, interview data)* | *No change in automaticity score – remained at 100% (SO: outcome data)*<br>*StepWatch<sup>TM</sup> outcomes very low (SO: outcome data)*<br>*Describes very inactive lifestyle (SO: interview, field notes)* | Yes, clinically significant increase and gains in automaticity to above 60% threshold (SO: outcome data, interview) | Yes, clinically significant gains in automaticity to above 60% threshold (SO: outcome data) New routines established and sustained even after wife passed away (SO: interview) | Yes, small increase at follow up but already automatized (i.e. above 60% at baseline (SO: outcome data)<br>Family members comment on new and frequent walking behaviours (SO: interview) |
| **9. Were walking skills transferred to new settings?** | *No change ( SO: interview)* | Described new walking-related activities undertaken after intervention such as walking to visit cousin, visiting brother different suburb and return to islands for vacation *but did not relate intervention to these achievements (SO: interview data)* | *No transfer to new settings (SO: interview)* | Yes, describes being out in garden much more, visiting local diary etc. and continuing with outdoor walking group. Describes no problems walking in real-world settings now (SO: Interview) | Yes, describes walking in many new settings such as going to church, shopping malls, friends' houses, parks and the beach.<br>(SO: Interview) |

| Expected Outcomes | Eva | Lily | Joy | Robert | Sione |
|---|---|---|---|---|---|
| **10.Was there improved physical integration?** | *No, high levels physical integration at baseline; small clinically significant loss at mid intervention but returned to normal levels post intervention and follow up.(SO: outcome data) Reasons why not clear from qualitative data (SO: interview data)* | *No, high levels of physical integration at baseline and did not change (SO: outcome data)-but see above* | Yes, clinically significant increase in physical integration.(SO: outcome data) Described doing more around house but not away from home; had cataract operation and more stable medically now with no epileptic seizures (SO: interview) | Yes, clinically significant large increase in physical integration (SO: outcome data) Several reports of satisfaction with walking in variety desired settings (SO: interview data) | *No, clinically significant reduction in SIPSO-P at mid intervention and at follow-up still less that baseline (SO: outcome data).* *Reports substantial change in physical integration including standing at church, first to get out of car for supermarket, attending funerals and even forgetting he is "disabled" (SO: interview)* |

| Expected Outcomes | Eva | Lily | Joy | Robert | Sione |
|---|---|---|---|---|---|
| **11. Was there improved social integration?** | Large clinically significant increase in social integration at mid intervention. Score back to baseline at end intervention. Gain in social integration at T3 (SO: outcome data). Describes pleasure walking with family member during first few weeks and. renewing old acquaintance at T3 (SO: T1, T3 interview) | Small clinically significant increase in social integration at post intervention and follow-up. (SO: outcome data). When prompted able to describe more contact with extended family now as shown on EcoMap at follow up interview (SO: interview) | Moderate clinically significant increase in social integration (SO: outcome data) describes being able to negotiate better with visitors so had more time to herself (SO: interview) | Large clinically significant increase in social integration end intervention, slight drop at follow-up but still above baseline (SO: outcome data) Wife passed away between T2 and T3. Describes making new friends, continuing to organise walking group, and relating better to family and friends (SO: Interview) | Large clinically significant increase in social integration at mid and end intervention. *Clinically significant decrease at follow-up (SO: outcome data)* Joins gym, enrols in healthy eating programme, initiates social contacts, forgets he is "disabled" at times (SO: interview) |
| **12. Did life circumstances and wellbeing improve?** | Slight change: Taking initiative in social relationships outside family and some change in relationships within family (SO: Interview, Reflective field notes) | Slight change: relationship with extended family improved, visited family in islands Denies change due programme but agrees social contact is different now (SO: Interview data) | Slight change: Feeling better and functioning better; likely be range of factors including improved health, vision, and better daily routines such as regular bed time and daily activities. (SO: Interview data) | Substantial change: Eating better, more organised, seeking go back to work, doing housework, easier to talk to (SO: Interview data) | Substantial change: More energy, enthusiasm, less angry with family members, forgets disabled, visits friends, family impressed (SO: Interview data) |

# Appendix Z: Phase 3b- Analytic jottings

**Analytic Jotting A; comparing outcome patterns of participants who had convergent findings**

More reflections are coming to mind as I am sitting with my data. What are the similarities in the outcome patterns between Sione and Robert? The outcome patterns do appear strikingly similar for two very different men.

The similarities include:

- Being nice and communicating better with people
- Being more open with people
- Commitment to being positive, focusing on positive
- Valuing sharing with group participants
- Making new friends
- Taking initiative in social relationships
- Markedly improved on confidence
- Commitment to growth (avoidance being  "dormant"/"bound" state)
- Taking a daily walk habit
- Relatively high levels of autonomous motivation at the outset, and slight increases in autonomous motivation over time, but larger increases in controlled motivation (although ratio still in favour of autonomous motivation)

So in comparison to what was predicted in the treatment theory, what did they do? They:  enacted plan, felt collaborative synergy, <u>did not self-monitor</u>, excellent self-regulation of walking skills, <u>increase in controlled motivation</u>, mild increase to maximal autonomous motivation, more energy, more willingness to try new things, automaticity in habits, transfer of skills to new settings as needed, excellent self-regulation in general actually, ability to keep on going, love and value of sharing, increase in perceptions of support, improved physical and social integration, improvement in life circumstances; and both attributed these changes directly to the resources provided by the intervention

It seems to me that they both have adopted a distinctive mind-set over the course of the programme, it reminds me of the literature on growth mind-sets in education. It also seems like they have a virtuous cycle going on, where one positive change leads to another. This is consistent with what was proposed by the treatment theory which probably means that several interventions mechanisms were activated.

How about the other participants? Their outcome patterns were less consistent that what was predicted. Joy only had the family meeting and not the rest. She did however manage to adopt a new habit that increased her walking and kept this up so could be integrated into daily life. She did not have increase in confidence...she did not experience as much positive change which suggest the automaticity route was activated but not the collaborative route- partially successful

Eva abandoned her goal, did not develop walking habit that was able to lead to sustained change, opted out social opportunities. Main limitation was fear and contextual factors outside her control meant that she could not sustain this goal. However she chose to redirect her energies and still managed to increase her social integration through a different route that provided by the programme- indirectly successful. Lily participated and managed to become more socially integrated in line with her goals, but she had difficulty reflecting and did not really want to walk more,

So in summary; programme worked in different ways; appeared to be two main routes at work. The most beneficial route is to have both routes (have synergistic effect) which has the potential to create a virtuous cycle with spill over into number unrelated areas. But just automaticity route has value. However overcoming unconscious fears seems a significant unexplored barrier.

**Example of analytic jottings B: Participants who showed divergent outcomes in social integration**

Eva did not come to any of the education groups during the first four weeks and only come to two out of the four walking groups in the second month.
But on reflection her SIPSO does make sense after all, 12 baseline, 15 mid assessment in tears because of social aspects walking with her family member, back down to 12 when that failed and back up to 15 at the end through her own efforts to initiate social contact with people. So the programme kind of fuelled her to take initiative to reach out after several years...

Oddly enough for Sione, SIPSO was low, yet the interview data shows he is the most socially integrated of all the participants after the intervention
One explanation for discordant finding might be his standards have changed, expectations have increased, identify has shifted, feel almost normal

I think that the mix of data is very useful to quantify direction and magnitude; as don't get that from qualitative data as clearly, and allows to go back and look for closely, for example social integration findings for Eva at the end of the interview after the questionnaires have been done

I wish I could have shown them the findings and discussed it with them. I wonder if that could be a useful strategy [in future]?

**Example of analytic jottings C: regarding rival explanations**

This process is not about building or increasing or finding motivation; it is about building confidence in one's competence which is about self-regulatory skills to overcome challenges
Sione has high motivation, he talks about energy, and he says it has nothing to do with motivation...

I think I am starting to see that this is not an internalisation of motivation going on here, but an internalisation of self-regulation. There is an identity change, he sees himself now as a daily exerciser, the exercise itself is what motivates him, it is intrinsically motivating, motivation is not the mediator, his thinking is shifting, moving, how he sees himself, not as lazy, but as some who exercises every day even if it is raining,

## Appendix AA: Phase 3b-Summary of quotes from first cycle coding

| | | Mid-Intervention (T1) | Post-Intervention (T2) | 3-month follow-up (T3) |
|---|---|---|---|---|
| Gaining energy Eating and Sleeping better | Robert | | Oh, even my eating, my sleeping, it all changed for the better. You feel healthier, it is good to wake up in the morning, have a good stretch, you are awake. I really enjoy it (Robert T2:257-258) | It makes you aware of things. Your eating pattern and your sleeping pattern have definitely got to change.....Definitely I am aware of what I put into my body today. Not just go and get a mince pie,or something ... (Robert T3 372,378) |
| | P5_Sione | I feel more energetic, yeah, because before I felt if I walk like, around there, I felt tired, but now no, I feel power! (Sione T1: 91-92) | Because before I short of breath. But not now... And when I am sleeping ..it feel easy to lie down and go straight to sleep. Before it very hard for me to go to sleep but now easy to go to sleep and sleep no more until morning.... Before ....I felt lazy and sleepy but now, it has gone! (Sione T2: 16-33) | Because I feel more energetic, yeah, because I walk every day, so I ..because if I stay here I feel useless, I don't do anything so I just sit in the couch but now I.. what I say I think that I have got the power to do whatever I want to do. (Sione T3: 68-70) |
| **Being active and walking everyday** | P4_Robert | | The best thing of all is to take the dog for a walk...we head out there every day (Robert T2: 169,177) | I have started getting back to the pools and everything surely but slowly... Last four or five weeks. Twice a day (Robert T3: 44, 47) Yes yes more active now. More healthy now than moping around. (Robert T3:173-174) |
| | P5_Sione | Because I exercise more, and I exercise everyday so it makes me more active. ( Sione T1:127) I tell myself now is the time to do your exercise.... Yeah. In the evening if I lie on the couch for | More energetic to walk around and about (Sione T2 12-13) I really don't know how to explain it, but within me I find there is a different between before and now...because I walk most days now and I feel fitter, fit | But now I do it on my own, I don't have to listen to them, when I woke up in the morning I just walk without letting them to telling me what to do. (Sione T3:20-21) |

| | | | | |
|---|---|---|---|---|
| | | nearly one hour, two hours. It is like someone said to you. 'Stand up and go for a walk' so I stand up and go for a walk (Sione T1: 136-138) | than before... And I told Caroline, the programme helped me a lot because of the, make me walk every day, doing my exercise every day (Sione T2: 95-97, 101-102) | |
| **Gaining & rebuilding confidence** | Robert | | More confidence in my mind (Robert T2:192) | I reckon I went backwards definitely backwards but slowly regaining, the pools and everything else build my confidence up again and getting back into it. And staying there. I didn't go very far backwards (Robert T3: 112-114)<br><br>Like in the mornings I can take my medication and grab the lead and away we go without a second thought (Robert T3: 247) |
| | Sione | I feel confident...yeah...about myself...not only here.. but when I go into public. I felt confident (Sione T1: 35-36)<br><br>If I am scared while I am walking-I try to keep on walking. Like when I go around the block and when I come through the alleyway. ...sometimes I feel that might be someone come and push me away from the walkway so I try to put it aside. I try to forget so that I keep on walking<br>(Sione T1: 170-174) | Sione: Now I am really confident. I think because of the strong of my foot. ...Because when I cross the road it is heavy, but now it is strong and I just walk. Yeah, not like before. Yeah I am very confident (T2:175-177) | Before I never go around, I used to stay here all day but now I can go anywhere, anywhere and whenever I want to go. I will go. (Sione T3 29-30) |

| Changing thinking from negative to positive | Robert | | ...a lot of positives in front of me, to challenge, to take one step at a time (Robert T2:211) | But working away at the programme and learning how to approach stuff again, that is the main goal. Once I feel, once I get all of that back into place then I will be able to carry on my journey in life.., it is that mental, that helps to get it going. Once you taken the first step it all follows, automatically fall back into place and keep it in place. But keeping it in place. That is the main thing ( Robert T3 135-137, 141-143). |
| --- | --- | --- | --- | --- |
| | | | Instead of being angry and just ignore it, go onto another path (Robert T2: 351) | |
| | | | Just face it head on and deal with those issues (Robert T2: 394) | |
| | | | That is the key to it all. It is the willingness to have a go (Robert T2:415) | Yes, stay positive. Eat healthy and exercise.. That is where I am about to take my journey, right on those lines. (Robert T3: 396-397) |
| | Sione | I think my thinking now is much better than before because I always think negatively, about my sickness...but now, when I look at things, I try to look at that ...in positive way. Because if I look at that with negative side it presses me down (Sione T1: 64-66) | If there is any negative stuff- because there is negative coming on your way...for me I try to *let it go*, I don't hold onto those stuff, or try to think about those stuff. (Sione T2: 83-95) | Because I found out the differences, so all I have to do, I keep on that level, I don't want to go back down ( Sione T3:77-78) |
| Walking, talking and sharing together | Robert | | We share more. We are open with each other more...When you are walking you have got time to think and share. (Robert T2:32,34). | The main benefit ...is the experience that we all went through, otherwise we all wouldn't have met the way we met, unfortunately but we look at the positive side, but if we can share what happened, where, why ...so we don't become dormant, |

| | | | | |
|---|---|---|---|---|
| | | | we are talking to another victim which has had the same experience as we have, affected them in a different way and affected us in a different way (Robert T2:56-57) | and just hopefully there is a good life ahead of us (Robert T3; 263-266) |
| | P5_Sione | We share with the groups…; because my experience is different from my brothers and sisters that we have stroke together so we share the experience…it make me feel confident; and help me a lot because what his experience is different from my experience so when we share and put it together it helps me a lot (Sione T1: 45-52) | Interviewer What part of the programme helped you the most to change this habit? Sione: I think the walking itself …yeah..and the other thing, when we join with other people. We talk about it, and we walk together (Sione T2: 44-45)  Because sometimes I think to myself I am the only one, the only one in the boat, but when I went there and shared with others that we have the same difficulty, I know there is someone there, will help me … maybe he is worser than me but he is walking alright. So, I need to learn from those people. Yeah that is what I love to go (Sione T2: 56-60) | Because I want to like to go and talk and walk with someone that you have disability together so if you see the improvement (Sione T3:99-100) |
| **Impacting daily routines and going out** | Robert | | Interviewer; this morning for example did you do anything different than what you would usually do? Robert: Yes definitely, getting up and going for a walk, making my bed…having breakfast | Well is still take the dog for a walk in the mornings. I am going back to the pools. Then after that I come round to see if there is anything to be done around the house. I just got to be allowed to use the stove. But other than that, I try to get out most of the |

| | | | | |
|---|---|---|---|---|
| | | | Interviewer: You weren't having breakfast before?<br><br>Robert: No. Just plop down and watch TV. Getting something ready for tea out of the freezer:<br><br>Interviewer: so, you are much more organised in all areas?<br><br>Robert: Even the washing. Yeah. I do the washing too (Robert T2:308-317) | time and I get to bed about half past ten, around those hours (Robert T3: 177-180). |
| | Sione | I tried to do more cleaning in the kitchen, and use my weak side..weak hand...so I try to do more things (Sione T1:180-181 | | Sometimes I do the dishes, even the vacuuming, Cleaning the dining table. Yeah, a little housing work. I didn't do it before but now I do it (Sione T3: 157-160) |
| | | I find it different now because before I never go to public because I felt scared or frightened. I don't really like to see people, but now I can go, like to the shopping and watching people.<br>(Sione T1: 38-40) | Yes very changed, before I never go church. I used to ...stay here by myself. I told my wife it is no good for me to go, but now I go with them, because I am alright to walk, and if the church sing, if they want to stand up to sing, I'll stand up for five to ten minutes and then sit down. So now I participate in church much more than before.<br>(Sione; T2: 199-205) | Man it is much, no words! because I see the difference, I see the difference. The starting of my stroke was very very hard because I never go out, I never meet friends, I never go shopping, I never go to church, I used to stay here all day and think what happened to me, but now. Sometimes I forgot that I am disability and I don't know why, I just go like a normal [person] It is funny eh? But I think that is the difference that I find.(Sione T3: 43-47) |
| **Impacting others Communicating better** | Robert | | Interviewer: How has that impacted others around you? Have they noticed a change? | Even going out into the community changes along the way. You don't see it, people will tell you. 'You sit down and talk |

| | | | | |
|---|---|---|---|---|
| | | | Robert: Oh, yes all of them. He is a different man…he is outside, he is having breakfast. Everything changes for the better, more friendlier and talk to him, he is not ignoring us or walking away (Robert T2 259-267) | to us'[they say]….One of the main persons is the shop keeper. You go in there and get a loaf of bread yesterday and you were 'bad bro' and now you stop and you talk. 'You are changing mate. What have you been up to?' Before you know it he is part of your life…Without realizing it I made an impact on his life or it might be just getting the newspaper or bread or something but we started sharing with each other, That was bloody awesome! (Robert T3:380-391) |
| | P5_Sione | Sometimes you angry, angry a lot, because like if my daughter don't listen to me I feel angry, but now no. Yeah and the way I see things. Yeah (Sione T1: 94-95) | My wife and the kids. They just said to me. They said 'Oh Dad you are getting stronger, not like before'. Yeah it is puzzling my family here, my sisters and brothers. They see me there is a change. Because before I never walk. But now I walk. And they said to me. 'Why?' 'I said to them, 'Oh I just fight my battle'. (Sione T2:73-76) | I think it is all the same, but the only difference is the way I communicate with them. Because I before I never freely communicated with others, but now, like going to a funeral, I never go to a funeral but now if there is any funeral in the family I'll go, and talk with them. (Sione T3:55-57) |
| **Keeping on going** | P4_Robert | | When walking you just take one step at a time, but those obstacles you got to think, you have to think and rethink. (Robert T2 236-237) | So I have just got to keep going, to motivate myself to keep going and get stronger and stay there because I know I am not going to cross over to that other door. (Robert T3: 161-163 |
| | | | | I have got a couple of goals there to see the light at the end of the tunnel but just working away, one step at a time (Robert T3:183-184) |
| | | | | The reality is though I can shift these goals. The reality is I can do it. The last couple of months I have had to let the lawn mowing |

| | | | go for a bit. But I definitely got to pick up on those again as well. (Robert T3: 208-210) |
|---|---|---|---|
| P5_Sione | it helped me a lot to think positively…and if it rain, try to find, just to do some exercise. Because sometimes If it rains, you feel lazy to do your exercise but during the day there is a fine weather so you go outside and do your exercise (Sione T1:83-85) | I want to walk. So, every day I keep on fighting. And I am looking around for sources to help me out. Yeah that is why I want to go to those people and walk together with them. (Sione T2:77-79) | Because I found out the differences, so all I have to do, I keep on that level, I don't want to go back down, I just keep on fighting, yeah because when I walk in the morning every day, it comes to my mind to keep on fighting, , don't lose hope, because I knew that there is somebody that had stroke now is doing alright now. So, I think to myself, if he can do it I can do it, that's the sort of thinking that push me to stick into those plans. (Sione T3: 77-81) |

# Appendix BB: Phase 3b- Example of narrative description of *Gaining Confidence* developed during second coding cycle

<u>Core processes-Self-regulatory Mastery- Gaining confidence</u>

<u>**Gaining confidence**</u>

***What is the <u>context</u> in which this is embedded?***

Before the intervention Sione lacked confidence to walk in public alone and felt scared and frightened when walking outside beside his house because he was concerned that someone would hurt him or push him off the path

> *Sione: It is the same going out in public or I just go for a walk because I feel I will have a fall, or someone push you away from the walk ..yeah*

When asked about confidence after stroke Robert describes how having a stroke leads to a kind of withdrawal from society

> *Interviewer: Can we talk about confidence now, because it is a really interesting issue because a lot of people talk about losing confidence after their stroke. Is that true for you?*
>
> *Robert: Yes. You become a closet, in remote control. Close the curtains. You don't want to know what is going on*

***What <u>conditions</u> give rise to this process in this story?***

Some practices seem to boost confidence (e.g. walking itself, overcoming fears during walking, walking that helps process emotions, going to the pool, sharing experiences with others.) Negative experiences that lead to being dormant seem to drain confidence

***What are the action/interaction strategies by which it is handled, managed, carried out?,***

- Repeated walking boosts confidence for Sione and helps him walk more efficiently which also helps his confidence
*Interviewer: What activities have increased your confidence the most?*

    *Sione: only the walking*

> *Interviewer- because at the beginning you told me you were a little scared?*
> *Sione : at the start of the programme yeah, but now I am really confident*
> *Interviewer: How come?*
> *Sione: I think because of the <u>strong of my foot</u>. That is a part of my thing. Because when I cross the road it is heavy, but now it is strong and I just walk. Yeah, not like before. Yeah I am very confident. ( 171-177 Post intervention)*

- During walking Sione has to face his fears of someone pushing him off the pavement and he tries to distract himself to overcome this fear

  *Interviewer: So if you are not feeling confident…little bit scared…what do you tell yourself to overcome this problem?*

  *Sione: if I am scared while I am walking- I try to keep on walking. Like when I go around the block and when I come through the alleyway. …sometimes I feel that might be someone come and push me away from the walkway so I try to put it aside. I try to forget so that I keep on walking…yeah*

  *Interviewer: How does that feel?*

  *Sione: Feel good. When I got here -I feel good ( 150- 174)*


- Going for a walk helps process emotional issues for Robert, this process gives confidence in the mind

  *Interviewer: So what is it you think about the walk that gives you the confidence? Can you try and think a bit. Can you tell me some of your thoughts that goes through your head when you go walking?*

  *Robert: I can explore a lot of things and open up a lot of things, a lot of issues that I had the night before, the day before, download or the garbage and try to work through it. you know going around the block once. Oh hang, I had better do it again, I am not ready for this yet*

  *Interviewer: So you use it to process all the garbage that is going on?*

  *Robert: Yes all the garbage that happened the night before a good night or bad night, or something it was last week or something forgot to do, or I should be doing*


- Getting back into the programme is expected to boost confidence for Robert

  *Robert: I reckon I went backwards definitely backwards but slowly regaining, the pools and everything else build my confidence up again and getting back into it. And staying there. I didn't go very far backwards ( 112- 114 Follow-up)*

  *Interviewer: Confidence means different things to different people, you have talked to me last about having confidence in your mind. So looking back what things have you done what activities have boosted your confidence the most?*

*Robert: Um [long pause] Me. That would be the best way to describe it. There is more of it now, thinking about it, like in the mornings I can take my medication and grab the lead and away we go without a second thought, in the afternoons when I have my bath and the washing it has improved a hell of a lot actually. Because I know that I don't have to be home for a certain time for [wife name] now I can use that for good reasons. There is heaps here now. Definitely*

*Interviewer: It sounds like a lack of confidence is not really an issue for you any more? It sounds like you are confident when you are out and about now.*

*Robert: Yeah , it is just getting back in this programme is going to boost it even even more. Yeah. Though hopefully in a couple of months I will just do it now (T3 :242-252)*

### What are the consequences of these strategies?

- Positive emotional sense that is closely related to confidence

  *Interviewer: Can you tell me about an experience recently when you had more motivation than usual?*

  *Robert: I feel confidence in myself, I feel good.*

- Sense of strength

  *Sione: give me strength*

  *Interviewer: So you feel stronger than before?*

  *Sione: Mmmm*

- Feeling very confident whatever the setting

  *Interviewer: Can you tell me about one time that you went for a walk and you felt more confident than usual?*

  *Sione: Every time*

- Knowing enjoy doing desired activity and feeling free from internal (e.g. fears) or external constraints (social obligations)

  *Interviewer: So which of the activities you have done have most boosted your confidence do you think, got you to that point now where you are?*

*Robert:: Just knowing that gotta do it, and knowing that I enjoy doing it, and knowing that [name of wife] is not an issue any more so I can do more and feel free more to do it and enjoy it more.*

## Appendix CC: Phase 3b- Matrix 2- Summary of time-oriented matrix over time

T1- Mid-Intervention, T2 Post Intervention, T3 Follow-Up at 3 months after end intervention

| Revised Core Processes | C | M | O | Causation Codes |
|---|---|---|---|---|
| Being active every day | Previous exercise habits + paralysed by negative emotion + desire change | relevant information + synergy +plan overcome internal and external obstacles + goal attainment > | regulation negative emotions> keeps on walking > experiences positive emotions > success > more energy > greater drive to be active > sleeps better > feels energetic and powerful> does more housework > walking automatically > greater confidence in public> greater awareness other healthy behaviours | Sione: <br><br> T1: keeps on walking greater drive to be active >feels energetic and powerful >greater confidence in public> walks more often + does more housework <br><br> T2: keep on walking >more energy+ better sleep quality +feels fit+ foot stronger > more confidence> keeps walking > family notice change <br><br> T3:> takes initiative to walk + does housework > participates enthusiastically social opportunities > keep on walking > change in self-concept <br><br> Robert: <br><br> T2: walking automatically as knows what to do + dog (friend) + fresh air + emotional ventilation > sense making? > emotionally ready for the day > household tasks + confidence <br><br> T3: walking automatised >greater awareness eating >open changes >commitment to work on health |
| Staying positive and open to learn | Avoids going out; | Learner mindset+ perceptions of | more self-determined and socially connected; Enhanced | Sione: <br><br> T1: avoids going out +feels scared> think positive +finds way around obstacles + let go worry + stay |

| | emotionally shut down | support + social comparison + cognitive participation + reflection , acceptance, reflective monitoring | wellbeing and resilience to setbacks; | focused >Keeps on going + enjoys going shopping by himself<br><br>T2: >doesn't feel alone + encouragement and example+ open to learn> less worry<br><br>T3; Enthusiasm + acceptance + reflect difference + keep working >feels free and autonomous<br><br>Robert:<br><br>T2: eye opening experience + challenge + one step at time thinking?> coherence> enjoyment + vision<br><br>T3: commitment be positive + knowing support available + sense achievement + focus > hope >resilience |
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| Gaining confidence by working through emotional obstacles | Fearful and lacking self-confidence | one step at a time + learner mindset + walking daily + overcoming fear + enjoyment | feeling confidence and strength and motivation | Sione:<br><br>T1 Not confident +fearful >walking + overcoming fear> feeling confidence and strength<br><br>T2 foot strong + confidence> just walks<br><br>T3 Does not think about confidence<br><br>Robert:<br><br>T2 Tackling challenges one step at a time + walking dog > Confidence gained +motivation<br><br>T3 Way of thinking help overcome + enjoyment + slow but surely > working way >building confidence |
| Gathering together to discuss | Coming to house; seen as intrusion and creates resistance by | Collaborative work (Discussion together face to face, | Enhanced self-determined behaviour | Sione:<br><br>T1: She came here + we discussed> most helpful<br><br>T2: Phone call > difficulty communicating > no change<br><br>T3: no discussion |

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| | some; others who are ready to change welcome it | cognitive participation and sense making;) + adoption learner mind-set + self-awareness ( persistence + Understanding | | Robert<br><br>T2 cognitive participation + sense making > adoption learner mind-set) + self-awareness > autonomous motivation/self-determined<br><br>T3 Emotional barriers to receiving help > persistence and understanding individual issues > agreement to accept help > readiness to collaborate > develop intrinsic motivation ; openness to receiving help |
| Walking, talking and sharing | Walking outdoors makes feel relaxed and pleasantly stimulated ; sharing stories; environment creates opportunities for social connection and mental stimulation | Coherence<br><br>+ perceptions of support + collective action + reflective monitoring | Coherence<br><br>+ emotional sustenance( ventilation and validation) + active coping via coherence building opportunities + perceptions of support + collective action + reflective monitoring | **Sione:**<br><br>T1 sharing stories>comparing own story>puts it together>confidence + coherence<br><br>T2 Walking + sharing > finding others face similar difficulties and share similar experiences > makes sense>coherence<br><br>Wants meet group see progress but not able to<br><br>Robert<br><br>T2 Walking + talking + feeling open to listen > shared understanding + friends<br><br>T3 Talking together>n stay engaged + people there for me > hope support > reduces anger > feeling not being alone> communicating better with others >hope future |
| Communicating better with others | Experiencing positive emotion, more aware of negative | Improved emotional regulation | People respond more positively , notice change, initiates more social connections outside home > better social integration | Sione<br><br>T1 feels more energetic > sees things differently >gets less angry at daughter |

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|---|---|---|
| emotions and have to regulate them | Communicates openly and honestly | T2 Communicates openly>greater understanding > family notice changes |
| | | T3 communicates openly and honestly with people outside family > initiates social interactions |
| More aware of emotions and experience positive emotions | | Robert |
| | | T2 Aware of emotions + asking questions + walking and talking>seeing people differently >being open to listen and learn > being friendlier >seen as different + more support given as needed |
| | | T3 accepting emotions + be open to communicate + family monitoring > people notice difference > more positive social connections |

**Appendix DD: Phase 3b- Summary of evidence for refined mechanisms of action from all five participants**

| Mechanisms | Definition | Eva | Lily | Joy | Robert | Sione | Action/ Interpretation |
|---|---|---|---|---|---|---|---|
| Energy (EB1) | Unspecified energy – related mechanisms that leads to sense greater energy and better sleeping | it was just when I got more energy, so it was just a little patch, only do a little patch but things start little and then get bigger. I'd say it was two weeks or maybe three weeks ago. <br><br> I: how comes felt more energy? <br><br> Eva: Well, I always think of it as a miracle!...**I am not really sure** (Eva T3: 73) | | | Oh even my eating, my sleeping, **it all changed for the better**. You feel healthier, it is good to wake up in the morning, have a good stretch you are awake, I really enjoy it?(Robert T2:258) <br><br> It makes you aware of things. Your eating pattern and your sleeping pattern have definitely got to change, (Robert T3: 372-373) | **I feel more energetic**, yeah, because before I felt if I walk like, around there, I felt tired, but now No, **I feel power**! Yeah more (Sione T1: 91-92) <br><br> More walking and exercising and energy. More energetic to walk around and about. ..Because before I short of breath. But not now, because I think that I do more exercise and it help me to, for my breathing. And when I am sleeping at night I feel; I feel what you call?; I feel [pause to find words]...it feel easy to lie down and **go straight to sleep**. <br><br> Energy to walk around and doing things over here, during the day. Before I used to sleep during the day. Sleep sleep sleep. But now I don't sleep during the day, I only sleep at night now. I **felt lazy and sleepy but now, No it has gone!** ... I find it is different. ( Sione T2: 12-25) | Added into refined outcome chain✓ <br><br> Intervention seemed to activate mechanism that helped increase energy and improve sleeping |

| Mechanisms | Definition | Eva | Lily | Joy | Robert | Sione | Action/ Interpretation |
|---|---|---|---|---|---|---|---|
| Information provision: knowledge about recommended behaviour (K1) | An awareness of the content of physical activity recommendations after stroke | | | Caroline.., coming to give me advice... "walking is important for you" (Joy T1 275-276)<br><br>Caroline said "walk as far as you can". I did it to walk near my home. It was so interesting to me. I said hello to passer-by. I walked with the walker (Joy T1 206-209) | Even those group sessions before we went on the walk, there was a lot of things that I was exploring you had a lot of the answers to what I was looking for and trying to achieve (Robert T2:123-125).<br><br>The thinking was always there but then the challenge about the pamphlets that you put in front of you, there is my answer there.. No, this is going to be good for me. (Robert T2 153-158) | I think everything, when she comes here and we gather together and discussed...about stroke, it is helpful (Sione T1:13)<br><br>I: How did that meeting go for you?<br>S: Good.<br>I: What was the most helpful thing about it?<br>S: About walking...about walking and wellbeing..<br>I: Was it the explanation she [Caroline] gave you, the support you got from people, what was it?<br>S: What she taught me, also the support from people ( Sione T1: 26-29) | Generic info provision (K1) supported by data and seen to be relevant for some but specific self-awareness not (K2) |

| Mechanisms | Definition | Eva | Lily | Joy | Robert | Sione | Action/ Interpretation |
|---|---|---|---|---|---|---|---|
| Planning: intention (P1) | A conscious decision to act in a certain way | ..it is good but I don't want to make something of it. Other than to say that **it fits what I am wanting to do anyway** (Eva T1 126-127) | | I just wanted **to devote myself** to walking, it is develop my wellbeing (Joy T1 11) | Oh definitely, when that envelope ended up in my mailbox, I jumped at the chance. (Robert T2: 142-145) | I think my thinking now is much better than before...but now I, when I look at things, **I try to look** at that with positive, in positive way (Sione T1: 64-66) | Intention to act and/or think in certain way influences engagement |

| Mechanisms | Definition | Eva | Lily | Joy | Robert | Sione | Action/ Interpretation |
|---|---|---|---|---|---|---|---|
| Planning: goal setting (P2) | A goal is a mental representations of outcomes or end states that an individual is committed to | I think it is important to see that my rehabilitation is a process and this 8 week course is a process in my life of getting back so whilst I acknowledge it | I: What most helpful thing she did during the meeting? L: The goal setting...for me I want to do my [specific teaching qualification]...And I like to airfare from NZ to [Pacific | {Goal not directly stated- ?walk more or take medication regularly to improve daily routines} | We all had big goals before but apparently it given us a second chance and we are taking it (Robert T2: 25-26) And getting involved with Mother Nature, your feelings just the real goals of | At the meeting The goal that we set about is only it is only my walking...I need to walk more confident..yeah. (Sione T1 79-80) | Articulating explicit goals could energise action especially when linked to meaningful personal goals |

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| | | is an important part of my process, it has to fit in with the goals I have already set for my whole life (Eva T1:107-110) | Island] (Lily T1: 71, 79) | | life. There was the answers right there, but it is keeping that door open that is going to be the biggest challenge (Robert T2: 160-162) Definitely trying to keep it open. Yeah you got to work at it. It just don't stay open, you have to achieve some goals, have some goals and go forward. (Robert T2: 274) | | |

| Mechanisms | Definition | Eva | Lily | Joy | Robert | Sione | Action/ Interpretation |
|---|---|---|---|---|---|---|---|
| Motivational-Autonomy (Mo 1) | Human autonomy includes the combination of volition (free will) and deep personal | No as you can hear, or may or may not have ascertained, but I am very determined | | ..I can **freely** walk around the house. I can *freely* walk to church without help | Yesterday it was two doors, one to **freedom**, one to trouble. Today the right door for opportunities to | I realise now that I am in this situation so I feel **freel**y now... I feel freely to go anywhere I want. Yeah. Even the beach! (Sione T3: 39-41) S: Like doing exercise I do it my own... before I listened to someone else to tell me what | Choosing to act in ways aligned with one's desires leads to sense freedom and produces positive |

| | Definition | Eva | Lily | Joy | Robert | Sione | Action/Interpretation |
|---|---|---|---|---|---|---|---|
| | relevance and is experienced as a sense of psychological freedom. | to get as much as I can out of rehabilitating because I have some very important goals for myself so this just reinforces what I am doing so (Eva T1:112-114) | | Walking with Caroline was the most important thing. I see the view, after a while I walked freely to house and garden and carpark neighbour by South Mall town (Joy T1: 22-23) | go forward (Robert T2:165)<br><br>Just knowing that gotta do it, and knowing that I enjoy doing it, and knowing that [name of wife] is not an issue any more so I can do more and feel free more to do it and enjoy it more.<br><br>(Robert T3: 258) | to do. Like my wife...said to me. 'Oh, go and have some exercise'. But now I do it on my own, I don't have to listen to them, when I woke up in the morning I just walk without letting them to telling me what to do. (Sione T3: 18-21)<br>S: Because I feel more energetic, yeah, because I walk everyday...because if I stay here I feel useless, I don't do anything so I just sit in the couch but now...I think that I have got the power to do whatever I want to do.<br>(Sione T3 168-170) | emotions which motivated behaviour |

| Mechanisms | Definition | Eva | Lily | Joy | Robert | Sione | Action/Interpretation |
|---|---|---|---|---|---|---|---|
| Motivational (contextual) transfer (M03) | Successful change in a specific context energises willingness to try new or similar | I have someone else to wash my hair but I did my own hair last week...Well... in as much | | | [the programme] opened another door that I thought wasn't possible. That I knew there was another door there someway. But I was trying to pull that open. But you eased it open, and this whole variety of things | I love the place like see the flowers and the trees. We went to the Botanical gardens I love it. I want to walk there all day! Even though the going up the hills I still walk. I still go. Because It is a different place. Different from where I...because | Added into refined outcome chain with focus on motivational transfer rather than greater efficiency of |

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| | behaviours in new contexts | as I am giving it another go Eva T1 189-192 | | | behind that door. I am experiencing that today…: In touch with your feelings and where you want to go , what you wanted to achieve, yesterday's goals they are no more, you have got to seek new example and take one step at a time (T2: 96-103)<br><br>**Even going out into the community changes along the way**. You don't see it, people will tell you. 'You sit down and talk to us'[they say]…. (Robert T3:380-391) | I walk around the road, same houses same place everyday but if you go somewhere else you see the different (T2: 138-144)<br><br>Now I am really confident. I think because of the strong of my foot. …Because when I cross the road it is heavy, but now it is strong and I just walk. Yeah, not like before. Yeah I am very confident (T2:175-177)<br><br>Before I never go around, I used to stay here all day but now I can go anywhere, **anywhere and whenever I want to go. I will go**. (T3 29-30) | movement as key factor in contextual transfer, and this is likely related to greater self-regulatory confidence |

| Mechanisms | Definition | Eva | Lily | Joy | Robert | Sione | Action/ Interpretation |
|---|---|---|---|---|---|---|---|
| Mastery: Greater perceptions of safety (Ma3) | Judgement made by person around how safe physical environment is for them | This is a sort of conundrum here….whilst I think I could just get up and do it …but there are also the safety issues, …there are…you never know what other | | I walked freely, with somebody else, Caroline was there, if anything happen, | | I:How confident were you before the programme?<br><br>S: not really confident<br><br>I: Was that only because you were scared of going out in public or was there anything else? | Data support this mechanism so keep in outcome chain; Walking with someone else could |

| Mechanisms | Definition | Eva | Lily | Joy | Robert | Sione | Action/ Interpretation |
|---|---|---|---|---|---|---|---|
| | | people have got.., because ...this is what I sometimes think, it could be that someone could be lurking around and **pounce on someone who is not 100%.** ... Only in sense that I like [name family] coming with me, and that has sort of reinforced through the programme and that is a good thing (Eva T1: 246). | | Caroline was there to support me. I think I walked with the group is most important thing for me. **Walking alone is not right for me** (Joy T1 26:28) | | S: It is the same going out in public or I just go for a walk because I feel I will have a fall, or someone push you away from the walk ..yeah<br>I: Can you tell me about one time that you went for a walk and you felt more confident than usual?<br>S: **Everytime**...<br>I: everytime?<br>S: yeah...most of the time (Sione T1: 151-151)<br>: yeah I find it different now because before I never go to public because I felt scared or frightened. I don't really like to see people, but now I can go, like to the shopping and watching people (Sione T2: 38-39) | temporarily increase perceptions of safety identifying and overcoming fear helpful to promote self-confidence over longer term [see emotional self-regulation Ma 4] |

| Mechanisms | Definition | Eva | Lily | Joy | Robert | Sione | Action/ Interpretation |
|---|---|---|---|---|---|---|---|
| Mastery: Cognitive Reappraisal of capabilities (Ma1) | Greater confidence and trust in capability of one's own body to meet the | | | I went as far as....I really enjoyed the garden...seeing the cars moving by...I enjoyed being | I: I was assuming you [were]talking about confidence not falling. But I think you are talking about a different kind of confidence aren't you? Because I know you | S: at the start of the programme yeah, but now I am really confident<br>N: How comes?<br>S: I think because of the strong of my foot. That is a part of my | Keep in outcome chain<br>Appraisals of capability are fluid, and change |

| | demands of daily life | | | outside…taking a walk along…and enjoying the environment…the cars went by. People saying Hi to me, it is a most important walk. I am healthy. I am healthy. Most important thing. I didn't have the pain I enjoyed the walk, **for so many months I didn't walk that far**. (Joy T179-82) | were nervous about walking? R: Yeah, **I got over that** (Robert T2: 209) R: I reckon I went backwards definitely backwards but slowly regaining, the pools and everything else build my confidence up again and getting back into it. And staying there. I didn't go very far backwards (Robert T3: 112) | thing. Because when I cross the road it is heavy, **but now it is strong and I just walk.** Yeah, not like before. Yeah I am very confident (Sione T2 172- 174 ) S: yes very changed, before I never go church. I used to go…stay here by myself. I told my wife it is no good for me to go, because I can't walk not only that but I don't want my children to take care of me like a little baby so when they go to church I'll stay here **but now I go with them, because I am alright to walk**, and if the church sing, if they want to stand up to sing, I'll stand up for five to ten minutes and then sit down. So now I participate in church much more than before. Yeah (Sione T2: 199-205) | depending on types of experiences and whether can find ways to adapt activity to make it more manageable |
|---|---|---|---|---|---|---|---|

| Mechanisms | Definition | Eva | Lily | Joy | Robert | Sione | Action/ Interpretation |
|---|---|---|---|---|---|---|---|
| Emotional regulation (Ma4) | The ability to effectively manage positive and negative feelings and respond to demanding situations flexibly and in a socially appropriate manner | | | My heart doesn't go pumping up. My arterial fibrillation ..., the more exercise I do, I don't feel the palpitations. The fibrillations. I don't feel it now.<br><br>I: You didn't feel the heart palpitating?<br><br>Joy: No<br><br>I: How did it change your thinking?<br><br>J: **I am going to not be sick**. Not going to be sick. (Joy T3 302-314) | I can explore a lot of things and open up a lot of things, a lot of issues that I had... the day before, download the garbage and try to work through it. You know going around the block once. "Oh hang, I had better do it again, I am not ready for this yet" (Robert T2: 201 )<br><br>In touch with your feelings and where you want to go, what you wanted to achieve, yesterday's goals they are no more, you have got to seek new example and take one step at a time(Robert T2 101-103)<br><br>R: Yes...**emotionally gone through stuff but I have worked at it as I have gone through it**. I don't just leave it and carry on (Robert T3: 116) | if I am scared while I am walking- I try to keep on walking. Like when I go around the block and when I come through the alleyway. ...sometimes I feel that might be someone come and push me away from the walkway **so I try to put it aside**. I try to forget so that I keep on walking...yeah<br><br>N: How does that feel?<br><br>S: Feel good. When I got here -I feel good(Sione T1: 170-174)<br><br>S: If there is any negative stuff- because there is negative coming on your way...for me I try to let it go, I don't hold onto those stuff, or try to think about those stuff. I just let it go, because everyone in my family want me to feel free especially in the set of my mind (Sione T2:82-91) | Add into refined theory<br><br>Intervention does not primarily increase autonomous motivation as already relatively motivated. Motivational gains come through improved emotional regulation so replace this mechanism for previous *internalisation* |

| Mechanisms | Definition | Eva | Lily | Joy | Robert | Sione | Action/ Interpretation |
|---|---|---|---|---|---|---|---|
| Mastery: Growth mind-set (Ma5) | Self-belief that goal attainment is possible with concerted effort, being open to learn and viewing challenges as learning opportunities | | | | Definitely trying to keep it open. Yeah you got to work at it. ...**stay open,** you have to achieve some goals, **have some goals and go forward.** (Robert T2 272-273)<br><br>I: Can you give me an example of something that you remember that was difficult for you?<br><br>R: That ladder. That ladder stuff. Yeah that was a good one. Getting smaller as you climb up. It doesn't. It looks wider at the base and it goes inwards but as you goes on that journey it stays the same. I don't think you will ever reach the top(Robert T2: 240-244)<br><br>Wasn't allowed to mow the lawn, or use the hot water, or the stove, **I seem to be getting over all those hurdles** (T3: 17-18) | I think my thinking now is much better than before because I always think negatively, about my sickness, about if someone see, look at me, but now I, when I look at things, I try to look at that with positive, in positive way, so that because if I look at that with negative side it press me down so **I try my best to look at that, forget it , don't worry about it, and keep going** (Sione T1: 56-71)<br><br>S: it helped me a lot to think positively, not and doing my exercise every day...and if it rain, try to find, just to do some exercise. Because sometimes  If it rains, you feel lazy to do your exercise but during the day there is a fine weather so you go outside and do your exercise not just stay too much on the couch, no good for you (Sione T1: 83-86) | Add in to refined theory<br><br>Decision adopt growth mind-set appears particularly important to manage thinking during self-regulated learning needed to persist in behavioural change |

| Mechanisms | Definition | Eva | Lily | Joy | Robert | Sione | Action/ Interpretation |
|---|---|---|---|---|---|---|---|
| Automaticity: situation specific and goal dependent (HF1, HF2) | initiation of goal directed responses are automatized to pre-selected cues | | I: Are there any changes in your daily habits and routines compared to back when you did this diary? Lily: Mmmm...I catch the bus and then stop. I walk to my brothers' place. Yeah. I: Is that close to here? Lily: No, Otara I; So it is quite a way from here Lily: I walk to my brother's place and then I walk back. I catch the bus and come back here I: Do you do that every day? Lily: Only on Friday. Once a week | Saying no to the visitors while I am walking around the house, and somebody is walking with me, come and have a walk with me. I wrote it down. Somebody ...if then plan, if somebody comes in and calls you, sitting down, if 3 hours sitting down terrible thing. I ask them to walk around with me **I do them automatically** (Joy 144 T3) | **it is automatic now. You just know what to do** (Robert T2 387-389) **Once you taken the first step it all follows, automatically fall back into place and keep it in place.** But keeping it in place. That is the main thing (Robert T3: 141) R:Yes yes more active no. More healthy now than moping around or something anyway. It is everyday things now really. There is more of it now, thinking about it, like in the mornings I can take my medication and grab the lead and away we go **without a second thought** (Robert T3: 246) | S: No no one told me to do my exercises. ..it is in me. I: So what do you tell yourself? S: I tell myself now is the time to do your exercise.. in the evening, I think the common sense. Yeah. In the evening if I lie on the couch for nearly one hour, two hours. **It is like someone said to you. 'Stand up and go for a walk' so I stand up and go for a walk** (Sione T1: 134-138) | Difficult in practice to distinguish between situation and goal dependent automaticity so combine two mechanisms If-then plans appear particularly effective at helping develop automaticity. |

| Mechanisms | Definition | Eva | Lily | Joy | Robert | Sione | Action/ Interpretation |
|---|---|---|---|---|---|---|---|
| Reappraisal of self-concepts (identity) (HF3) | Revaluation of a person's perceptions of their behaviour, ability and unique characteristics, a mental picture of how a person views themselves | | | Right thing, right time, eating nicely, sleeping the hours appropriate, sleeping time, early to rise, early, going to bed early, motivated me actually this thing help me, this programme is help me – help me right away, right away,  I calm myself. **I am not lazy**. I do activities. It is these help me. I don't rely on anybody else. I do my brain, to use the brain, to do gardening, activities, caregiver is putting the line off the line clothes line, I do sometime go and help caregiver, I eat right thing, going to church, is everybody help me. **Everyday, I exercise**, exercise (Joy T1: 198) | that I haven't done anything stupid or reached for anything stupid either. I know **I am over all that things**. (Robert T3: 101) | The starting of my stroke was very very hard because I never go out, I never meet friends, I never go shopping,  I never go to church, I  used to stay here all day and think what happened to me, but now. **Sometimes I forgot that I am disability and I don't know why, I just go like a normal [laughing]**. It is funny eh But I think that is the difference that I find.  **(Sione T3 43-47)** | Add changes to self-concept into theory,  Repeated habits can lead to changes in self-identity because they become seen as something that is 'typically me' |

| Mechanisms | Definition | Eva | Lily | Joy | Robert | Sione | Action/ Interpretation |
|---|---|---|---|---|---|---|---|
| Normalisation: coherence (including social comparison) (N1) | Process by which a person makes sense of their situation, can involve differentiation between themselves and others to aid understanding | It is good to hear from other people who is similar issues and it was quite interesting to see that people also have the same sort of limp. I found that quite interesting. And just being able to hear other people, not being able to say what they want to say. Some people couldn't say what they wanted to say, but it was still a good thing to see that.<br><br>I: But how did it help you?<br>Eva: it didn't help me, no it didn't help me but it was good to see it and hear it. (Eva T2 50-59)<br><br>Eva: It was just nice to get out, and be with other people in the same situation ( Eva T2 69-74) | | | But when you are walking you have got **time to think** and share our experience and what happened and how come and when and what we all want to try and achieve.(T2 34-35)<br><br>**It has opened our eyes** to varieties of strokes that affected us and our families and our mates and where we are today. Where are our friend and who was are our mates. The ones we have kept in contact with and we are spending more time in the homes around our gardens and talking to the shop keeper (T2 44-47) | N: How do you think the programme helped you?<br>S: it has helped me a lot, from my exercising and how to meet people, talk to friends, yeah and the other thing; we share with the groups; **because my experience is different** from my brothers and sisters that we have stroke together so we share the experience. It make me feel confident; and help me a lot because what **his experience is different from my experience so when we share and** *put it together* it helps me a lot (Sione T1: 44-52)<br>S: Because sometimes I think to myself I am the only one, the only one in the boat... So I need to learn from those people. Yeah that is what I love to go.<br>(Sione T2: 54-59) | Add *coherence* into refined theory and remove *social comparison.*<br><br><br>Comparing what is similar and what is different about each person's experiences helps stroke survivors make sense of their situation and can provide an important coping resource for some |

| Mechanisms | Definition | Eva | Lily | Joy | Robert | Sione | Action/ Interpretation |
|---|---|---|---|---|---|---|---|
| Normalisation: Cognitive participation (N2) | The process and work of engaging cognitively with a new practice | [referring to washing her hair herself]...well I feel tired, but yeah I do it regularly now... I try to do it every three weeks... I do it more regularly than not<br><br>N: So how does that make you feel, how is that? How is that?<br><br>Eva: Well before I thought it was a big triumph, but now I see it more as my daily routine now, I put in my things that I can do. (Eva T3 68-71) | | Everything is I forgot, **just devote my walking.** Walking was the most important thing (Joy T1 14)<br><br>I made walking [the] most important thing, walking around the house, walking to the letter box and church is important for me (Joy T1 138) | Well there was a lot of obstacles, when you are walking, breathing in fresh air- you are breathing in fresh air. Around the table, those questions those factors and everything you have got more challenge on your plate. When walking you just take one step at at a time, but those obstacles you got to think **you have to think and rethink**. (Robert T2: 234-237) | S: So because I think that if I am lazy and staying here sitting in the couch and feel sleepy all the time, it will come to my mind, **heaps of those things will come to my mind**, that what I think to myself but if I keep me busy walking, and going to the park and spend one hour and half in the park, so it is really good. And I told Caroline, the programme helped me a lot because of the, make me me walk every day, doing my exercise every day. I love to go with those people. If once or twice I week that will be alright. But now I arrange for a gym, to go to a gym, it will help me ( Sione T2: 94-103 | Add into refined theory. The process of embedding new practice such as walking more requires cognitive focus and effort to overcome obstacles to goal attainment |

| Mechanisms | Definition | Eva | Lily | Joy | Robert | Sione | Action/ Interpretation |
|---|---|---|---|---|---|---|---|
| Normalisation: Reflective action (N4) | The work involved in appraising a new practice to assess its advantages and disadvantages which develops comprehension of the effects of the new practice | | | | but when walking you are more calmer and relaxed. Just enjoying each other's company at the moment (Robert T2: 62-63)<br><br>I. Can you put your finger on what has made the biggest difference?<br>R: Yeah. That programme. Asking those questions around the table<br>I: Can you remember any particular questions ?<br>R: instead of being angry and just ignore it, go onto another path. Yeah. This listening, watching, reading, **learning, asking the right questions** (Robert T3 347-352) | S: Man it is much, no words! **because I see the difference, I see the difference..**<br>Like doing exercise I do it my own, and not only that, but **before** I listened to someone else to tell me what to do. Like my wife, my wife said to me. 'Oh, go and have some exercise'. **But now** I do it on my own, I don't have to listen to them, when I woke up in the morning I just walk without letting them to telling me what to do. like even going to church, **before** I don't go church, I don't really like to sit and looking at me, the way I walk, **but now** I have a confident to go into church and sit there like I used to be, like before. **Yeah I find it heaps of things that I find it different from before, compared to what I am now**. Yeah. Yeah. Like going to friends, I woke up this morning and I went to my mate and I talked with them for like three hours [chortle] before I came to wait for you, **but before** I never go around, I used to stay here all day **but** | Include in refined treatment theory. |

| | | | | | **now** I can go anywhere, anywhere and when ever I want to go. I will go | |
|---|---|---|---|---|---|---|

| Mechanisms | Definition | Eva | Lily | Joy | Robert | Sione | Action/ Interpretation |
|---|---|---|---|---|---|---|---|
| Normalisation: collective action (N3) | The work needed to enact a new practice | | | | We share more. We are open with each other more than share within the club ...you know we are just in the boundaries of doing this and that but when you are walking you have got time to think and share our experience and what happened and how come and when and what we all want to try and achieve (Robert T2:32-35) | My wife and the kids. They just said to me. They said 'Oh Dad you are getting stronger, not like before'. Yeah it is puzzling my family here, my sisters and brothers. They see me there is a change. Because before I never walk. But now I walk. And they said to me. 'Why?' I said to them, '**Oh I just fight my battle**'. I just, I don't want to sit here disabled walking in a wheelchair. I want to walk. **So every day I keep on fighting**. And I am looking around for sources to help me out. Yeah that is why I want to go to those people and **walk together with them.** Yeah ( Sione T2: 72-79) | Add into refined theory. Adopting and sustaining new practices requires work and this seems to be helped by collective efforts and recognition of challenges such as family or peer group |

| Mechanisms | Definition | Eva | Lily | Joy | Robert | Sione | Action/ Interpretation |
|---|---|---|---|---|---|---|---|
| Belonging and empathetic understanding (SC3, SC4) | Affirmative or esteem support provides sense of belonging to a caring group of people, a sense of mattering which promotes self-regard | I: Yeah? So what was the thing you found most helpful of the programme?<br><br>E: [crying again]- Being with [name of family member], being with [name] Being with [name] I enjoyed it. I just enjoyed it –I like the closeness with [name].It is very nice communicating with [name]. I don't know what else to say (T1 26-47)<br><br>E: [long pause]. It was interesting to find out the um... the support that my family have for me. I mean I already knew that, but I already knew that personally but it was good to hear it (T1:55-57) | It was good, because sometimes she don't like me, I don't like her and yet she come!<br><br>(Lily T1: 113)<br><br><br>Walking and talking to someone else, you know when you walk<br><br>(T1: 135) | I talked to cell group. Everybody likes me. They pray for me. Pastor [name], he come pray to me, I haven't gone to cell group, he wants to say come back again. He is a great support to people<br><br>(Joy T3 139-141) | Yes the calmness and the sense that of we are not at each other, yahooing or talking to a nurse or doctor, we are talking to another victim which has had the same experience as we have, affected them in a different way and affected us in a different way (Robert T2; 55-57)<br><br>We become mates, we become friends, we become close bond friends without realizing. We all got affected one way or another and we came through that hospital and the OT's and the doctors and we just don't want to blow it. We don't want to slip back into to old patterns and the old ways. (Robert T2 86-89)<br><br>Knowing that there is a support group out there that will get you back (Robert T3:99) | How was it to have your family involved?<br><br>S: Good<br><br>I: Why is that?<br><br>S: because I want them to know what happened to me and what is going on (Sione T1: 119) | Mechanisms of emotional sustenance important to participants<br><br>Understanding by peers and family both important. Opportunities strengthen social connections were especially valued and intervention provided positive opportunity to reinforce social connections |

| Mechanisms | Definition | Eva | Lily | Joy | Robert | Sione | Action/ Interpretation |
|---|---|---|---|---|---|---|---|
| Trust & Synergy (SC1) | Teamwork by two or more people based on a trusting bond and agreement to collaborate and work toward shared goals | it has to **fit in** with the goals I have already set for my whole life (T1: 109) | | It was clear, is talking with Caroline, talking with son, talking with Caroline and me.., just as a friend talking to a friend. Caroline is supportive of me (Joy T1 267-268) | R: That human in us just need a little bit of encouragement to help them put the left foot in front of the right foot and then carry on with what they got but fortunately there are other people that are going to come into their lives and **for us to accept these people is a challenge on its own**. It is like this I don't want nothing to do with you. Just because you have got a fucking degree, and you did something. How is that going to help me? I am an angry bastard, slog away at the grinder you will break down those barriers. Those barriers are put there for a reason. And those reason are 'Do I want the help?' or do I need the help?" My family can look after me. I will be a burden to them. What do you want? What do you get out of it? ... They have got to have a strong backbone to come through that door because they will get all sorts of stuff thrown at them, and then will they come back? That is the main goal, will they come back because sooner or later we are going to get tired of telling you to f of. **They are still coming**! <br><br> I: So are you saying that someone involved needs to have a lot of persistence because there will be quite a bit of resistance? <br><br> R: Yes (Robert T3: 336) | I think everything, when she comes here **and we gather together** and discussed some [inaudible] about stroke, it is helpful (T1: 13-14) | Collaborative work important but cannot be assumed and may take time and effort to build trust and overcome resistance. |

# Appendix EE: Outputs from this thesis

## Publications arising directly from this thesis

Stretton, C.M**.**, Mudge, S., Kayes, N., Taylor, D., & McPherson, K. M. (2017). Interventions to improve real-world walking after stroke: A systematic review and meta-analysis. *Clinical Rehabilitation* 31(3), 310-318. https://doi.org/DOI: 10.1177/0269215516640863

Stretton, C. M., Mudge, S., Kayes, N. M., & McPherson, K. M. (2014). Can we improve real world walking after stroke? A systematic review and meta-analysis. *Archives of Physical Medicine and Rehabilitation*, 95(10), e10.

## Conference presentations arising from this thesis

Stretton, C. M., Mudge, S., Kayes, N., & McPherson, K. M. (2017). Motivating oneself to keep on going: insights from a realist evaluation of walking after stroke. Short Paper presented at the International Conference for Realist Research, Evaluation and Synthesis, Brisbane, Australia.

Stretton, C. M., Mudge, S., Kayes, N. M., & McPherson, K. M. (2017). Walking for wellbeing: exploring perspectives of walking after stroke. A paper presented at the New Zealand Rehabilitation Association, Christchurch, New Zealand.

Stretton, C., Mudge, S., Kayes, N., & McPherson, K. (2014a). Developing an intervention to improve real world walking after stroke: a realist review. A paper presented at the Mixed Methods International Research Association, Boston, USA

Stretton, C. (2013) Improving real world walking and physical activity after stroke: a systematic review. A paper presented at the Neurosymposium-Participation for Life. Wellington

Stretton, C. (2012) Developing optimal behaviour change interventions to improve usual walking for people with stroke. Paper presented at the meeting of the Rethinking Rehabilitation, Toronto, Canada.