The myMoves Program: Development of a remote self-management program to increase physical activity after acquired brain injury

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Abstract

Acquired brain injury (ABI) is a significant cause of disability globally, with common causes being stroke and trauma. Individuals living with ABI often display high levels of physical inactivity and sedentary behaviour, which increases their risk of morbidity and mortality. However, many adults with ABI experience barriers to participation in effective physical activity interventions. Remotely delivered self-management programs focussed on teaching individuals how to improve and maintain their physical activity levels have the potential to improve the overall health of adults with ABI.

The development of a complex and multifaceted health intervention, such as self-management program to increase physical activity, requires a scholarly and systematic approach to the development process, underpinned with a sound theoretical basis. The work presented in this Thesis demonstrates this rigorous development process, using an Intervention Mapping framework, to develop an innovative remotely delivered self-management program focussed specifically on assisting individuals living in the Australian community to increase their physical activity.

The development process commenced with a comprehensive needs assessment; including a systematic review of the literature on the efficacy of self-management programs to increase physical activity after ABI (Study I), and a survey of potential participants regarding barriers to physical activity and interest in a program of this nature (Study II). The detailed developmental process is outlined (Study III),

and resulted in a comprehensive self-management program, the myMoves Program. Initial testing of this program has been conducted (Study IV) demonstrating that it is both feasible to deliver, and highly acceptable to participants. Testing also informed an iterative review of the program (Study V) to conclude the developmental process and inform future testing of efficacy. In essence, the work presented in this Thesis has demonstrated the successful development of a remotely delivered self-management program focused at increasing physical activity for individuals living in the community with ABI.

Statement of Candidate

I, Taryn Jones, hereby declare that the work contained within this Thesis, *The myMoves Program: Development of a remote self-management program to increase physical activity after acquired brain injury*, is my own and has not been submitted to any other university or institution, in part or in whole, as a requirement of a degree.

I, Taryn Jones, hereby declare that I was the principal researcher of all work included in this Thesis, including the work published with multiple authors. A statement from co-authors confirming the authorship contribution of the PhD candidate is provided in each of the relevant chapters.

I, Taryn Jones, also hereby declare that this Thesis is an original piece of work and it is written by me. Any assistance that I have received in the preparation of this Thesis has been appropriately acknowledged. In addition, I also certify that all information sources and literature used are indicated in this Thesis.

Signed: Jones.

Date: 16th September 2015

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An African proverb states, "*It takes a village to raise a child*". I believe the same is true of a PhD. My PhD would not have been possible without an amazing village of people, supporting me and inspiring me.

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Somewhere ages and ages hence:
Two roads diverged in a wood, and I,
I took the one less travelled by,
And that has made all the difference."
~Robert Frost~

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List of Publications and Presentations

Publications

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Conference presentations

Oral presentations

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List of Abbreviations

ABI	Acquired brain injury
ADL	Activities of daily living
ANOVA	Analysis of variance
ASGC	Australian Standard Geographical Classification
B-PADS	Barriers to Physical Activity and Disability Survey
CDC	Centers for Disease Control and Prevention
CHD	Coronary heart disease
CI	Confidence interval
CVD	Cardiovascular disease
DALYs	Disability-adjusted life years
DIY	Do-It-Yourself
DM	Diabetes mellitus
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders – fourth edition
ESES	Exercise Self Efficacy Scale
FITT	Frequency, intensity, time, type
FBM	Fogg Behavioral Model
HBM	Health Beliefs Model
HDL	High density lipoprotein
IQR	Inter-quartile range
K-10	Kessler Scale of Psychological Distress
MD	Mean difference
MET	Metabolic equivalent of task
MOST	Multiphase optimization strategy
MRC	Medical Research Council
MRD	Mean risk difference
mRNLI	Modified Reintegration to Normal Living Index
MVPA	Moderate to vigorous physical activity
NHMRC	National Health and Medical Research Council

PA	Physical activity
PDF	Portable document format
PSQ	Program Satisfaction Questionnaire
PTSD	Post-traumatic stress disorder
QOL	Quality of life
RA	Remoteness Areas
RE-AIM	Reach, efficacy, adoption, implementation, maintenance
RRMA	Rural, Remote and Metropolitan Areas
SCI	Spinal cord injury
SCT	Social Cognitive Theory
SD	Standard deviation
SMD	Standardised mean difference
SPSS	Statistical package for the Social Sciences
TAMS	Telephone Assessed Mental State
TPB	Theory Planned Behaviour
TTM	Transtheoretical Model
TBI	Traumatic brain injury
UK	United Kingdom
US	United States
WHO	World Health Organization

CHAPTER 1

Introduction

Knowledge regarding the health enhancing benefits of physical activity dates back to antiquity (Berryman 2010, Tipton 2014). Hippocrates, although not the first, identified the importance of physical activity: *"…eating alone will not keep a man well; he must also take exercise"*(Hippocrates, *Regimen 1*, IV: 229). The idea of taking responsibility for our health through behaviours, such as physical activity, can also be seen in his writings: "*A wise man should consider that health is the greatest of human blessings, and learn how by his own thought to derive benefit from his illnesses*" (Hippocrates, *Regimen in Health*, IV: 59).

More than two thousand years on we face an epidemic of chronic disease as the result of declining levels of physical activity and increasing levels of sedentary behaviour. Physical inactivity is now the fourth leading risk factor for global mortality (World Health Organization 2010) and is regarded by some as the greatest public health problem of the 21st century (Blair 2009). Physical inactivity both causes and accelerates chronic diseases, such as cardiovascular disease (CVD), including stroke; Type 2 diabetes mellitus (DM); and breast and colon cancer (Marcus, Williams et al. 2006, Mathers, Stevens et al. 2009). As Robinson wrote in 1732, "*Those Persons above all others, …if they indulge in a Luxurious Manner of Living, seldom escape a sudden, fatal stroke*" (Pound, Bury et al. 1997, Daneski, Higgs et al. 2010).

Individuals with disabilities are at substantially increased vulnerability to low levels of physical activity and high levels of sedentary behaviour. The Centers for Disease Control report that nearly 50% of working age adults living with a disability undertake no aerobic activity at all, and are three times more likely to have heart disease, stroke, diabetes or cancer than adults without disability (Centers for Disease Control and Prevention 2014).

Acquired brain injury (ABI) is a significant cause of disability globally. ABI refers to any damage to the brain that has occurred after birth, with common causes being stroke and trauma (O'Rance 2007). Stroke is one of the greatest causes of disease burden globally (Thrift, Cadilhac et al. 2014), while traumatic brain injury (TBI) is the leading cause of disability in children and young adults worldwide (World Health Organization 2006). Individuals with ABI often have more complex disability than other disability groups (O'Rance 2007) and face many barriers to increasing physical activity levels (Driver, Ede et al. 2012, Nicholson, Sniehotta et al. 2013). Despite this, ABI is often a lower priority for research and services than other conditions with a less significant disease burden (Thrift, Cadilhac et al. 2014) and there is a significant lack of physical activity promotion programs targeting those with ABI (Pawlowski, Dixon-Ibarra et al. 2013, Cleveland, Driver et al. 2015).

Self-management is a crucial part of prevention and management of chronic disease (Glasgow, Jeon et al. 2008). With physical inactivity a modifiable risk factor for chronic disease (Lee, Folsom et al. 2003, Mathers, Stevens et al. 2009), increasing self-management of physical activity is a crucial component in reducing the risk of further morbidity and mortality (World Health Organization 2005). However, only one third of Australian stroke survivors were offered any information regarding self-management programs on discharge from acute services and individuals with ABI report that access to services, such as self-management programs, is problematic (National Stroke Foundation 2007, National Stroke Foundation 2008, National Stroke Foundation 2014) The potential of remotely delivered interventions, that is, interventions without face-to-face contact with a clinician, for physical activity has been shown (Foster, Richards et al. 2013). Remotely delivered interventions have the potential to ameliorate the difficulties associated with access, as well as providing support in an individual's own environment where skills can be applied (Satink, Cup et al. 2014). However, remotely delivered interventions have yet been unharnessed in the ABI population.

Therefore, the studies included in this thesis aim to answer the following questions:

1. What is the efficacy of self-management programs in increasing physical activity for adults living in the community with acquired brain injury?
2. What are the characteristics and barriers to physical activity faced by Australian adults living in the community with acquired brain injury?
3. Is there interest in a remotely delivered self-management program aimed at increasing physical activity after acquired brain injury?
4. Can a remotely delivered self-management program aimed at increasing physical activity in adults with acquired brain injury living in the community be developed in a systematic and scholarly manner?

5. Is a remotely delivered self-management program aimed at increasing physical activity in adults with acquired brain injury living in the community feasible and acceptable?

The studies described in this thesis attempt to address these questions. This introductory chapter will describe in more detail the current physical activity status of those with ABI; theoretical models of behaviour change that are commonly used to increase physical activity; and the role of self-management programs in managing chronic disease, including those delivered remotely. The specific aims of this thesis will also be introduced.

1.1 The nature of acquired brain injury

1.1.1 Definition of acquired brain injury

Acquired brain injury (ABI) is defined as any injury to the brain that occurs after birth (O'Rance 2007). The most common causes of ABI are trauma and stroke, however other causes include hypoxia, drugs or alcohol, infection, and degenerative neurological conditions (Brain Injury Australia (BIA) Inc , O'Rance 2007). However, in this thesis, we will exclude any degenerative conditions from the definition of ABI; such as Parkinson's Disease, Multiple Sclerosis, and brain cancers. Therefore, from here forth, the term ABI will be referring only to non-degenerative forms of ABI. As stroke and trauma are the most common causes of ABI, the definitions of these conditions are also given.

Although there are calls to update the definition of stroke to incorporate clinical and tissue criteria in line with advances in science and technology (Sacco, Kasner et al. 2013), we will use the definition of stroke currently employed by the World Health Organization (WHO), which is "…the clinical syndrome of rapid onset of focal (or global, as in subarachnoid haemorrhage) cerebral deficit, lasting more than 24 hours (unless interrupted by surgery or death), with no apparent cause other than a vascular one" (World Health Organization 2006).

Traumatic brain injury is defined as "…an alteration in brain function, or other evidence of brain pathology, caused by an external force" (Menon, Schwab et al. 2010). TBI can appear as a focal injury, resulting when bleeding, bruising, or a penetrating injury is isolated to a localized portion of the brain; or as a diffuse injury with more widespread tissue damage; or as a mixture of both forms (Centers for Disease Control and Prevention 2015). A TBI may also be described as a closed head injury, where the dura remains intact, in comparison to an open trauma where the dura is torn (Bešenski 2002).

1.1.2 The impact of ABI

ABI is common. In Australia there are over 600 000 people living with an ABI (O'Rance 2007), 75% of whom are under 65 years of age (Brain Injury Australia (BIA) Inc). In the United Kingdom (UK) there were over 340 000 ABIs reported in 2013-14 alone (Headway - the brain injury association 2015). More males than females have an ABI across all age groups (O'Rance 2007, Headway - the brain injury association 2015).

The impact of stroke

Stroke is the second most common cause of death globally, the third in the industrialised world, and one of the leading causes of disability, resulting in the WHO calling it one of the main noncommunicable diseases of public health importance (World Health Organization 2006). Globally there is a first time incidence of stroke every two seconds (Stroke Association 2015), with an estimated 4.5 million deaths per year and approximately 9 million stroke survivors (Wolfe 2000). In Australia, there are approximately 60 000 people who have a new stroke every year (Brain Injury Australia (BIA) Inc), whilst in the UK there were 130 551 admissions to hospital for stroke in 2013-14 (Headway - the brain injury association 2015). In America, 2.7% of the adult population have had a stroke (Blackwell, Lucas et al. 2014), with 795 000 people having a stroke annually (Go, Mozaffarian et al. 2013). In China, there are 2.5 million new stroke cases every year, and 7.5 million stroke survivors (Liu, Wang et al. 2011), whilst the countries of South Asia, including the populous nations of India, Pakistan and Bangladesh, are thought to account for probably 40% of global stroke deaths each year (Wasay, Khatri et al. 2014).

Stroke has enormous socioeconomic consequences. Reflecting this, stroke cost Australia $5 billion in 2012 (Deloitte Access Economics 2013). The direct and indirect cost of stroke in America in 2008 was estimated to be $65.5 billion, whilst the 27 European Union nations have a total annual cost estimated to be €27 billion (Di Carlo 2009). Lifetime costs worldwide are estimated to be between US$59 800 and US$230 000 per patient, while there is an estimated loss of 49 million disability-adjusted life years (DALYs) worldwide annually (World Health Organization 2006).

The impact of traumatic brain injury

Globally, TBI is the leading cause of death in children and young adults, and the leading cause of disability in people under the age of 40 years (World Health Organization 2006). In 2010, TBI's accounted for approximately 2.5 million emergency department visits (Centers for Disease Control and Prevention 2015). In the UK there 162 344 TBIs reported in 2013-14 (Headway - the brain injury association 2015), whilst in Australia, there were 21 800 hospital stays for TBI in 2004-5 (O'Rance 2007). The main causes of TBI are falls, road traffic accidents and violence (World Health Organization 2006, Roozenbeek, Maas et al. 2013). Reliable quantification of the burden of TBI worldwide is difficult due to variability in the definition of TBI, inadequate standardisations and incomplete data collection (World Health Organization 2006, Roozenbeek, Maas et al. 2013). In America there is estimated to be around 5.3 million people living with a TBI-related disability, whilst in Europe there are approximately 7.7 million people who have had a TBI have a disability (Roozenbeek, Maas et al. 2013).

1.1.3 Sequelae of ABI

The consequences of ABI are multiple and significant; and, although ABI stems from an acute event, there is evidence that there is deterioration over time resulting in a reasonable consideration of ABI as a chronic health condition (Corrigan and Hammond 2013). ABI can affect an individual's physical ability, cognition, behaviour and emotional wellbeing. Due to the nature of ABI each individual is affected differently, often with many of the non-physical disabilities 'hidden' and not well understood by the community (O'Rance 2007).

Physical sequelae

Common physical impairments resulting from ABI include weakness, loss of coordination, spasticity, reduced sensation, visual and hearing disturbances, and seizures. Secondary impairments, such as a loss of cardiorespiratory fitness, can also develop (Michael and Macko 2007, Baert, Daly et al. 2012). Mobility is commonly affected, with many individuals with ABI experiencing ongoing gait disturbances (Michael and Macko 2007, Niechwiej-Szwedo, Inness et al. 2007, Williams, Morris et al. 2009, Balaban and Tok 2014), reduced walking endurance (Mayo, Wood-Dauphinee et al. 1999, Pohl, Duncan et al. 2002, Danielsson, Willen et al. 2011), and reduced levels of community ambulation (Lord, McPherson et al. 2008, Alzahrani, Dean et al. 2011). Upper limb function is also frequently impaired, leading to activity and participation restrictions (Franceschini, La Porta et al. 2010, Hayward, Barker et al. 2010).

Fatigue is very common following ABI; with prevalence rates ranging from 16% to 75% following stroke (Michael, Allen et al. 2006, van de Port, Kwakkel et al. 2007, Hoang, Salle et al. 2012, White, Gray et al. 2012, Miller, Combs et al. 2013, Wu, Mead et al. 2015) and 16% to 80% following TBI (Cantor, Gordon et al. 2013). Chronic pain following ABI is also a significant issue, with studies reporting between 11% and 49% of participants experiencing pain one year after stroke (Appelros 2006, Lundstrom, Smits et al. 2009, Hansen, Marcussen et al. 2012); and 34% to 73% of participants reporting pain one year after TBI (Hoffman, Pagulayan et al. 2007, Nampiaparampil 2008, Sullivan-Singh, Sawyer et al. 2014), even in those with mild TBI (Nampiaparampil 2008).

Cognitive sequelae

Individuals with ABI often experience changes in cognition, such as poor memory, slowed information processing, distractibility, difficulty concentrating, inflexible thinking, reducing problem-solving and planning ability, communication impairments and cognitive fatigue (Hochstenbach, Mulder et al. 1998, Martin, Viguier et al. 2001, Colantonio, Ratcliff et al. 2004, Knight, Harnett et al. 2005, Knight, Titov et al. 2006, O'Rance 2007, Cumming, Marshall et al. 2013). Cognitive sequelae are the leading source of TBI-related disability (Rabinowitz and Levin 2014). Individuals who have suffered a TBI resulting in acceleration and deceleration forces being applied to the brain are particularly likely to experience cognitive impairments. This is because the frontotemporal lobes are susceptible to damage as they are situated above bony protuberances within the skull where they are easily injured with forceful movements of the brain (Bigler 2007).

Behavioural sequelae

Individuals with ABI can demonstrate a range of changes in behaviour, with increased irritability and anger, inappropriate social behaviour, apathy, impulsivity and emotional lability (Hanks, Temkin et al. 1999, Caeiro, Ferro et al. 2013, Arciniegas and Wortzel 2014). As for cognitive sequelae, individuals with a TBI resulting in forceful movement of the brain, and therefore damage to the frontotemporal brain regions are particularly vulnerable to changes in their behaviour (Bigler 2007).

Emotional sequelae

The emotional sequelae of ABI are significant. Depression rates are high amongst individuals with ABI. Following stroke an estimated 31% of survivors will experience depression (Hackett and Pickles 2014), whilst following TBI approximately 26% of individuals have been found to experience major depression (Hart, Brenner et al. 2011). Depression following ABI is significantly associated with pain (Appelros 2006, Hoffman, Pagulayan et al. 2007, Lundstrom, Smits et al. 2009, Sullivan-Singh, Sawyer et al. 2014); and related to ongoing disability and poorer outcomes (Hackett and Anderson 2005, van Wijk, Algra et al. 2006, Lo, Cheng et al. 2008, Hart, Hoffman et al. 2012, Kutlubaev and Hackett 2014). Anxiety is also a common sequelae of ABI, and has been found to affect Health-related Quality of Life (QOL) after stroke (Tang, Lau et al. 2013). Self-efficacy for many activities, including physical activity and falls, are reduced; which also impacts levels of activity and participation (Pang, Eng et al. 2007, Jones and Riazi 2011, Korpershoek, van der Bijl et al. 2011).

In summary, individuals with ABI face many diverse and complex consequences from their brain injury. As a result, individuals with ABI demonstrate reduced participation in home, work and community activities; and reduced satisfaction and QOL (Ponsford, Olver et al. 1995, Pound, Gompertz et al. 1998, Sturm, Dewey et al. 2002, Colantonio, Ratcliff et al. 2004, Sturm, Donnan et al. 2004, Hartman-Maeir, Soroker et al. 2007, Franceschini, La Porta et al. 2010, Wise, Mathews-Dalton et al. 2010, Braden, Cuthbert et al. 2012). Individuals with ABI report feeling socially isolated and neglected (Pound, Gompertz et al. 1998, National Stroke Foundation 2007), often having high levels of unmet needs (McKevitt, Fudge et al. 2011).

1.2 Physical activity after acquired brain injury

1.2.1 Definition and classification of physical activity

Definition of physical activity

The WHO defines physical activity as "any bodily movement produced by skeletal muscles that requires energy expenditure" (World Health Organization 2013). All physical activities result in energy expenditure, with a continuum from low level sedentary activities to extreme levels in higher intensity activities performed by conditioned athletes (Norton, Norton et al. 2010).

It is important to note that the terms 'physical activity' and 'exercise' are not interchangeable. Exercise is a subcategory of physical activity, and is defined as physical activity that is planned, structured and repetitive, with a purpose of obtaining or maintaining one or more components of physical fitness (Caspersen, Powell et al. 1985).

Classification of physical activity by intensity

In order to analyse and prescribe physical activity, activities are normally grouped into intensity categories. However, these categories can vary in their definitions and metabolic cut offs, such as energy expenditure ranges using metabolic equivalent of task (MET) (Norton, Norton et al. 2010). Based on the position statement on physical activity terminology by Norton and colleagues (2010) we will classify physical activity into the following categories:

- *Sedentary* – an activity that involves sitting or lying, and has little additional movement and a low energy requirement (< 1.6 MET).
- *Light* – an activity that does not cause a noticeable change in breathing rate, and that can be sustained for at least 60 minutes (1.6 < 3 MET).
- *Moderate* – an activity that takes some effort, causing an individual to breathe more deeply, or "huff and puff"; however conversation can still be maintained. Moderate activities can generally be sustained for 30 to 60 minutes (3 < 6 MET).
- *Vigorous* – an activity requiring much more effort causing breathing to become harder and faster, and where conversation cannot generally be maintained uninterrupted. The activity may last up to about 30 minutes, but may be performed in shorter bursts (6 < 9 MET).
- *High* – an activity that can generally not be sustained for more than 10 minutes (> 9 MET).

Classification of physical activity by type

Traditionally, physical activity classification by type has focused on whether the activity is an aerobic activity, a muscle strengthening activity, or an activity focused on flexibility or balance. However, physical activity can also be classified in a way that characterises the varied contextual, behavioural and psychological aspects of different physical activities. Marttila and colleagues (1998) propose five categories of physical activity: (1) Occupational activity, (2) Lifestyle activity, (3) Recreational activity, (4) Fitness activity, and (5) Sport; with each of the categories offering differences in the degree of personal choice, potential health benefits, emotional consequences and expectations that accompany them. More broadly physical activity can be classified as being either *Planned* or *Incidental*. Most occupational and lifestyle activities, as well as some recreational activities would be classified as incidental, whilst planned activities tend to incorporate the more traditional concept of exercise, predominantly fitness and sporting activities.

1.2.2 Risks of physical inactivity

All-cause mortality

Individuals who are physically active are significantly less likely to experience many of the most prevalent chronic diseases; with an inverse linear relationship between volume of physical activity and all-cause mortality, for men and women, young and old (Blair, Kampert et al. 1996, Lee and Skerrett 2001, Macera and Powell 2001, Warburton, Nicol et al. 2006, Gulsvik, Thelle et al. 2012). For most chronic diseases there is a direct dose-response relationship with physical activity (Warburton, Nicol et al. 2006, Haskell, Blair et al. 2009, World Health Organization 2010), as well as indirect responses through contribution to other risk factors, such as hypertension, atherogenic lipoprotein profile and insulin-mediated glucose uptake (Haskell, Blair et al. 2009, Durstine, Gordon et al. 2013). It is estimated that physical inactivity accounts for approximately 9% of premature deaths globally (range 5.1% to 12.5%) (Lee, Shiroma et al. 2012).

Cardiovascular disease

The strongest evidence for the benefits of physical activity is for prevention of CVD, including coronary heart disease (CHD) and stroke; with evidence of occupational physical activity relating to CHD dating back to leading research by Morris and colleagues (1953), and Paffenbarger and colleagues (1975). There is now strong evidence for a direct dose-response relationship between cardiovascular disease and physical activity, with those who are at the highest levels of physical activity and fitness having the lowest risk of CVD (Blair, Kampert et al. 1996, Warburton, Nicol et al. 2006).

Type 2 diabetes mellitus (DM)

There is strong evidence for physical activity preventing the development of metabolic syndrome and Type 2 DM (Warburton, Nicol et al. 2006, Healy, Wijndaele et al. 2008, World Health Organization 2010), with incidence rates of Type 2 DM reducing as energy expenditure increases (Helmrich, Ragland et al. 1994, Hu, Sigal et al. 1999). Physical activity as part of a lifestyle intervention has been found to prevent Type 2 DM, even in those high-risk individuals (Tuomilehto, Lindström et al. 2001, Lindström, Louheranta et al. 2003), and was found to be more effective than metformin (Diabetes Prevention Program Research Group 2002).

Obesity

In 2011-12 of Australians aged 18 years and over, 70% of males and 55% of females were overweight or obese (Australian Bureau of Statistics 2015). Physical activity is associated with weight loss and prevention of obesity, particularly when combined with dietary management (Shaw, Gennat et al. 2006, Durstine, Gordon et al. 2013). A dose-response exists between the amount of physical activity undertaken and weight loss (National Health and Medical Research Council 2013), with time spent in physical activity having a high inverse association with obesity (Cameron, Welborn et al. 2003). Maintaining high levels of physical activity (approximately 60 minutes per day) combined with other behavioural strategies may reduce weight gain (Wing and Phelan 2005, National Health and Medical Research Council 2013).

Cancer

Physical activity is associated with reduction in the risk of developing certain site-specific types of cancer, particularly colon and breast cancer (Thune and Furberg 2001, Lee 2003, Friedenreich, Neilson et al. 2010). Physically active men and women are thought to experience a 30-40% lower risk of developing colon cancer than inactive individuals, while there is thought to be a 20-30% reduction in breast cancer risk (Lee 2003). Whilst it does appear that a dose-response does exist, the evidence points to risk reduction requiring at least 30-60 minutes of moderate to vigorous activity per day, at least 5 days per week (Lee 2003). It also appears probable that physical activity may have a preventative effect for prostate cancer (Friedenreich and Orenstein 2002, Durstine, Gordon et al. 2013) and endometrial cancer (Friedenreich, Neilson et al. 2010), while it is less clear regarding lung and ovarian cancers (Friedenreich, Neilson et al. 2010).

Musculoskeletal health

Physical activity has benefits for a broad range of musculoskeletal conditions. There is strong evidence that physical activity can be effective in preventing low back pain, however there are increased levels of low back pain reported in those undertaking long-term heavy physical loading (Vuori 2001, Dijken, Fjellman-Wiklund et al. 2008, Heneweer, Vanhees et al. 2009).

There is no clear evidence that physical activity directly prevents osteoarthritis (Vuori 2001). An indirect relationship exists between obesity and the development of osteoarthritis, particularly in women (Felson, Anderson et al. 1988). However, there is evidence that large amounts of intensive physical activity, particularly with high impacts, torsional loading, or high risk of injury, can cause osteoarthritis (Vuori 2001).

Physical activity that involves bone loading is osteogenic at the site of loading, and thought to contribute to a lower risk of osteoporosis (Vuori 2001, Warburton, Nicol et al. 2006). The exact intensity, frequency and duration of physical activity required remains unclear (Kannus 1999); although it does appear that low-moderate loading is less effective than higher loads (Vuori 2001), and adequate hormone levels need to be present to maximise the osteogenic response (Drinkwater 1994). Physical activity, particularly that involving resistance training, agility or balance activities, is also associated with a lower risk of falls and fall related fractures (Joakimsen, Fønnebø et al. 1998, Carter, Kannus et al. 2001, Liu-Ambrose, Khan et al. 2004, Warburton, Nicol et al. 2006). Physical activity is also associated with reducing the risk of functional decline and the development of sarcopenia (Waters, Baumgartner et al. 2010).

Emotional wellbeing

Physical activity is thought to contribute to reduced depression and anxiety (Camacho, Roberts et al. 1991, Dunn, Trivedi et al. 2001, Teychenne, Ball et al. 2008, Roshanaei-Moghaddam, Katon et al. 2009). It is unclear what the dose-response pattern may be at this time with varying results cited in the literature (Dunn, Trivedi et al. 2001, Teychenne, Ball et al. 2008), although it may appear that even low doses of physical activity can have a positive impact on emotional well-being (Teychenne, Ball et al. 2008). There is also evidence for a positive relationship between leisure time physical activity and sleep (Sherrill, Kotchou et al. 1998, Myers, Malott et al. 1999, Lang, Brand et al. 2013, Wennman, Kronholm et al. 2014, Tsunoda, Kitano et al. 2015), with a lower prevalence of disturbed sleep symptoms in those who engage in regular physical activity (Sherrill, Kotchou et al. 1998). This is thought to be due to alterations in sleep architecture (i.e. duration, frequency and patterns of stages of sleep) and sleep efficiency (i.e. total time spent asleep as a percentage of total time attempting to sleep) (Sherrill, Kotchou et al. 1998), although this may not extend to high levels of occupational physical activity (Wennman, Kronholm et al. 2014).

In summary, there is strong evidence that being physically active is good for overall health and well-being, both physical and emotional. Inversely, the risks to health of physical inactivity are significant.

1.2.3 Risks of sedentary behaviour

In addition to the risks of physical inactivity, increased time in sedentary behaviour carries specific risks to health and well-being, and is associated with greater risk of all-cause mortality (Chau, Grunseit et al. 2013). Prolonged sedentary behaviour displaces time spent in higher intensity physical activities, contributing to an overall reduction in energy expenditure (Owen, Healy et al. 2010, Gomersall, Norton et al. 2015). However, there are additional physiological effects from prolonged sedentary time that are distinct from those of too little physical activity (Owen, Healy et al. 2010), with direct impact on metabolism, bone mineral content and vascular health (Tremblay, Colley et al. 2010).

Sedentary behaviour following acute events, such as in the case of ABI, commences early with hospitalisation being linked with high levels of sedentary activity, particularly prolonged bed rest (Sjöholm, Skarin et al. 2014, Mattlage, Redlin et al. 2015). Prolonged bed rest has long been known to have significantly negative consequences to health and results in profound deconditioning of the body. The deleterious effects on the cardiovascular, muscular and skeletal systems are well recognised with an ultimate reduction in maximal oxygen consumption, diminished muscular strength, and reduction in bone mass (Stuempfle and Drury 2007). Following stroke, an increased time in bed in the acute phase is associated with a significantly poorer functional outcome at 3 months (Askim, Bernhardt et al. 2014).

As well as prolonged bed rest, and high levels of sedentary behaviour, in the early stages following ABI, ongoing sedentary behaviour once in the community also has significant consequences. Prolonged sitting time reduces contractile stimulation of skeletal muscle leading to suppression of lipoprotein lipase activity and reduced glucose uptake (Bey and Hamilton 2003, Hamilton, Hamilton et al. 2004). Prolonged television viewing time, a common indicator of prolonged sitting, has been shown to have a dose-response with 2-hour plasma glucose and fasting insulin levels (Dunstan, Salmon et al. 2007), and is strongly associated with undiagnosed abnormal glucose metabolism and metabolic syndrome, particularly when viewing is four hours or more per day (Dunstan, Salmon et al. 2005). Prolonged sedentary behaviour is also detrimentally associated with triglycerides, HDL (high density lipoprotein) cholesterol, and resting blood pressure (Healy, Dunstan et al. 2008, Healy, Wijndaele et al. 2008, Tremblay, Colley et al. 2010). Most significantly, all associations persist after adjustment for moderate-to-vigorous physical activity and waist circumference (Dunstan, Salmon et al. 2005, Dunstan, Salmon et al. 2007, Owen, Healy et al. 2010). Conversely, breaking up prolonged sitting time with short bouts of light-to-moderate physical activity has been shown to have beneficial effects on these biomarkers (Healy, Dunstan et al. 2008, Dunstan, Kingwell et al. 2012).

In summary, the risks of prolonged sedentary behaviour on health need to be considered in addition to those of physical inactivity. Behavioural patterns associated with entrenched sedentary habits should be considered, and individuals should be encouraged and supported to reduce prolonged bouts of sitting time.

1.2.4 Guidelines for physical activity and sedentary behaviour

The Australian Government currently recommends that adults aged 18 to 64 years are physically active on most, preferably all, days every week; and that physical activity include at least 150 to 300 minutes of moderate intensity physical activity each week, or 75 to 150 minutes of vigorous intensity activity, or an equivalent combination of moderate to vigorous activity. They also recommend that muscle strengthening activities be undertaken on at least 2 days of each week. Within the guidelines the point is made that doing any activity is better than doing none at all; and that if individuals are currently doing no physical activity then they should start by doing some, and gradually build up to the recommended amount (Department of Health 2014).

In addition to these physical activity guidelines the Australian Government, in the most recent guidelines released in 2014, has also made recommendations regarding reducing sedentary behaviour. These recommendations include minimising the amount of time spent in prolonged sitting, and breaking up long periods of sitting as often as possible (Department of Health 2014).

For Australians aged 65 years and over, the Australian Government recommends that participation in some form of physical activity, no matter what the person's age, weight, health problems or abilities. A range of physical activities is best; that incorporates fitness, strength, balance and flexibility. It is recommended that older Australians accumulate at least 30 minutes of moderate intensity physical activity on most, preferably all, days. For those who have stopped physical activity, or who are starting a new physical activity, they should start at a level that is easily manageable and gradually build up to the recommended amount, type and frequency of activity; whilst those who continue to enjoy a lifetime of vigorous physical activity should carry on doing so in a manner suited to their capability into later life, provided recommended safety procedures and guidelines are adhered to (Brown, Moorhead et al. 2005).

The Australian guidelines align with current recommendations by the WHO (World Health Organization 2010), as well as those from the UK (Bull and Expert Working Groups 2010, All-Party Commission On Physical Activity 2014), America (US Department of Health and Human Services 2008), Canada (Tremblay, Warburton et al. 2011), and the nations of the European Union (Expert Group of the EU Working Group "Sport & Health" 2008); as well as those for other cultural populations, such as Asian Indians (Misra, Nigam et al. 2012) and Pacific Islanders (World Health Organization 2008).

1.2.5 Recommendations for physical activity after ABI

Individuals with ABI can experience the same benefits of physical activity as their healthy counterparts (Gordon, Gulanick et al. 2004). Regular physical activity can reduce musculoskeletal impairment (Morris, Dodd et al. 2004, Pang, Eng et al. 2005, Harris and Eng 2010), improve mobility and function (Mead, Greig et al. 2007, English and Hillier 2011, Saunders, Sanderson et al. 2013), improve cardiorespiratory fitness (Bateman, Culpan et al. 2001, Pang, Eng et al. 2006), improve emotional well-being (Driver and O'Connor 2003, Driver and Ede 2009, Wise, Hoffman et al. 2012), and increase health-related QOL (Rand, Eng et al. 2010, Chen and Rimmer 2011, Wise, Hoffman et al. 2012). Significantly, participation in physical activity can also reduce risk factors for chronic disease or future cardiovascular events (Rincon and Sacco 2008); with improvements in glucose tolerance (Ivey, Ryan et al. 2007), total cholesterol (Rimmer, Rauworth et al. 2009), arterial function (Takatori, Matsumoto et al. 2012, Tang, Eng et al. 2014) and blood pressure (Rimmer, Rauworth et al. 2009) reported after physical activity in individuals with stroke. Therefore, it is strongly recommended that individuals with ABI participate in regular physical activity in order to both maximise their functional capacity and quality of life, as well as to prevent future or further chronic disease and subsequent cardiovascular events (American College of Sports Medicine 2009, National Stroke Foundation 2010, Irwin, Ede et al. 2011, Billinger, Arena et al. 2014).

For individuals with ABI, physical activity promotion should emphasise low-to-moderate aerobic activity with the aim of ultimately achieving 30 minutes of moderate activity on most, preferably all, days of the week (American College of Sports Medicine 2009, National Stroke Foundation 2010, Irwin, Ede et al. 2011, Billinger, Arena et al. 2014). Physical activity should also entail muscle-strengthening activity, reduction of sedentary behaviour and risk management for secondary prevention of stroke (American College of Sports Medicine 2009, Irwin, Ede et al. 2011, Billinger, Arena et al. 2014). Physical activity preferences and environment should also be considered to maximise enjoyment and safety, and minimise any negative experiences. For example an individual who finds it difficult to concentrate in a busy environment may find group activities frustrating, whilst an individual who suffers from apathy following ABI may find a group environment more beneficial to maintaining long-term physical activity (American College of Sports Medicine 2009).

1.2.6 Physical activity status of individuals with ABI

Despite the benefits associated with increasing levels of physical activity and reducing sedentary behaviour, the physical activity status of individuals living with ABI remains low. Individuals with ABI typically have a low functional capacity, and their increased submaximal oxygen uptake and reduced peak oxygen uptake makes physical activity harder and sedentary behaviour more likely (American College of Sports Medicine 2009).

A pattern of physical inactivity after ABI is seen across the spectrum of care from the acute stage to those years after the event. Sjöholm and colleagues (2014) reported hospitalised patients following stroke spent an average of 74% (standard deviation (SD) 21%) of the day in sedentary activities. More alarmingly was that 44% (SD 32%) of the day was spent in continuous bouts of sedentary activity lasting 1 hour or more (Sjöholm, Skarin et al. 2014). Even higher levels of sedentary behaviour were found by Mattlage and colleagues (2015) who reported hospitalised adults with acute stroke spent 94% of the day in sedentary activities, 5% of their time in light activity, and nearly no time at all in MVPA. Kunkel and colleagues (2015) reported that individuals 3 years post-stroke spent an average of 73% (range 31-100%) of their day in sitting or lying. Hornnes and colleagues (2010) reported the proportion of community-dwelling stroke survivors who were physically inactive increased from 36% before stroke to 59% 1 year after their stroke. This is a similar proportion to the 58% of stroke survivors not reaching recommended physical activity levels reported by Rand and colleagues (2009), with stroke survivors expending a median of 10.3 MET (metabolic equivalent of task) hour/day (inter-quartile range (IQR) 6.1-17.1) out of a possible 199.5 MET hour/day (Rand, Eng et al. 2010). A systematic review by English and colleagues (2014) reported physical activity data from 26 studies of individuals post-stroke. Most of these studies (22/26) reported steps per day, of which there was a consistent reporting of less than half of that of age-matched normative values.

Following TBI, objective physical activity data are more scarce. However, Driver (2008) reported individuals with TBI spending an average of 48.6 minutes per week in physical activity, 70% of which was reported to be 'mild' activity. This was only mildly increased in a second study, with individuals with TBI reporting spending only 46 minutes per week in moderate physical activity (Driver, Ede et al. 2012).

These figures are similar to those reported by the Centers for Disease Control and Prevention (CDC) who report that nearly 50% of all adults with a disability get no physical activity at all, whilst an additional 22% do not get enough physical activity; and, in comparison to active adults with a disability, those who are inactive are more than 50% likely to have a chronic disease (Centers for Disease Control and Prevention 2014). In comparison to age-matched populations those with ABI are less physically active (Alzahrani, Ada et al. 2011, Danielsson, Meirelles et al. 2014), have reduced health and wellness (Braden, Cuthbert et al. 2012), and reduced participation levels (Colantonio, Ratcliff et al. 2004, Hartman-

Maeir, Soroker et al. 2007). Individuals with ABI, including those with TBI, are at higher risk of a future stroke (Hardie, Hankey et al. 2004, Gall, Dewey et al. 2009, Chen, Kang et al. 2011), and other chronic diseases (O'Rance 2007); and have a mortality rate twice that of the normal population (Hardie, Hankey et al. 2003, Anderson, Carter et al. 2004).

1.2.7 Barriers to physical activity after ABI

Individuals with ABI face many barriers to physical activity making it more difficult for them to achieve the levels of physical activity for optimal health and well-being. Barriers to physical activity after ABI have been examined in only a small number of studies, with the majority focused on individuals with stroke. A systematic review by Nicholson and colleagues (2013) found only four studies that had examined barriers to physical activity following stroke. The largest of these, a study by Rimmer and colleagues (2008), administered the Barriers to Physical Activity and Disability Survey (B-PADS) to eighty-three individuals with stroke recruited from surrounding clinics and hospitals. This survey focused predominantly on exercise and access to fitness centres, as opposed to overall physical activity. Barriers were divided into environmental or facility barriers, and personal barriers. The major environmental barriers cited were the cost of the program (61%), a lack of available transport (57%), a feeling that the trainer in the facility is not able to help (36%), and not feeling comfortable exercising in a facility (26%). Common personal barriers were not knowing how (46%) or where (44%) to exercise, having a lack of energy (39%) and motivation (37%), feeling 'too lazy' (33%), and having concerns about their health (28%) (Rimmer, Wang et al. 2008).

Others have used focus groups to elicit barriers to exercise. Damush and colleagues (2007) conducted focus groups with thirteen individuals with stroke who were enrolled in an existing research study. Again the focus was predominantly on exercise. They reported three main groups of barriers: impairments from their stroke, lack of motivation, and environmental barriers (Damush, Plue et al. 2007). A further two studies examined community participation more broadly, of which physical activity is just a component (Hammel, Jones et al. 2006, Robison, Wiles et al. 2009). Hammel and colleagues (2006) also conducted environmental audits as part of their study, examining access and engagement with different venues. Both studies found that barriers were both personal, such as physical and cognitive impairments, as well as environmental, such as access to facilities and transport (Hammel, Jones et al. 2006, Robison, Wiles et al. 2009). Hammel and colleagues (2006) also reported system and policy barriers, such as a lack of available resources and programs to individuals following stroke.

Driver and colleagues (2012) have examined barriers to physical activity following TBI. Twenty-eight individuals in an outpatient rehabilitation program completed the B-PADS, also with a focus predominantly on exercise. Similarly to Rimmer and colleagues in 2008, identified barriers were divided into environmental and personal categories. The most commonly cited environmental barriers were lack of transport (25%) and lack of access to a facility (17.9%). Common personal barriers were lack of endurance (28.6%), feeling self-conscious in a fitness facility (25%), lack of time (21.4%), and their disability (17.9%) (Driver, Ede et al. 2012). Further exploration of barriers to physical activity after

TBI have been explored by Self and colleagues (2013) in a qualitative exploration of the physical activity experiences of seventeen individuals undergoing outpatient rehabilitation following a TBI. This study found that the safety guidelines given by health professions to these individuals in the rehabilitation centre they attended resulted in a focus on what these individuals could not do, and inherently became a barrier to physical activity (Self, Driver et al. 2013). They also found that, although the individuals interviewed demonstrated a positive attitude to physical activity, they were often unsure of exactly what constituted physical activity and how much they were doing, as well as how much physical activity is required to receive benefits (Self, Driver et al. 2013).

Information remains limited about barriers to physical activity following ABI. Prior to this thesis, no study had examined barriers to physical activity in individuals living in Australia following ABI. The National Stroke Foundation has reported that Australians living in the community following stroke feel isolated and neglected, and that there is a lack of adequate information and programs available to them. They reported that access to health professionals and access to programs, such as self-management programs are highly desirable (National Stroke Foundation 2007).

1.3 Supporting self-management of physical activity

The WHO has called on nations of the world to take urgent action to address the underlying causes of chronic disease, such as physical inactivity, particularly in those individuals at high risk and those with an established chronic disease (World Health Organization 2005). However, despite the vulnerability of those with disabilities, there is a lack of development and implementation of health promotion programs for these people (Francis and Adams 2010), particularly those with ABI (Pawlowski, Dixon-Ibarra et al. 2013, Cleveland, Driver et al. 2015).

Physical activity interventions for individuals with ABI, such as treadmill training, circuit classes and group exercise, have been shown to be effective in improving mobility outcomes (English and Hillier 2011, Dean, Rissel et al. 2012, Ada, Dean et al. 2013); whilst fitness training interventions have also shown to have short term benefits (Mead, Greig et al. 2007, Hassett, Moseley et al. 2009, Hassett, Moseley et al. 2012). However, these short term benefits are often not maintained and cease once intervention ceases (Jurkiewicz, Marzolini et al. 2011, Ada, Dean et al. 2013).

Self-management is an integral part of managing a chronic disease or disability (Holman and Lorig 2004, Glasgow, Jeon et al. 2008). Building self-management skills and supporting self-management of physical activity is a crucial part of empowering individuals with ABI to optimise their health and well-being.

1.3.1 Definition of self-management

Individuals are always self-managing. Decisions made by individuals living with ABI every day reflect a style of self-management, regardless of whether this is positive or negative in outcome (Lorig and Holman 2003). However, the term self-management has become more synonymous with an *"individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition"* (Creer and Holroyd 2006).

The UK Department of Health defines self-management more broadly as the *"actions individuals and carers take for themselves, their children, their families and others to stay fit and maintain good physical and mental health; meet social and psychological needs; prevent illness and accidents; care for minor ailments and long term conditions; and maintain health and wellbeing after an acute illness or discharge from hospital"* (Department of Health 2005). Therefore, self-management of physical activity is one component of managing overall health and wellbeing.

Hill-Briggs stipulates that for effective self-management of chronic disease individuals must: (1) possess motivation, confidence, and skills necessary to manage their condition; (2) be effective problem-solvers, capable of self-monitoring and adjusting self-management behaviours in response to objective and subjective information about their condition; and (3) successfully adapt self-management strategies to the unique social and environmental factors that make up their daily life (Hill-Briggs 2003, Creer and Holroyd 2006). Thus, self-management is a dynamic and continuous process (Barlow, Wright et al. 2002).

The concept of *self-management support* is about providing individuals with the information, skills and encouragement they need to effectively manage their condition. Self-management programs are designed to support self-management by imparting the knowledge and skills required for individuals to better understand their condition, monitor their health and take appropriate action as required (de Silva 2011).

However, conceptualising self-management is complex, with little known about the perspectives of all the stakeholders, nor of the preferred outcomes of self-management support (Boger, Ellis et al. 2015, Ellis, Boger et al. 2015). The impact of self-management programs often focus on individualistic measures, such as self-efficacy, health status, mood and quality of life without clear articulation of the relationship of such indicators to self-management (Boger, Ellis et al. 2015). These tools have also been developed with a lack of patient input and poor methodological quality, raising questions about their validity and reliability (Boger, Demain et al, 2013). There can also be wide variations in how different stakeholders perceive an improvement in self-management, with a qualitative study by Ellis and colleagues (2015) reporting that patients and family members are focussed on feeling well and participating fully in everyday life; while health professionals and those involved in the administration of health services emphasised biomedical outcomes and consequential reductions in service demands (Ellis, Boger et al. 2015). These issues do represent critical limitations of the design and evaluation of self-management programs (Boger, Ellis et al. 2015).

1.3.2 Evidence for self-management programs after ABI

Knowledge in the area of self-management is developing. However, there is growing evidence for the efficacy of self-management interventions. A review by de Silva for The Health Foundation in the UK examined more than 550 high quality research papers and concluded that the evidence supported the benefits of self-management, particularly when there is a focus on changing behaviour and increasing self-efficacy (de Silva 2011).

Self-management programs for individuals after ABI have recently been developed and trialled in different settings and using different formats. The majority of programs currently available are targeted to individuals after stroke. A systematic review by Jones and Riazi found that there is emerging evidence for benefits to be gained from self-management programs for individuals after stroke that are founded on self-efficacy principles. This finding is in line with the large review conducted by de Silva, however the optimal format for delivery of these principles is still unclear (Jones and Riazi 2011). In addition, a systematic review by Lennon and colleagues (2013) explored self-management programs for people post-stroke and found favourable improvements in disability, physical health, confidence in recovery and stroke specific quality of life. Kendrick and colleagues (2012) found favourable results from a self-management program in individuals with chronic mild ABI, most of who had sustained a TBI (90.6%), in regards to performance and satisfaction with activities of daily living (ADL) as measured by the Canadian Occupational Performance Measure.

Given the potential benefits to be gained from enhancing physical activity self-efficacy and changing physical activity behaviour, specifically targeting physical activity through a self-management program founded on these principles may support individuals with ABI to increase their physical activity levels. However, at the time of commencing this thesis, the efficacy of self-management programs at specifically enhancing physical activity after ABI was unknown. There is also very limited empirical data about the most appropriate content and the best form of delivery of self-management programs (Lennon 2013). However, it is likely that individual needs and preferences for self-management support may influence the suitability of different program styles and modes of delivery (Lawn and Schoo 2010).

1.3.3 Remote delivery of a self-management program

The remote delivery of self-management programs, for example, via the internet or telephone, is becoming increasingly popular. Remote delivery offers a way of potentially increasing accessibility to programs for those who face multiple barriers to accessing optimal health care, such as cost, mobility restrictions, transportation or service availability in rural or remote regions (Jerant, Friederichs-Fitzwater et al. 2005, Lorig, Ritter et al. 2013).

Remotely-delivered self-management programs have been shown to be successful in a variety of populations, such as those with chronic pain (Dear, Titov et al. 2013, Dear, Gandy et al. 2015), anxiety and depression (Titov, Andrews et al. 2010, Titov, Dear et al. 2013, Titov, Dear et al. 2014), post-traumatic stress disorder (Spence, Titov et al. 2011), arthritis (Lorig, Ritter et al. 2008), and cerebral palsy (Maher, Williams et al. 2010). Remote telehealth interventions (incorporating internet, phone and teleconference communication) have also shown to be effective in reducing risk factors for and secondary prevention of, coronary heart disease (Neubeck, Redfern et al. 2009); whilst a systematic review by Webb and colleagues (2010), found that internet-based behaviour change interventions were enhanced by additional methods of communication, particularly short text messages.

A Cochrane review by Foster and colleagues (2013) examining remote interventions aimed at changing physical activity behaviour highlighted the potential of remote delivery methods in changing behaviour. Eleven studies met the inclusion criteria, with a total of 5862 healthy adults. Nine studies examining 4547 participants, examining the effect of remotely delivered physical activity interventions on self-reported physical activity at one year generated results that were positive and moderate (Standardised mean difference (SMD) 0.20; 95% CI 0.11 to 0.28; moderate quality evidence). Similarly, two studies examining 444 participants found the effect on cardiovascular fitness at one year to be positive and moderate (SMD 0.40; 95% CI 0.04 to 0.76; high quality evidence) (Foster, Richards et al. 2013). The most effective interventions were found to be those where a tailored approach to physical activity was used, and telephone contact to support change in physical activity behaviour was provided. Additionally, a systematic review of non-face-to-face physical activity interventions by Muller and colleagues (2014) also found remote interventions effectively promoted physical activity in older adults aged 50 years and over.

Remote delivery of a self-management program to individuals with ABI has been trialled in a small number of studies, although not always in isolation from face-to-face intervention sessions (Kosma, Cardinal et al. 2005, Huijbregts, McEwen et al. 2009, Taylor, Cameron et al. 2009, Damush, Ofner et al. 2011, Kim and Kim 2013, Kim, Lee et al. 2013). Remote delivery modes have included web-based interventions, telehealth and telephone supported programs. These remote modes of delivery appear to be feasible and acceptable to individuals with ABI, although information is still limited and efficacy had not been examined in relation to physical activity specifically at the time of commencing this thesis. There has also not been any examination of feasibility and acceptability of a remotely delivered self-management program aimed specifically at increasing physical activity after ABI.

1.3.4 Supporting physical activity behaviour change

Self-management programs aimed at increasing physical should be founded on behaviour change principles and target clinical variables associated with physical activity. For example, a review by Morris and colleagues (2012) found that psychological factors, such as self-efficacy and physical activity beliefs, as well as social support appear to be particularly relevant to the uptake of physical activity after stroke.

Physical activity has a unique set of characteristics when compared to many other health behaviours (Rhodes and Nigg 2011). Physical activity can be an aversive experience, bringing people out of resting homeostasis; requiring effort and resulting in physiological adaptations over time (Maddux 1997, Rhodes and Nigg 2011). Physical activity is not immediately necessary, unlike eating; and requires adoption of, or an increase in, behaviour, as opposed cessation (e.g. with smoking or drinking). Physical activity requires an ongoing time commitment, different to tasks that are short (e.g. sunscreen application) and/or temporary (e.g. cancer screening). (Rhodes, de Bruijn et al. 2010, Rhodes and Nigg 2011). The complex mix of these characteristics do, to some degree, set physical activity apart from other health behaviours upon which theories of health-related behaviour change have been founded (Rhodes and Nigg 2011). This may require augmentation of current theories of behaviour change through integration of models, with examination of the constructs that are best applied specifically to physical activity behaviour (Rhodes and Nigg 2011). However, this requires a thorough understanding of what is currently known about changing physical activity behaviour and examination of how to best support an uptake of this behaviour in individuals with ABI.

Theories of behaviour change and physical activity

There are numerous theories of behaviour change that have been applied to physical activity behaviour. Here we will examine the most commonly applied theories.

Social Cognitive Theory (SCT)

Bandura's SCT is a theory in which self-efficacy beliefs operate with goals, outcome expectations, and perceived environmental impediments and facilitators in the regulation of human motivation, behaviour and wellbeing (Bandura 2004). Self-efficacy denotes an individual's confidence in their capability to accomplish a certain level of performance (Bandura 1977). It is at the core of SCT, being the primary factor in the decision to change a health behaviour, mobilise the motivation and perseverance required, overcome setbacks and lapses, and maintain changes in habits once they have occurred (Bandura 2004).

Bandura stipulates that self-efficacy is derived from four principle sources, these being (1) performance accomplishments, (2) vicarious experiences (modelling), (3) verbal persuasion, and (4) physiological states; with more dependable sources yielding greater influence on self-efficacy (Bandura 1977). Efficacy beliefs can affect physical activity both directly, and indirectly by influencing self-regulation, such as goal setting, problem solving and self-persuasion; and perceptions about sociocultural environments that present barriers or provide support for physical activity (Bandura 2004). Physical activity self-efficacy has been shown to have a significant influence on physical activity participation in numerous studies

(McAuley and Blissmer 2000, Rhodes and Nigg 2011). Oman & King (1998) report that self-efficacy has differential effects across the time course of exercise, with it being a more significant predictor in exercise adoption whilst playing a lesser role in exercise maintenance, which is likely associated at the time exercise has become more habitual (Oman and King 1998, McAuley and Blissmer 2000). However, it is important to recognise that there is likely variability to this rule. For example, self-efficacy has been shown to be predictive of maintenance of more vigorous activity over a prolonged period of time (Sallis, Haskell et al. 1986). There are indications that self-efficacy is central to the adoption and maintenance of physical activity after a brain injury (Driver 2006). Individuals with ABI face a significant number of barriers to physical activity (Driver, Ede et al. 2012, Nicholson, Sniehotta et al. 2013). They are also spend a high amount of time in sedentary activities (Sjöholm, Skarin et al. 2014, Mattlage, Redlin et al. 2015, Kunkel, Fitton et al. 2015), resulting in a reduction in maximal oxygen consumption (Stuempfle and Drury 2007). This leads to individuals with ABI requiring a higher relative level of effort when they are physically active, therefore making it likely that they require a high level of self-efficacy to both adopt and maintain a physically active lifestyle.

Self-efficacy has also been linked to the success of self-management programs (Marks, Allegrante et al. 2005, Marks, Allegrante et al. 2005, de Silva 2011), including those following stroke (Jones and Riazi 2011). Following stroke, self-efficacy is associated with an improvement in various outcomes, such as quality of life or perceived health status, depression, ADL and, to a certain extent, physical functioning (Jones and Riazi 2011). However, further empirical evidence is required, particularly in regards to the role of self-efficacy in relation to physical activity following ABI. It is important to recognise that self-efficacy is but one determinant of physical activity behaviour, and it's contribution should be considered in conjunction with other personal and social variables (McAuley and Blissmer 2000).

Transtheoretical Model (TTM)

The TTM was initially developed to study behaviour change associated with quitting smoking, but has since been applied widely to a number of health behaviours, including physical activity (Rhodes and Nigg 2011). The TTM also recognises *self-efficacy* as one of its core components, but it brings a temporal dimension to behaviour change, with the introduction of the *stages of change* concept. The TTM proposes six stages of change (i.e., precontemplation, contemplation, preparation, action, maintenance, and termination) through which an individual progresses. It recognises these stages as dynamic and cyclical, so a relapse in behaviour can result in a fall back to a previous stage. Individuals progress through the stages via ten *processes of change,* the covert and overt processes individuals employ to move through the stages, with earlier stages being more influenced by cognitive processes and later stages by action oriented processes. The fourth construct of the TTM is that of *decisional balance* – the weighing up of the pros and cons of behaviour change, with the premise being that action occurs when the pros outweigh the cons (Prochaska and DiClemente 1983, Prochaska, Velicer et al. 1994, Prochaska and Velicer 1997).

The stages of change construct has been used in physical activity programs to identify an individual's readiness to change (Marcus and Simkin 1994), including for those following stroke (Garner and Page 2005); and to match them to an appropriate physical activity intervention, based on processes of change (Marcus and Simkin 1994). Stages of change have been shown to have construct validity with physical activity behaviours (Kosma and Ellis 2010), and correlates with physical activity levels in the normal population (Booth, Macaskill et al. 1993, Garber, Allsworth et al. 2008). Stages of change and other TTM constructs have been applied successfully in numerous physical activity interventions (Marcus, Banspach et al. 1992, Nigg 2001, Marshall, Bauman et al. 2003). Marcus and colleagues (1992) used tailored materials based on stage of change in a physical activity intervention for community-dwelling adults, resulting in a increase in activity in 62% of those in the contemplation stage and 61% of those in the Preparation stage (Marcus, Banspach et al. 1992). TTM has also been found to be a valid framework for physical activity interventions for individuals with physical disabilities, with stages of change found to be a greater predictor of physical activity than self-efficacy (Kosma, Ellis et al. 2007, Kosma, Ellis et al. 2012). However, a web based physical activity motivational intervention based on the constructs of the TTM was not found be effective in changing physical activity behaviour in individuals with a physical disability (Kosma, Cardinal et al. 2005).

Health Beliefs Model (HBM)

The HBM was developed in the 1950's as an attempt to understand the widespread failure of individuals to comply with disease prevention strategies, and was later applied to individuals' responses to disease and compliance with medical regimens. It consists of four core constructs: (1) *perceived susceptibility* – a perception of risk, (2) perceived severity – a perception of possible consequences, (3) *perceived benefits* – a perception of the behaviour being feasible and efficacious, and (4) *perceived barriers* – perceived impediments to a behaviour. The premise is that the combined levels of perceived susceptibility and severity provide the motivation to act, whilst the perceived benefits and barriers determine the preferred path to action (Becker 1974, Janz and Becker 1984). The HBM also incorporates the concept of a cue to action (internal or external) which triggers this decision making process (Janz and Becker 1984). Later research on the HBM has led to inclusions of perceptions of self-efficacy and social influences missing from earlier versions (Bartholomew, Parcel et al. 2011).

Sullivan and colleagues (2008) did find a significant pattern of correlation between HBM variables, and subjective norms and self-efficacy when examining intention to exercise in individuals following stroke, with perceived benefits of exercise and exercise self-efficacy being the two most important determinants of exercise intention. In testing a brief psychological intervention based on an extended version of the HBM, Gill & Sullivan (2011) found that although the intervention significantly increased exercise self-efficacy in individuals after stroke, it did not alter any of the other constructs of the HBM.

Although components of the HBM appear to be useful, there are some thoughts that the HBM in its entirety may be better suited to more simple, shorter health behaviours (Bartholomew, Parcel et al. 2011). Physical activity can be an aversive physiological experience in the short term, as well as being associated with other detriments, such as being time consuming (Maddux 1997), while perceived benefits, such as improved health, often exist further into the future, therefore effectively reducing their value (Green and Myerson 2004). This may result in HBM not being the ideal model of choice for changing physical activity behaviour, however, aspects of the HBM may be useful in small components of a complex behaviour change intervention.

Theory of Planned Behaviour (TPB)

The TPB posits that intention, as the most important determinant of behaviour, is predicted by three core constructs: (1) *attitude* – a disposition to respond favourably or unfavourably to a behaviour, (2) *subjective norm* – perceived social influence or pressure from others, and (3) *perceived behavioural control* – perception of the ease or ability to perform a behaviour, likened to self-efficacy and locus of control concepts (Ajzen 1985, Blue 1995, Aarts, Verplanken et al. 1998, Bartholomew, Parcel et al. 2011, Rhodes and Nigg 2011).

Studies of TPB and exercise behaviour show that exercise is most strongly associated with intention and perceived behavioural control (Blue 1995, Symons Downs and Hausenblas 2005). Intention appears to have some predictive capacity of exercise behaviour, whilst attitude and perceived behavioural control predicted intention (Symons Downs and Hausenblas 2005), Subjective norm, however, shows very little predictive capacity in exercise intention (Blue 1995, Symons Downs and Hausenblas 2005). However, despite the association between exercise behaviour and intention, there is still an “intention-behaviour gap” with more people intending to be active than those who actually are active (Rhodes, Plotnikoff et al. 2008). Similarly to the HBM, the TPB may be better applied to shorter health behaviours, rather than a long term physical activity intervention due to the potentially aversive nature of physical activity (Maddux 1997), and the reduced value of long term health benefits of physical activity (Green and Myerson 2004), which could be an underlying cause of the “intention-behaviour gap” noted by Rhodes and colleagues (2008). However, it may also be the case that facets of this model are useful for some components of a complex physical activity intervention.

Habits

In recent years there has been a growing interest in the role of habits in the physical activity domain. Most models of health behaviour do not take into account the repetitive nature of behaviours, such as physical activity. Models, such as TPB, emphasise the deliberate nature of behaviour. However, the repetition of behaviour not only has an important cumulative effect on health, but also forms the basis of habits, a form of automaticity (Aarts, Verplanken et al. 1998, Verplanken and Melkevik 2008, Rhodes, de Bruijn et al. 2010). Habits are now being considered an important construct in better understanding, and changing, physical activity behaviour (Aarts, Verplanken et al. 1998, Verplanken and Melkevik 2008, Rhodes, de Bruijn et al. 2010, Gardner 2011).

A habit is defined as a goal-directed behavioural pattern that is enacted automatically in response to a situation in which the behaviour has been performed repeatedly and consistently in the past (Aarts, Verplanken et al. 1998, Verplanken and Melkevik 2008, Lally and Gardner 2013). A habit is greater than just behavioural frequency, although frequency is required for habit establishment. However, it is the automaticity of the behaviour that is provides important information about the way physical activity is enacted over time (Verplanken and Melkevik 2008). Deliberate intentions are less predictive of behaviour as habit increases (Aarts, Verplanken et al. 1998). This can be beneficial, as behaviours that are habitual are less likely to be influenced by decision-making processes, where factors such as emotions and decisional balance can influence behavioural choices (Verplanken and Melkevik 2008, Eagleman 2011). This is particularly useful given that many of the benefits of physical activity are experienced in the future, and therefore, as previously discussed, are inherently less valued (Green and Myerson 2004).

Establishing physical activity habits can be made difficult by the presence of old, undesirable habits, such as sedentary behaviour (Verplanken and Melkevik 2008). Additionally, the nature of physical activity, in that it provokes a possibly aversive physiological response, is time-consuming, and is often not a behaviour performed 'without conscious thought' means that establishing physical activity as a habit, if possible at all, is not easy (Maddux 1997). However, Verplanken and Melkevik

(2008) argue that the decision to be active can become habitual. In this way, establishing a strong habit to be active implies that regular physical activity is self-evident, does not require thought or deliberation to initiate, and is incorporated into a person's normal routine.

In establishing physical activity as a habit, a number of key features are considered to be important. The activity should be enacted in the presence of the same contextual and situational cues frequently and consistently in order to establish a new behavioural pattern (Lally and Gardner 2013). This contextual focus may be the reason that many physical activity interventions do not result in long term behaviour changes, particularly those that provide an intervention in a clinical setting and expect behaviour to carry over to everyday living. To establish a habit the behaviour should also be positively reinforced by a reward – intrinsic or extrinsic. Performance that is highly rewarding, particularly by immediate intrinsic reward, such as pleasure or satisfaction, is more likely to be established as a strong habit (Lally and Gardner 2013). The use of immediate rewards should be carefully considered when designing a physical activity intervention when many short consequences can be negative in nature (Maddux 1997).

Fogg Behavioral Model

A recent model of behaviour that considers the formation of habits in changing behaviour is the Fogg Behavioral Model (Fogg 2009, Fogg 2011). The Fogg Behavioral Model has three principle components: (1) *motivation*; (2) *ability*, and (3) a *trigger*. The model stipulates that for a behaviour to occur an individual must have sufficient motivation, sufficient ability and an effective trigger all present at the same time. Motivation has six contributing elements: (1) pleasure, (2) pain, (3) hope, (4) fear, (5) social acceptance, and (6) social rejection; whilst ability also has six contributing factors: (1) time, (2) money, (3) physical effort, (4) brain cycles, that is mental effort, (5) social deviance, and (6) non-routine.

The Fogg Behavioral Model stipulates that motivation and ability trade off against one another. That is, a difficult behaviour requires a higher level of motivation, whilst an easier behaviour requires less motivation. A premise of the model is that as behaviour becomes more routine, or habitual, it becomes easier to do and requires less motivation. Fogg argues that too often, behaviour change interventions have focused predominantly on motivation. He considers that motivation is emotionally driven, causing it to naturally fluctuate over time in a wave like pattern. Therefore, remaining highly motivated to perform a behaviour, particularly if difficult, over long periods of time, is unrealistic. This concept is particularly pertinent to physical activity behaviour.

Fogg recommends that to create a habit of a desired behaviour it is best to make the behaviour easier (and less aversive), rather than focusing solely on increasing motivation. He also recommends finding the precise trigger for that behaviour, so the habit may embed into an individual's daily routine (Fogg 2009, Fogg 2011). Although there are no studies examining the efficacy of the Fogg Behavioral Model in changing physical activity behaviour, this model potentially provides a conceptually useful framework for changing physical activity behaviour.

When developing complex interventions it is encouraged that intervention developers break away from the traditional approach of using a single theory to guide the change they want to make, instead using a variety of theories that consider the complexity of behaviour change (Bartholomew, Parcel et al. 2011). Drawing on multiple theories, allows for different methods to be applied to different aspects of a complex intervention, such as increasing knowledge and awareness, building self-efficacy and establishing new physical activity habits (Bartholomew, Parcel et al. 2011). Therefore, a variety of these behaviour change models have been incorporated into the work presented in this thesis.

1.3.5 Developing a complex self-management intervention

Developing effective and acceptable self-management programs is challenging. Too often there is also inadequate development and piloting of interventions, with a rush to conduct treatment efficacy trials missing the opportunity to develop and evaluate the theoretical and practical aspects of intervention (Craig, Dieppe et al. 2008). This can result in less useful interventions that are harder to evaluate and less likely to be implemented (Campbell, Fitzpatrick et al. 2000, Craig, Dieppe et al. 2008, Bartholomew, Parcel et al. 2011, Glasgow 2013). Redfern and colleagues (2006) have noted that few interventions in stroke care have been adequately developed or evaluated, which may explain the lack of efficacy for some of these interventions. Foster and colleagues (2005) have reported similar concerns with physical activity interventions, stating that there is an inability to evaluate the quality of components of these programs due to a lack of information regarding the theoretical basis for the intervention and the way in which this theory was translated into practice. A review by Cervantes and Taylor (2011) examining physical activity interventions for adults with disabilities reported that fewer than 50% of the interventions specified a theoretical framework to guide the intervention. This is significant, as having an explicit theoretical basis to a behaviour change intervention, including those examining physical activity, has been shown to be predictive of efficacy (Webb, Joseph et al. 2010, Michie and Johnston 2012, Taylor, Conner et al. 2012).

The UK Medical Research Council has recommended that all complex interventions should include a coherent theoretical basis that clearly underpins the development process, and that this process should be described fully to allow for implementation, replication and robust evaluation. The process for developing these interventions should be made up of several distinct phases, which may progress iteratively rather than linearly, through from preclinical or theoretical phases, to testing of feasibility and acceptability, before planning methodology for an efficacy trial and implementation (Campbell, Fitzpatrick et al. 2000, Craig, Dieppe et al. 2008).

The development of an intervention that builds from a theoretical basis, yet bridges the gap from theory to practice, is difficult. Intervention Mapping is an established approach used to develop complex health promotion interventions with a problem-focused perspective suited to real-life situations (Kok, Schaalma et al. 2004, Bartholomew, Parcel et al. 2011). Developed by a group of US and Dutch health promotion researchers (Kok, Schaalma et al. 2004), the construction of the Intervention Mapping framework has been based on the authors experience in developing of complex self-management programs for individuals with cystic fibrosis and asthma (Bartholomew, Parcel et al. 2011, Bartholomew, Parcel et al. 1998, Bartholomew, Parcel et al. 1991). Given that myMoves is also a self-management program, it is useful that the Intervention Mapping framework has been developed from this interventional background. Intervention Mapping has also been used to develop complex health promotion interventions in areas such as AIDS prevention and management; obesity prevention; workplace health; cancer screening; and sexual health (Bartholomew, Parcel et al. 2011).

The purpose of Intervention Mapping is to provide a framework for effective decision making at each step of intervention development, including the planning, design, implementation and evaluation (Bartholomew, Parcel et al. 2011). It is designed to reflect the complexity of the decision-making process, recognizing this process to be collaborative, iterative and cumulative (Schaalma and Kok 2009). It also allows for practical and political considerations that relate to efficiency, feasibility and ethics (Schaalma and Kok 2009). Intervention Mapping consists of six steps that serve as a blueprint for the design, implementation and evaluation of an intervention based on a foundation of theoretical, empirical and practical information. These steps are: (1) needs assessment; (2) identification of outcomes, performance objectives and change objectives; (3) selection of theory-based intervention methods and practical applications; (4) organisation of methods and applications into an intervention program; (5) creation of an implementation plan; (6) generation of an evaluation plan. These steps are presented in a linear manner; however, as recommended by the UK Medical Research Council, the process is both iterative and cumulative. Thus, in reality, intervention developers move back and forth between the steps to refine and improve aspects of the intervention as information is gained (Bartholomew, Parcel et al. 2011).

1.4 Aims of the Thesis

The overarching aim of this research is to develop a remote self-management program to increase physical activity after ABI. This is to be achieved by undertaking the following studies:

Study I

The primary aim of Study I is to examine the efficacy of self-management programs in increasing physical activity in adults living in the community with ABI. The secondary aims are to examine how effective and acceptable remote delivery of self-management programs aimed at increasing physical activity after ABI are to this population, and to examine the components of self-management programs associated with the best clinical outcomes regarding physical activity and participant satisfaction. In order to meet these aims a systematic review of the literature will be performed based on a protocol developed and published *a priori*.

Study II

The primary aim of Study II is to conduct a specific needs analysis of potential users of an internet-delivered self-management program to increase physical activity after ABI. This needs analysis consists of an online survey where the specific aims are to (1) examine the current physical activity status of community dwelling adults in Australia with ABI and the level of satisfaction with this status;

(2) establish the main barriers to physical activity experienced by community dwelling adults in Australia with ABI and the level of confidence to overcome these barriers; and (3) establish the level of interest in an internet based self-management program focused specifically on increasing physical activity for adults in Australia with ABI.

Study III

The primary aim of Study III is to develop a self-management program aimed specifically at increasing physical activity in adults living in the community with ABI. The development process of this complex and multifaceted self-management intervention, called *The myMoves Program*, is to be undertaken in a systematic and scholarly manner with a strong theoretical foundation using an Intervention Mapping approach.

Study IV

The primary aim of Study IV is to examine whether a remotely delivered self-management program to increase physical activity in adults with ABI living in the community is both feasible and acceptable. Secondary aims are to examine changes in the level of physical activity, physical activity self-efficacy, levels of psychological distress, and participation in myMoves participants.

Study V

The primary aim of Study V is to examine the feedback from participants in Study IV and to make recommendations to enhance the next iteration of the myMoves

Program. Post-doctoral research is planned to test the efficacy of the next iteration of the myMoves Program in a randomised controlled trial.

By conducting these studies, and with the development of the *myMoves* program, it is hoped that this body of work will significantly enhance the services available for improving the health and wellbeing of individuals living with ABI.

CHAPTER 2

Study I - The efficacy of self-management programs in increasing physical activity in community-dwelling adults with acquired brain injury

2.1 Preface

In Chapter 1, it was recognised that the efficacy of self-management programs to increase physical activity in community-dwelling adults with ABI had not been examined. As part of a comprehensive needs assessment when developing a complex and multifaceted intervention, it is important to examine what is currently known about the efficacy of such interventions. Therefore, Chapter 2 outlines the work undertaken to establish what is currently known regarding the efficacy of self-management programs on physical activity outcomes in individuals with ABI.

This Chapter consists of two publications, the first of which is a protocol paper:

Jones T. M., Hush J. M., Dear B. F., Titov N. and Dean C. M. (2014). "The efficacy of self-management programmes for increasing physical activity in community-dwelling adults with acquired brain injury (ABI): a systematic review." *Systematic Reviews* 3(1): 39.

Jones T. M., Dean C. M., Hush J. M., Dear B. F. and Titov N. (2015). "A systematic review of the efficacy of self-management programs for increasing physical activity in community-dwelling adults with acquired brain injury (ABI)" *Systematic Reviews* 4(51): 17.

The following conference abstracts also relate to the work conducted in this Chapter:

Jones T. M., Dean C. M., Hush J. M., Dear B. F. and Titov N. (2015). "A systematic review of the efficacy of self-management programs for increasing physical activity in community-dwelling adults with acquired brain injury (ABI)" *Australian Physiotherapy Association Connect Physiotherapy Conference 2015*. 3-6 October 2015. Gold Coast Exhibition Centre, Queensland, Australia.

The search strategies for this systematic review are provided in Appendix 1.

2.2 Co-authors statement

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Faculty of Medicine and Health Sciences

MACQUARIE
University

Co-authors' Statement

As co-authors' of the paper, *The efficacy of self-management programmes for increasing physical activity in community-dwelling adults with acquired brain injury (ABI): a systematic review (protocol paper)*, we confirm that Taryn Jones has made the following contributions to this study:

- Conception and design of the research
- Drafting and revising of the manuscript
- Critical appraisal of the content

Professor Catherine Dean: C Dean .... Date: 14:09:15

Associate Professor Julia Hush: .... Date: 14.09.15

Dr Blake Dear: .... Date: 14.09.15

Professor Nickolai Titov: .... Date: 14.09.15

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Co-authors' Statement

As co-authors' of the paper, *A systematic review of the efficacy of self-management programs for increasing physical activity in community-dwelling adults with acquired brain injury (ABI)*, we confirm that Taryn Jones has made the following contributions to this study:

- Conception and design of the research
- Collection and extraction of data
- Analysis and interpretation of the findings
- Drafting and revising of the manuscript
- Critical appraisal of the content

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2.3 Protocol for a systematic review of the literature

Jones *et al. Systematic Reviews* 2014, **3**:39
http://www.systematicreviewsjournal.com/content/3/1/39

SYSTEMATIC REVIEWS

PROTOCOL **Open Access**

The efficacy of self-management programmes for increasing physical activity in community-dwelling adults with acquired brain injury (ABI): a systematic review

Taryn M Jones[1,3], Julia M Hush[1,3], Blake F Dear[2,3], Nickolai Titov[2,3] and Catherine M Dean[1,3*]

Abstract

Background: Acquired brain injury (ABI), often arising from stroke or trauma, is a common cause of long-term disability, physical inactivity and poor health outcomes globally. Individuals with ABI face many barriers to increasing physical activity, such as impaired mobility, access to services and knowledge regarding management of physical activity. Self-management programmes aim to build skills to enable an individual to manage their condition, including their physical activity levels, over a long period of time. Programme delivery modes can include traditional face-to-face methods, or remote delivery, such as via the Internet. However, it is unknown how effective these programmes are at specifically improving physical activity in community-dwelling adults with ABI, or how effective and acceptable remote delivery of self-management programmes is for this population.

Methods/Design: We will conduct a comprehensive search for articles indexed on MEDLINE, EMBASE, CINAHL, PsychINFO, AMED, Cochrane Central Register of Controlled Trials (CENTRAL), PEDro and Science Citation Index Expanded (SCI-EXPANDED) databases that assess the efficacy of a self-management intervention, which aims to enhance levels of physical activity in adults living in the community with ABI. Two independent reviewers will screen studies for eligibility, assess risk of bias, and extract relevant data. Where possible, a meta-analysis will be performed to calculate the overall effect size of self-management interventions on physical activity levels and on outcomes associated with physical activity. A comparison will also be made between face-to-face and remote delivery modes of self-management programmes, in order to examine efficacy and acceptability. A content analysis of self-management programmes will also be conducted to compare aspects of the intervention that are associated with more favourable outcomes.

Discussion: This systematic review aims to review the efficacy of self-management programmes aimed at increasing physical activity levels in adults living in the community with ABI, and the efficacy and acceptability of remote delivery of these programmes. If effective, remote delivery of self-management programmes may offer an alternative way to overcome barriers and empower individuals with ABI to increase their levels of physical activity, improving health and general wellbeing.

Trial registration: Our protocol has been registered on PROSPERO 2013: CRD42013006748.

Keywords: Self-management, Physical activity, Brain injury, Stroke, Remote delivery, Internet

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Background

Physical inactivity is globally recognised as a major cause of morbidity and mortality. Physical inactivity is now identified as the fourth leading risk factor for global mortality with levels of inactivity rising in most countries [1]. Acquired brain injury (ABI) is a significant cause of morbidity and burden globally, leading to significantly reduced levels of physical activity. Individuals with ABI suffer reduced health and wellbeing as a result of being inactive, increasing the global burden of non-communicative disease (NCD) caused by physical inactivity [2-4].

ABI refers to any damage to the brain that occurs after birth. The most common cause of ABI is stroke or trauma. Stroke is the second most common cause of mortality worldwide, while traumatic brain injury (TBI) is the leading cause of death and disability in children and young adults around the world [1]. ABI is a major cause of disability - stroke alone accounts for a loss of 49 million disability-adjusted life years (DALYs) worldwide annually [1]. Disability directly reduces physical activity levels, causing a spiral of deteriorating health and quality of life in those affected by ABI. People with ABI report more disability and more health disorders than the average person with disability [3]. Almost half (46%) of people with severe or profound disability have poor health status, compared to only 5% of those without disability [4]. An Australian report indicates that one in 45 Australians has an ABI with activity limitations or participation restrictions, and that these individuals are substantially less active than those without [3].

Physical inactivity both causes and accelerates chronic disease. Rising levels of physical inactivity have major implications for the general health of people worldwide and for the prevalence of NCDs such as cardiovascular disease, diabetes and cancer, and their risk factors such as raised blood pressure, raised blood sugar and obesity [5]. It is currently estimated that six out of every 10 deaths globally are attributable to non-communicable conditions [6]. These conditions resulting from physical inactivity have very high societal burden, causing considerable morbidity and mortality [7]. Those already affected by disability, such as individuals with ABI, are at significantly greater risk of developing further chronic health conditions due to physical inactivity [3].

Despite the heightened risk of chronic health conditions in this population, services to help people living in the community with ABI increase their levels of physical activity are very limited. In Australia for example, over 50% of stroke survivors report being dissatisfied with their access to information about stroke recovery, as well as being frustrated in trying to determine what services are available, where they are located, and whether they meet their personal circumstances [8]. There are a number of common barriers, such as direct and indirect costs of treatment, transport difficulties and limited local specialist services [8-10], which significantly reduce the uptake of physical activity among individuals with ABI. In developing countries, the situation is even worse with a substantial lack of resources, funding and knowledge available to assist those with disability resulting from ABI [2].

The challenge of sustaining physical activity is also often complicated in people with ABI because the impact of their condition changes over time, especially as individuals enter different stages of their life. In Australia, 75% of individuals with an ABI are aged under 65 years, and two out of three of these individuals are aged under 25 years [11]. Thus, many people are left to manage their physical activity levels over a long period of their life and encounter different challenges at different times. For example, an individual may alter their employment status or start a family. Life changes, such as these, can present different challenges to physical activity. In order to best sustain physical activity in the long term it is imperative that individuals living with ABI be empowered with adequate knowledge and self-management skills to adapt to changing barriers. Self-management skills, such as problem-solving, decision making and resource utilisation, are paramount to building self-efficacy and enabling individuals to make informed choices in managing their health over their lifespan [12].

The World Health Organization (WHO) has estimated that by 2020, chronic disease will account for 75% of all deaths globally [13]. The WHO has argued for nations to do more to prevent chronic disease [7], particularly through the introduction of strategies to increase physical activity [1]. In response, the Australian Government developed the National Chronic Disease Strategy (NCDS) of which a key focus is self-management. The NCDS emphasises the importance of tailoring self-management approaches to the unique needs of different disease populations in order to improve uptake of physical activity. Information needs to be delivered in an appropriate format for people to comprehend and people must be offered approaches that are personally relevant, yet evidence-based [13]. There is considerable evidence that self-management programmes result in better long-term outcomes for people with chronic diseases [14-16]. This includes programmes for individuals with ABI, specifically stroke [17,18]. Despite this, many people with ABI do not receive self-management training. In the National Stroke Audit undertaken in Australia in 2012, only 25% of stroke survivors were informed about self-management programmes, a decline from 40% in 2008 [19].

The mode of self-management programme delivery can alter the scope of access. Compared with face-to-face delivery, remote delivery modes, such as the Internet, may increase accessibility for those who face multiple barriers to accessing optimal healthcare [20], such as cost, mobility restrictions or service availability in rural or remote regions. Delivery of self-management programmes via the Internet has been used with success in a variety of populations, such as chronic pain [21], anxiety and depression [22], post-traumatic stress disorder [23], arthritis [24] and cerebral palsy [25]. The potential for remote-based delivery methods to be utilised to increase physical activity has also been reported by Foster and colleagues in a recent Cochrane review [26]. However, to date, there has been no systematic review of the literature examining the efficacy of self-management programmes on physical activity for individuals with ABI.

The aim of this systematic review is to address this knowledge gap. We will conduct a systematic review to investigate the efficacy of self-management programmes on physical activity specifically in individuals with ABI. We aim to answer the following questions:

1. How effective are self-management programmes in improving physical activity in community-dwelling adults with ABI?
2. How effective and acceptable is remote delivery of self-management programmes aimed at improving physical activity in community-dwelling adults with ABI?
3. Which features of self-management programmes aimed at improving physical activity in community-dwelling adults with ABI are associated with the best clinical outcomes and client satisfaction?

Methods/Design

Study registration

The protocol of this systematic review has been registered on PROSPERO 2013 (registration number: CRD4201300 6748) [27]. The systematic review protocol has been conducted and reported using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement guidelines [28].

Search strategy for identification of relevant studies

We will conduct a comprehensive search for articles indexed on MEDLINE, EMBASE, CINAHL, PsycINFO, AMED, Cochrane Central Register of Controlled Trials (CENTRAL), PEDro and Science Citation Index Expanded (SCI-EXPANDED) databases from their inception to December 2013. A search strategy has been designed with the assistance of an experienced research librarian. We have developed a search strategy in MEDLINE (Appendix 1) which has been customised to account for differences in indexing across other databases. We will screen the reference lists of relevant reviews on this topic to identify further studies for potential inclusion in this review. Non-English language studies will be included, where a translation can be made available.

Eligibility criteria

Types of study

We will include only those studies that are randomised controlled trials, or quasi-randomised controlled trials. A quasi-randomised controlled trial is defined as a trial in which the participant's allocation is not truly random, such an allocation by date of birth.

Participants

We will include studies of adults (aged 18 years or older) living in the community who have a non-degenerative ABI. ABI refers to any damage to the brain that occurred after birth, such as from trauma or a stroke. We will exclude any studies that examine ABI that is degenerative in nature, such as studies of Parkinson's disease, or studies of people undergoing significant medical or surgical intervention, such as chemotherapy. However, participants who have sustained an ABI as a result of an adverse outcome from a surgery will be included. We will also exclude papers where this status is unclear, such as various types of brain cancer. We will also exclude any studies of people residing in nursing homes or other non-independent care facilities, or who are inpatients in a hospital or other healthcare facility. There will be no restriction of duration since injury.

In studies where it is unclear that participants meet our inclusion criteria we will contact the study author for verification. We will exclude any studies where verification cannot be made by the author in regards to our inclusion criteria. Studies in which there is a mixed sample (with respect to residential status, age or health condition) will only be included if at least 75% of the participants meet our inclusion criteria.

Intervention

We will include studies that have assessed the efficacy of a self-management intervention which aims to enhance levels of physical activity or other outcomes specifically associated with physical activity. Physical activity refers to any bodily movement produced by skeletal muscles that requires energy expenditure [29]. Other outcomes associated with physical activity include physical activity related self-efficacy, physical self-concept, social support or decisional balance for physical activity, and stages of change in regards to physical activity.

Interventions can be provided by health professionals, lay people or a combination of both. Interventions can be delivered in a group setting or on an individual basis. The self-management intervention may be generic or specific to a health condition; however it must include at least one of the following components: problem-solving, goal-setting, decision-making, self-monitoring, coping strategies or another approach to facilitate behaviour change. Studies including advice and education only will be excluded.

The self-management programme can be administered in a variety of settings, such as a private home, a hospital or a community centre. However, participants must be community-dwelling.

For review question 1, the intervention may be delivered via a variety of delivery formats, such as face-to-face, text messages, telephone, Internet or postal delivery. For review question 2, the intervention will include only those studies that have self-management programmes delivered remotely, such as via the Internet, text messages, telephone or by postal delivery. Any studies that have directly compared two types of self-management approaches will be included for content analysis.

Comparator or control

For review question 1, we will include studies that compare a self-management intervention with any of the following: usual care, waiting list control, no treatment, written information only, education and advice only, or an alternative treatment that is not considered to be self-management. For review question 2, comparative studies will be those papers that met all the inclusion criteria for review question 1, and delivered the self-management programme via face-to-face delivery. As stated above, any studies that have directly compared two types of self-management approaches will be included for content analysis.

Outcome measures

Primary outcomes

We will include studies that have examined at least one of the following primary outcome measures:

- A measure of physical activity, either from a physical activity monitoring device (for example, accelerometer, pedometer), or from a self-report measure of physical activity; and/or;
- A primary study outcome associated specifically with physical activity; such as physical activity self-efficacy or physical self-concept.

We will extract data for primary outcomes assessed at baseline and all follow-up time points.

Secondary outcomes

For studies that meet inclusion criteria the following secondary outcomes will also be examined:

- Self-efficacy (general) - usually measured by a self-efficacy scale, such as the General Self-Efficacy Scale [30] or the Stroke Self-Efficacy Scale [31];
- Participation measures - such as the Modified Reintegration to Normal Living Index (mRNL) [32], Life Habits questionnaire (LIFE-H) [33] or the Community Integration Questionnaire (CIQ) [34];
- Activity measures - such as the Step test, 10 m walk test , 6 min walk test, Timed Up and Go test;
- Impairments - such as depression (for example, PHQ-9 [35]), anxiety (for example, GAD-7 [36]), strength, cardiovascular fitness;
- Quality of life measures - such as the WHO Disability Assessment Schedule (WHODAS-II) [37], or the WHO Quality of Life assessment instrument (WHOQoL) [38];
- Participant satisfaction - either quantitative or qualitative;
- Cost-effectiveness.

We will extract data for secondary outcomes assessed at baseline and all follow-up time points.

We will also record any adverse outcomes that are reported in studies included in this review.

Screening of studies

Studies will be selected for this review by two authors who will independently assess the titles and abstracts of all records identified from the searches of the electronic databases by excluding studies that do not meet all inclusion criteria. The full text of the remaining studies will be obtained and independently reviewed by two authors for eligibility according to the criteria using a standardised eligibility criteria sheet. If needed, further information will be obtained from the authors where possible. Disagreements will be resolved by discussion and consensus. If required, arbitration will occur by a third review author blinded to previous eligibility ratings.

Data extraction

Data from the remaining included studies will be extracted independently by two reviewers using a standardized data extraction form. This form will include collection of the following data: source, year of publication, country of origin, study design, sample size (including participants that have been lost to follow-up), characteristics of the study population (age, gender and cause of ABI), characteristics of the intervention (delivery mode and method, duration, description of content), characteristics of control/comparison (delivery mode, duration, description of content), type of outcome measures used - primary and secondary, outcome measures for identified time points as above and statistical analysis.

Risk of bias (quality) assessment

Two reviewers will independently assess the risk of bias for each included study using *The Cochrane Collaboration's tool for assessing bias* [39]. The criteria included in this tool are: random sequence generation, concealed allocation, blinding, completeness of data collection and selective outcome reporting. We will summarise bias as being 'low', 'high' or 'unclear' for each criterion. A summary of risk of bias across all studies within each domain will also be provided.

Strategy for data synthesis
For review questions 1 and 2, Review Manager software, *RevMan* [40], will be used to conduct a meta-analysis where possible to calculate an overall effect size for physical activity. Where data are too heterogeneous to perform a meta-analysis, the results from individual studies will be summarised in a table and a narrative synthesis will be conducted. If, during this synthesis, homogeneity is established within a subgroup, a meta-analysis of data for this subgroup will be performed. A risk of bias assessment of included studies will be summarised in a table and results and implications will be critically discussed.

In order to examine the features associated with greater efficacy and participant satisfaction, a content analysis will be conducted to compare aspects of the intervention that are associated with more favourable study outcomes.

Analysis of subgroups or subsets
In order to address review question 2, a subgroup analysis of different mechanisms of intervention delivery will be conducted, where appropriate, to enable a comparison of remote delivery methods with traditional face to face methods of delivery.

If appropriate a subgroup analysis may be conducted to compare efficacy of self-management programmes to enhance physical activity in young adults (aged 18–50 years) *versus* older adults (aged over 50 years), and in stroke *versus* traumatic brain injury.

Discussion
This review will examine the efficacy of self-management programmes for increasing physical activity specifically in adults living in the community with ABI. We will also examine the efficacy of remote delivery in comparison to traditional face-to-face methods. With physical inactivity being a significant cause of global morbidity and mortality it is important that effective, sustainable strategies for increasing physical activity in high-risk populations, such as those with ABI, are implemented in a manner that enhances accessibility and uptake.

Appendix 1
Medline search strategy
1. exp Self Care/
2. exp health education/or exp patient education as topic/
3. exp consumer participation/or exp patient participation/
4. exp health communication/or exp health promotion/
5. exp Self Concept/or exp Self Efficacy/
6. (self adj care*).mp.
7. (self adj manage*).mp.
8. (patient adj educat*).mp.
9. (self adj monitor*).mp.
10. (self adj efficacy).mp.
11. (self adj concept).mp.
12. ((consumer or patient) adj participat*).mp.
13. ((consumer or patient) adj inform*).mp.
14. (health adj educat*).mp.
15. (health adj promot*).mp.
16. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15
17. exp Motor Activity/
18. exp "activities of daily living"/or exp leisure activities/ or exp recreation/
19. exp gait/or exp locomotion/or exp walking/
20. exp sports/or exp physical fitness/
21. exp Exercise/or exp Exercise Therapy/
22. exp Health Behavior/
23. (physical adj activity).mp.
24. (leisure or recreation*).mp.
25. (sport* or fit* or exercis*).mp.
26. (walk* or ambulat* or mobil* or locomotion or gait).mp.
27. 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26
28. 16 and 27
29. exp brain damage, chronic/or exp brain injuries/ or exp cerebrovascular disorders/
30. (brain adj (injur* or damage)).mp.
31. stroke*.mp.
32. (cerebrovascular adj accident*).mp.
33. exp Stroke/
34. 29 or 30 or 31 or 32 or 33
35. 28 and 34
36. Randomized controlled trial.pt.
37. random*.mp.
38. trial*.mp.
39. control*.mp.
40. controlled clinical trial.pt.
41. placebo*.mp.
42. (intervention adj group*).mp.
43. (treatment adj group*).mp.
44. 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43
45. 35 and 44
46. limit 45 to humans
47. remove duplicates from 46

Competing interests
The authors declare that they have no competing interests.

Authors' contributions
TMJ: conception and design, data collection, analysis and interpretation, manuscript writing and final approval of manuscript. JMH: conception and design, data analysis and interpretation, manuscript writing and critical revision, and final approval of manuscript. BFD: conception and design, data analysis and interpretation, critical revision of the manuscript, and final approval of manuscript. NT: conception and design, interpretation of data, critical revision of the manuscript, and final approval of manuscript. CMD: conception and design, data collection, analysis and interpretation, manuscript writing and critical revision, and final approval of manuscript. All authors read and approved the final manuscript.

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2.4 A systematic review of the literature

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SYSTEMATIC REVIEWS

RESEARCH Open Access

A systematic review of the efficacy of self-management programs for increasing physical activity in community-dwelling adults with acquired brain injury (ABI)

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Abstract

Background: Individuals living with acquired brain injury, typically caused by stroke or trauma, are far less likely to achieve recommended levels of physical activity for optimal health and well-being. With a growing number of people living with chronic disease and disability globally, self-management programs are seen as integral to the management of these conditions and the prevention of secondary health conditions. However, to date, there has been no systematic review of the literature examining the efficacy of self-management programs specifically on physical activity in individuals with acquired brain injury, whether delivered face-to-face or remotely. Therefore, the purpose of this review is to evaluate the efficacy of self-management programs in increasing physical activity levels in adults living in the community following acquired brain injury. The efficacy of remote versus face-to-face delivery was also examined.

Methods: A systematic review of the literature was conducted. Electronic databases were searched. Two independent reviewers screened all studies for eligibility, assessed risk of bias, and extracted relevant data.

Results: Five studies met the inclusion criteria for this review. Studies were widely heterogeneous with respect to program content and delivery characteristics and outcomes, although all programs utilized behavioral change principles. Four of the five studies examined interventions in which physical activity was a component of a multifaceted intervention, where the depth to which physical activity specific content was covered, and the extent to which skills were taught and practiced, could not be clearly established. Three studies showed favorable physical activity outcomes following self-management interventions for stroke; however, risk of bias was high, and overall efficacy remains unclear. Although not used in isolation from face-to-face delivery, remote delivery via telephone was the predominant form of delivery in two studies with support for its inclusion in self-management programs for individuals following stroke.

Conclusions: The efficacy of self-management programs in increasing physical activity levels in community-dwelling adults following acquired brain injury (ABI) is still unknown. Research into the efficacy of self-management programs specifically aimed at improving physical activity in adults living in the community following acquired brain injury is needed. The efficacy of remote delivery methods also warrants further investigation.

Systematic review registration: PROSPERO CRD42013006748

Keywords: Management, Exercise, Trauma, Cerebrovascular accident, Remote delivery, Internet

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Background

Acquired brain injury (ABI) refers to any damage to the brain that occurs after birth with common causes including stroke or trauma [1]. ABI is a significant public health issue globally. Stroke is one of the greatest causes of disease burden globally [2] and is one of the main non-communicable diseases of public health importance [3], while traumatic brain injuries are the leading cause of disability in children and young adults globally [3].

Individuals with ABI often have more complex disabilities than other groups with disability [1] and often face many barriers in increasing their levels of physical activity, such as mobility impairments, fear, pain, financial costs, transport difficulties, and limited local specialist services [4-9]. Physical activity interventions are effective in improving physical, psychosocial, and cognitive status; however, maintaining these improvements once intervention ceases is challenging, and physical activity participation levels after ABI remain low [5,10-16].

Physical inactivity both causes and accelerates chronic diseases, such as cardiovascular disease, diabetes, and cancer [17], with individuals with ABI at elevated risk [1]. In fact, the World Health Organization (WHO) report that almost a third of all strokes occur in those who have previously had a stroke [3]. Despite this, ABI is often a lower priority for research and services than conditions with a similar, or lower, public health priority [2] and there is a significant lack of physical activity promotion programs targeting those with ABI [18,19].

The WHO has argued for nations to do more to prevent chronic disease [20], particularly through the use of strategies to increase physical activity [21]. Self-management is seen as integral to optimal chronic disease prevention and management [22]. Given that physical inactivity is a significant modifiable risk factor for chronic diseases, such as stroke [17,23], increasing the self-management of physical activity specifically in individuals with ABI appears crucial for the long-term prevention of further morbidity and mortality.

Self-management ultimately reflects an individual's responsibility for the day-to-day management of their disease including decisions regarding engagement in healthy behaviors [24]. The most promising way of supporting self-management is to empower and activate people, primarily through the expansion of skills, such as problem-solving and decision-making, therefore building self-efficacy to alter long-term behaviors [24,25]. There is considerable evidence that self-management programs result in better long-term outcomes for people with chronic diseases [26-29], including programs for individuals with ABI, specifically stroke [30,31]. Despite this, many people with ABI do not receive and cannot access self-management programs. For example, in the National Stroke Audit undertaken in Australia in 2012, only 25% of stroke survivors were informed about self-management programs, a decline from 40% in 2008 [32].

Implementation of self-management programs may be enhanced through the use of innovative modes of remote program delivery. Compared with face-to-face delivery, remote delivery modes, such as telephone and the Internet, may increase accessibility for those who face multiple barriers to accessing optimal health care [33], such as cost, mobility restrictions, or service availability in rural or remote regions. Delivery of self-management programs via the Internet has been used with success in a variety of populations, such as chronic pain [34], anxiety and depression [35-37], post-traumatic stress disorder [38], arthritis [39], and cerebral palsy [40]. The potential for remote-based delivery methods to be utilized to increase physical activity has also been highlighted by Foster and colleagues in a recent Cochrane review [41]. However, to date, there has been no systematic review of the literature examining the efficacy of self-management programs specifically on physical activity in individuals with ABI, whether delivered face-to-face or remotely. Therefore, the objectives of this systematic review were to address the following questions:

1. How effective are self-management programs in improving physical activity in community-dwelling adults with ABI?
2. How effective and acceptable is remote delivery of self-management programs aimed at improving physical activity in community-dwelling adults with ABI?
3. Which features of self-management programs for community-dwelling adults with ABI are associated with the best clinical outcomes and client satisfaction?

Methods

Study registration

The systematic review has been conducted and reported using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement guidelines [42]. The Cochrane Collaboration guidelines for reviewing interventions were also closely followed [43]. The protocol of this systematic review has been registered on PROSPERO 2013 (registration number: CRD42013006748) [44] and has been published [45].

Search strategy

We conducted an extensive search of the literature for articles indexed on MEDLINE, EMBASE, CINAHL, PsycINFO, AMED, Cochrane Central Register of Controlled Trials (CENTRAL), PEDro and Science Citation Index Expanded (SCI-EXPANDED) databases from their inception to December 2014. We developed a search strategy in MEDLINE using the following steps: (1) development of keywords by examining relevant key terms used in existing systematic reviews, (2) a thorough examination of the MeSH Database, and (3) expert guidance and review by a specialist librarian. Finally, the search strategy was trialed and refined in order to ensure it was the most effective strategy for this review (Additional file 1). This strategy was then customized for differences in indexing across other databases [45] published to allow for replication [45]. We also screened the reference lists of relevant reviews to identify further studies for potential inclusion in this review. Non-English language studies were also considered for inclusion, where a translation could be made available.

Eligibility criteria

Our eligibility criteria were defined *a priori* and are outlined in Table 1. ABI was defined as damage to brain occurring after birth. However, for the purpose of this review, studies examining individuals with degenerative ABI (for example Parkinson's disease or multiple sclerosis), cerebral palsy, developmental delay, fetal alcohol spectrum disorder (FASD), concussion, or transient ischaemic attacks (TIA) were not included. There was no limit based on time since injury. In studies where it was unclear that participants met our inclusion criteria, we contacted the study author for verification. We excluded any studies where verification could not be made by the authors.

Table 1 Inclusion criteria

	Inclusion
Study design	Randomized controlled trial (RCT)
	Quasi-randomized controlled trial (QRCT) - for example, allocation by date of birth, location, medical record number
Participants	Adults (18 years and over)
	Non-degenerative acquired brain injury (ABI)
	Currently living in the community
	Are not undergoing significant medical or surgical intervention
Intervention	Self-management program which:
	Includes at least one of the following components: problem-solving, goal-setting, decision-making, self-monitoring, coping strategies, or another approach to facilitate behavior change;
	Has at least a component of the program focusing on increasing physical activity.
Outcomes	Must include at least one of the following:
	A measure of physical activity: either from a physical activity monitoring device (for example, accelerometer, pedometer) or a self-report measure;
	And/or
	A study outcome associated specifically with physical activity, for example, physical activity self-efficacy, physical self-concept, or stages of change in relation to physical activity.

Identification of relevant studies

Two authors (TMJ, CMD) independently assessed the titles and abstracts of all records identified from the searches of the electronic databases. Records identified as not meeting the eligibility criteria were excluded. The full text of the remaining studies was obtained and reviewed for eligibility independently by the same two authors. In one case, an independent translation from Korean to English was required in order to assess eligibility. At each stage of the process, records were marked 'accept', 'reject', or 'unsure'. Those records marked 'unsure', or where disagreements between reviewers arose, discussion between the reviewers was undertaken in order to reach consensus.

Data extraction

Data from included studies were extracted independently by two reviewers (TMJ, CMD) using a standardized data extraction form. Data were extracted for all available time points on the outcome measures that were defined *a priori* as per our protocol [45]. We also recorded any adverse outcomes that were reported in the studies included in this review.

Risk of bias assessment

Two reviewers (TMJ, CMD) independently assessed the risk of bias for each included study using *The Cochrane Collaboration's tool for assessing bias* [46]. A summary of risk of bias across all studies within each domain was also performed.

Data synthesis

A meta-analysis was not possible due to significant heterogeneity of the outcome measures utilized in each of the studies. Instead, a detailed summary of the results from the individual studies was collated into a table, and a systematic narrative synthesis was conducted. A comparison of remote-delivery methods with traditional face-to-face delivery methods was also not possible because all studies included in the review included a face-to-face delivery mode for at least some portion of their program.

Results

Results of the search

Our search of electronic databases generated 3,654 references. An additional 20 references were obtained from handsearching the reference lists of nine systematic reviews identified from the electronic searches [31,47-54]. Following duplicate removal and screening of titles and abstracts, 124 full-text articles were assessed for eligibility. Assessment resulted in 119 references being excluded with reasons outlined in Figure 1. Five studies met the eligibility criteria and were included in this review [55-59].

Details of included studies

Details of the included studies are reported in Table 2. Four of these studies were published in English. The fifth study was published in Korean [58], and an independent translation was obtained. Two studies were performed in the USA [55,56], one in Australia [57], one in Korea [58], and one in Hong Kong [59]. The interventions examined in each study varied in regard to both content and delivery characteristics. The studies also vary greatly in regard to outcome measures used.

Demographic characteristics

Demographic details of study participants are outlined in Table 2. Four of the studies examined participants following stroke [56-59], while one studied participants with traumatic brain injury (TBI) [55]. Most studies included in this review had relatively small sample sizes, although one study had 190 participants [59]. The mean age of all stroke participants ($n = 336$) was 64.42 (SD = 10.81) years, while the TBI participants ($n = 74$) had a mean age of 43.83 (SD = 15.34) years. A measure of severity of ABI was reported in two of the five studies [55,56]. Four out of the five studies [55,56,58,59] reported eligibility criteria that required cognitive and communication skills to be adequate for participation in a self-management program; however, assessment of this criterion differed in each study.

Intervention content

The content of the intervention programs applied in each of the studies is also summarized in Table 2. The extent to which physical activity was specifically addressed and targeted differed between each program. In

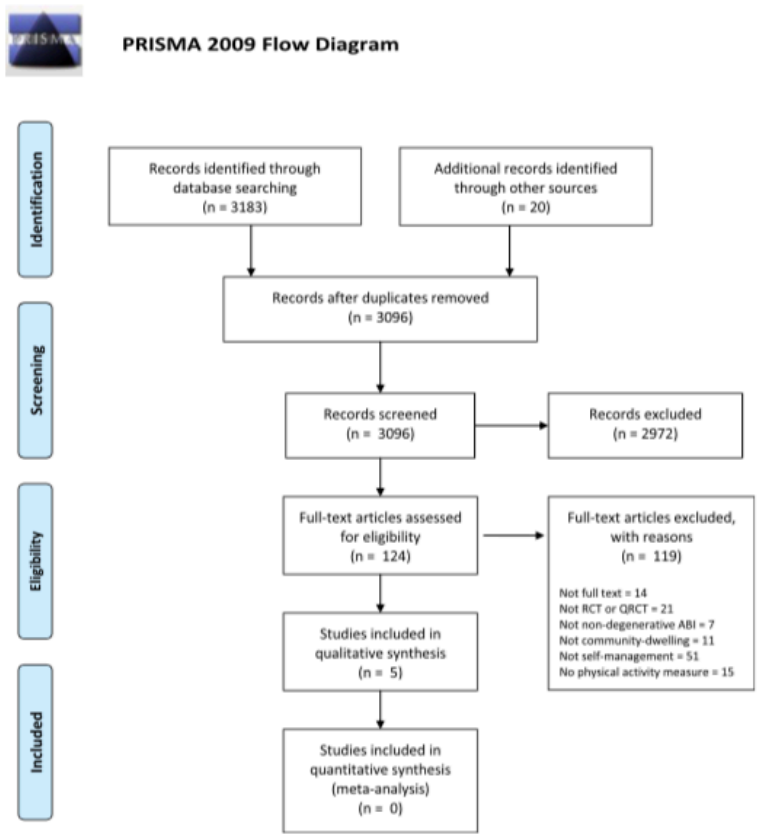

Figure 1 Study flow diagram.

Table 2 Summary of included studies

Study (year, country, study design)	Type of ABI	Participants	Intervention: Content	Intervention: Delivery characteristics	Intervention: Theoretical model	Control	Follow-up assessments/ Drop outs/ Sample size analyzed
Brenner *et al.* (2012, USA, RCT)	TBI	Sample size: $n = 74$ IG = 37; CG = 37 Gender: Male: IG = 29 (78.4%) CG = 32 (86.5%) Female: IG = 8 (21.6%) CG = 5 (13.5%) Mean age (years): IG = 43.46 (SD 16.00); CG = 44.14 (SD 14.97) Mean (SD) time since ABI (years): IG = 11.74 (13.80); CG = 12.50 (13.75)	'Health and Wellness therapy group': program provided information to facilitate health promotion while emphasizing self-assessment to help participants to set individualized goals, problem-solve to reduce barriers, and strategies to enhance self-efficacy. Program aimed to take advantage of the group process, as well as encouraging participants to involve an identified resource person to assist in self-assessment and behavior change. Physical activity specific content: Two sessions (sessions 5 and 6) focus on fitness self-assessment, getting started with physical exercise, measuring resting heart rate, benefits of exercise.	Duration: 12 × 1.5 h sessions; 1 session/week for 12 weeks Delivery mode: face-to-face group sessions with workbook Facilitators: social worker, speech pathologist, physical therapist, and nurse who rotated in groups of 2	TTM SCT	Wait-list control	Follow-up: 3 months and 6 months Drop outs: $n = 9$ IG: $n = 7$; CG: $n = 2$ Sample analyzed: $n = 65$ IG: $n = 30$; CG: $n = 35$
Damush *et al.* (2011, USA RCT)	Stroke	Sample size: $n = 66$ Gender: Male: IG = 30 (100%) CG = 32 (97.0%) Female: IG = 0 (0%) CG = 1 (3.0%) Mean age (years): IG = 67.3 (SD 12.4); CG = 64.0 (SD 8.4) Time since ABI: participants identified during hospital admission for ischemic stroke.	'Stroke self-management program': The sessions followed a standardized manual based on the CDSMP with a focus on enhancing self-efficacy to manage symptoms and foster behavior change. Techniques employed included goal setting and behavioral contracting. Telephone follow-up focused on reinforcing, monitoring, and adjusting the goals and self-management strategies. Physical activity specific content: 2 topics out of 24 focused on physical activity specifically - 'Getting Active at Home' and 'Walking for Health'. An additional topic on rehabilitation included discussion on following prescribed exercises at home.	Duration: 6 sessions over a 3-month period (3 face-to-face and 3 via telephone) as well as biweekly telephone follow-up. Average session length was 20 min. Delivery mode: face-to-face and telephone with standardized manual Facilitators: a nurse, a physician assistant, and a master's level social scientist	SCT (specifically self-efficacy)	Written patient educational materials on stroke warning signs and pamphlets from the American Stroke Association on prevention of secondary strokes. Telephone calls were also made by the case manager on the same schedule as IG to discuss how participant felt that day.	Follow-up: 3 months and 6 months Drop outs: $n = 3$ No info regarding groups Sample analyzed: $n = 63$ IG: $n = 30$; CG: $n = 33$

Table 2 Summary of included studies *(Continued)*

Gill and Sullivan (2011, AustraliaQRCT)	Stroke	Sample size: $n = 26$ IG: $n = 14$; CG: $n = 8$ Gender: Male: IG = 5 (35.7%) CG = 6 (75%) Female: IG = 9 (64.3%) CG = 2 (25%) Mean age (years): IG = 60.21 (SD 7.74); CG = 67.75 (SD 19.30) Time since ABI: <12 months: IG: $n = 2$; CG: $n = 1$; 1 to 5 years: IG: $n = 7$; CG: $n = 4$; >5 years: IG: $n = 5$; CG: $n = 3$	'Stay Active and Stop Stroke (SASS)': Intervention targets exercise beliefs with didactic instruction and group-based activities. Session 1 aimed to increase stroke knowledge and highlight risk factors. Session 2 aimed to facilitate a change in beliefs. Session 3 intended to strengthen motivation by illustrating decisional balance processes. Participants identified personal barriers to increasing physical activity, generated possible solutions, and prepared personal activity goals. Physical activity specific content: Whole program focused on exercise.	Duration: 3 × 1 h sessions, 1/week for 3 weeks. Delivery mode: face-to-face group sessions with manual Facilitators: psychology students	eHBM TTM	No intervention	Follow-up: 3 weeks Drop outs: $n = 0$ IG: $n = 0$; CG: $n = 0$ Sample analyzed: $n = 26$ IG: $n = 14$; CG: $n = 8$
Kim and Kim (2013, Korea QRCT)	Stroke	Sample size: $n = 61$ IG: $n = 32$; CG: $n = 29$ Gender: Male: IG = 19 (59.4%) CG = 19 (65.5%) Female: IG = 13(40.6%) CG = 10 (34.5%) Mean age (years): IG: 67.41 (8.46) CG: 66.71 (9.40) Median (range) time since ABI (months): IG: 24 (2 to 124)CG: 36 (2 to 188)	'Lifestyle modification coaching program': Aimed to modify lifestyle to prevent secondary stroke, particularly through reduction in physiological parameters, such as blood pressure, blood lipids, and body fat. Program focused on education regarding stroke risk factors and acknowledgement of necessity for lifestyle modification, as well the setting up and attainment of individual goals. Physical activity specific content: Participants were classified according to their baseline level of activity and encouraged to acknowledge their current level of activity. Subjects educated about optimum levels of exercise to prevent stroke recurrence, and assisted to set goals and keep records on exercise performed. The researcher checked if reasonable exercise was being done, offered encouragement, and gave support to identify and overcome barriers.	Duration: 8 weeks Delivery mode: Initial session was face-to-face, then telephone (1× week for 8 weeks) Facilitators: not specified	None specified	Control received the 1× face-face session but no ongoing telephone coaching.	Follow-up: 8 weeks Drop outs: n = 12 IG: n = 5; CG: n = 7 Sample analyzed: $n = 61$ IG: $n = 32$; CG: $n = 29$

Table 2 Summary of included studies *(Continued)*

Sit *et al*. (2007, Hong Kong, QRCT)	Stroke	Sample size: $n = 190$ IG: $n = 107$; CG: $n = 83$ Gender: Male: IG = 55 (51.4%) CG = 50 (60.2%) Female: IG = 52 (48.6%) CG = 33 (39.80%) Mean age (years): IG = 62.83 (SD 10.25); CG = 64.02 (SD 12.03) Time since ABI: not specified	'Community-based stroke prevention program': Focus was on improving knowledge about stroke, improving self-monitoring of health and maintenance of behavioral changes when adopting a healthy lifestyle. Participants selected the risk behavior on which they wanted to focus, addressing them one at a time, setting short-term practical goals, practicing learnt skills, and implementing action plans. Physical activity specific content: Participants were given log sheets and pedometers to track goal achievement. Physical activity was focused on in session 7: 'Establishing regular exercise habit'.	Duration: 8 × 2 h sessions held 1/week for 8 weeks. Delivery mode: face-to-face group sessions with 10 to 12 participants. Facilitators: experienced community nurses.	None specified	Conventional medical treatment and health promotion pamphlets on stroke and stroke prevention.	Follow-up: 1 week following intervention and 3 months Drop outs: $n = 44$ IG: $n = 28$; CG: $n = 16$ Sample analyzed: $n = 190$ IG: $n = 107$; CG: $n = 83$

IG = Intervention group; CG = Control group; TTM = Transtheoretical Model; SCT = Social Cognitive Theory; CDSMP = Chronic Disease Self-Management Program; eHBM = expanded Health Beliefs Model.

four of the five studies, physical activity, or exercise, was included as a subtopic within a larger program covering numerous aspects of self-management skills following acquired brain injury, such as diet modification, stress management, and medication compliance [55,56,58,59]. The intervention evaluated by Gill and Sullivan [57] was the only one that focused solely on exercise, with an intervention designed to boost exercise beliefs and motivation.

Three of the five studies applied theoretical models of health behavior change in developing their intervention content [55-57]. Theories utilized included Bandura's social cognitive theory (SCT) [60,61], Prochaska's transtheoretical model (TTM) [62], and the expanded health beliefs model (eHBM) [63]. The remaining two studies [58,59] utilized similar behavior change principles in an educational framework, with a focus on building knowledge regarding current stroke management and stroke risk factors, individual goal setting, and self-monitoring.

Delivery characteristics

The delivery characteristics of the intervention programs are outlined in Table 2. Most of the interventions were delivered during an 8- to 12-week time frame. All the interventions included at least some element of face-to-face delivery; however, two studies delivered the majority of their intervention remotely via telephone [56,58]. The three studies that utilized only face-to-face delivery all did this via group sessions [55,57,59]. Standardized manuals or workbooks to assist in the delivery of the intervention were utilized in three studies [55-57]. All interventions were facilitated by health professionals, including a multidisciplinary team facilitating sessions in two of the five studies [55,56]. Nurses were most commonly engaged in the role of facilitator [55,56,59].

Outcome measures

Each of the included studies reported on a different set of outcome measures to examine physical activity, as summarized in Table 3. Three studies measured physical activity specifically [56,58,59]. Damush and colleagues recorded self-reported time spent in aerobic activity each week [56]. Kim and Kim recorded weekly metabolic equivalent of task (MET) minutes by using self-reported information from a translated version of the International Physical Activity Questionnaire (IPAQ) [58]. Sit and colleagues utilized an exercise subscale modified from Lorig [64] and reported physical activity data as the proportion of the group that participated in walking exercise [59]. The remaining two studies utilized different validated questionnaires regarding physical activity, including the Health Promoting Lifestyle Profile - II (HPLP-II) Physical Activity subscale [55], the Self-Rated Abilities for Health Practices (SRAHP) Exercise subscale [55], and the Cerebrovascular Attitudes and Beliefs Scale - Revised (CABS-R) Exercise subscale [57].

In addition to these specific physical activity measures, a wide variety of secondary outcome measures were used by the authors to examine other factors associated with self-management of acquired brain injury, such as self-efficacy for communicating with physicians [56] or smoking and alcohol behavior [58]. We extracted data only from those measures that were aligned with the secondary outcome measures outlined in our protocol [45]. These results are summarized in Table 3. No studies employed outcome measures to examine participant satisfaction or program cost-effectiveness. Adverse events were also not reported in any of the studies included in this review.

Risk of bias of included studies

Risk of bias for each study is summarized in Figure 2, with a summary of each risk of bias item detailed in Figure 3. Overall, risk of bias was generally high across all parameters. Four of the five studies are at high risk of selection bias with only one study providing clear information regarding adequate random sequence generation and allocation concealment [55]. Blinding of facilitators is impossible in these types of studies and blinding of participants is also challenging, but none of the included studies demonstrated clarity regarding blinding of participants [56-59]. This is particularly pertinent in these studies where data was collected through self-report measures. As a result, all studies were considered to be at high risk of performance bias. Three studies were considered to be at high risk of reporting bias with data not fully presented and/or difficult to analyze [55,56,59]. Other potential sources of bias arose due to differences in groups at baseline regarding physical activity measures, issues regarding the delivery and monitoring of control interventions, and the use of *post hoc* statistical analysis techniques [55,56,58].

Effects of interventions

Efficacy in improving physical activity

A summary of results is displayed in Table 3. As stated previously, a meta-analysis was not possible due to the significant variability in outcome measures utilized in each study. Therefore, a pooled estimate of efficacy cannot be established at this stage. However, in one study of stroke survivors, there is evidence that an 8-week lifestyle modification coaching program that included physical activity specific content relative to baseline levels of physical activity was effective in increasing the amount of physical activity as measured in weekly MET minutes with a median increase of 610.5 weekly MET minutes (range: −2,628 to 3,696) in the intervention group and

Table 3 Summary of results

Study	Measure used	Results
Brenner et al. [55]	Physical activity	Raw data: No raw data reported.
	measure: HPLP-II Physical Activity Subscale SRAHP Physical Activity & Exercise domain	Group comparisons: Data reported as time-by-treatment interaction (P) - no significant differences between the IG and CG in regard to HPLP-II (Physical Activity) ($P = 0.2375$) or SRAHP (Exercise) ($P = 0.3661$).
	Other measures: Participation Assessment with Recombined Tools-Objective (PART-O)	Both these values reached significance ($P = 0.0216$ and $P = 0.0001$ respectively); however, the authors state differences are due to time, not treatment.
	Diener Satisfaction with Life Scale	
Damush et al. [8]	Physical activity measure: Self-reported time spent in aerobic activity (min/week)	Raw data [1] :
		IG: Baseline = 78.5 min/week; 3 months = mean increase of 47.6 min/week. CG: Baseline = 107.4 min/week; 3 months = mean decrease of 3 min/week.
	Other measures: Stroke-Specific Health-Related Quality of Life (SSQOL)	Between-group comparison: 3 months: $t_{(51)} = 1.18$, $P \leq 0.13$, effect size = −0.43;6 months: $P \leq 0.50$, effect size = −0.19
		Not all data supplied. At baseline, the IG had significantly lower (worse) scores for several SSQOL scales including mobility, thinking, energy, and work, as well as the total overall score. For both the subscales of Family Roles and Social Roles, the IG improved at 3 months, while the CG declined with differences between the groups reaching significance ($P \leq 0.01$ and $P \leq 0.06$, respectively).
Gill and Sullivan [57]	Physical activity measure:	Raw data: Mean (SD) self-ratings.
	Cerebrovascular Attitudes and Beliefs Scale-Revised (CABS-R) Exercise subscale	Barriers: IG: T1 = 2.19(0.76), T2 = 2.35(0.67); CG: T1 = 2.22(0.49), T2 = 2.27(0.74)
		Benefits: IG: T1 = 3.90(0.73), T2 = 3.94(0.46); CG: T1 = 3.59(0.67), T2 = 3.53(0.60)
		Susceptibility: IG: T1 = 3.62(0.86), T2 = 3.69(0.60); CG: T1 = 2.42(0.94), T2 = 2.92(0.61).
		Seriousness: IG: T1 = 4.18(1.05), T2 = 4.26(0.76); CG: T1 = 3.71(1.38), T2 = 3.50(1.41)
	SOEQ (stages of change, 1 item)	Self-efficacy: IG: T1 = 3.31(0.90), T2 = 3.77(0.53); CG: T1 = 3.13(1.09), T2 = 3.25(1.00)
		Subjective norms: IG: T1 = 4.27(0.53), T2 = 4.08(0.53); CG: T1 = 4.06(0.18), T2 = 4.06(0.18)
		Within-group comparison: IG showed a significant increase in self-efficacy from baseline to follow up ($F(1, 11) = 7.33$; $P = 0.02$).
		Between-group comparison: IG reported significantly higher perceptions of susceptibility than CG at both time points (baseline $P = 0.007$ and 3 weeks $P = 0.010$). No other differences were found.
		The IG had a small movement of 14.3% ($n = 2$) from the preparation stage to the active stage at 3 weeks which was not seen in the CG on SOEQ categorical data. No other changes were found.
Kim and Kim [58]	Physical activity measure: Physical activity: MET minutes/week	Raw data: Median (range)
		IG: Baseline = 462.0 (0.0 to 3,942.0), 8 weeks = 1,365.5 (132.0 to 4,158.0)
	Other measures: General Self-Efficacy Scale	CG: Baseline = 984.0 (0.0 to 6,906.6), 8 weeks = 990.0 (0.0 to 25,638.0)
		Within-group comparison: IG showed significant increase in weekly MET minutes at 8 weeks with a difference in median between baseline and 8 weeks to be 601.5 MET min/week (range −2,628.0 to 3696.0; $T = 149$; $P = 0.001$); CG showed a

Table 3 Summary of results *(Continued)*

		non-significant change with a difference in median to be 133.0 MET min/week (range −4,976.0 to 25,638.0; $T = -30.50$; $P = 0.474$).
		Between-group comparison: Difference in change over 8 weeks was significantly different between groups in favor of IG ($T = 692.50$; $P = 0.002$).
		No significant differences found within groups or between groups in general self-efficacy.
Sit *et al.* [59]	Physical activity measure: Participation in walking exercise	Raw data: Percentages reported; T0 = baseline, T1 = postone week, T2 = 3 months
		IG: T0 = 78.9%, T1 = 78.9%, T2 = 77.1%
		CG: T0 = 72.3%, T1 = 63.9%, T2 = 55.4%
		Within-group comparison: At 3 months: IG Q = 0.051; $P = 0.975$, CG Q = 7.697; $P = 0.021$
		Between-group comparison: At 3 months, there was a significant difference between groups in favor of the IG ($P < 0.001$)

Data from Damush *et al.* (2011) included 6 month data that reported a mean increase in the IG of 24.4 min/week and a mean increase in the CG of 4 min/week, with a between-group comparison of $t_{(52)} = -0.69$, $P \leq 0.50$, effect size = −0.19; however, this data was not reported in this table as it was unclear as to whether these increases were from baseline or from 3 months.

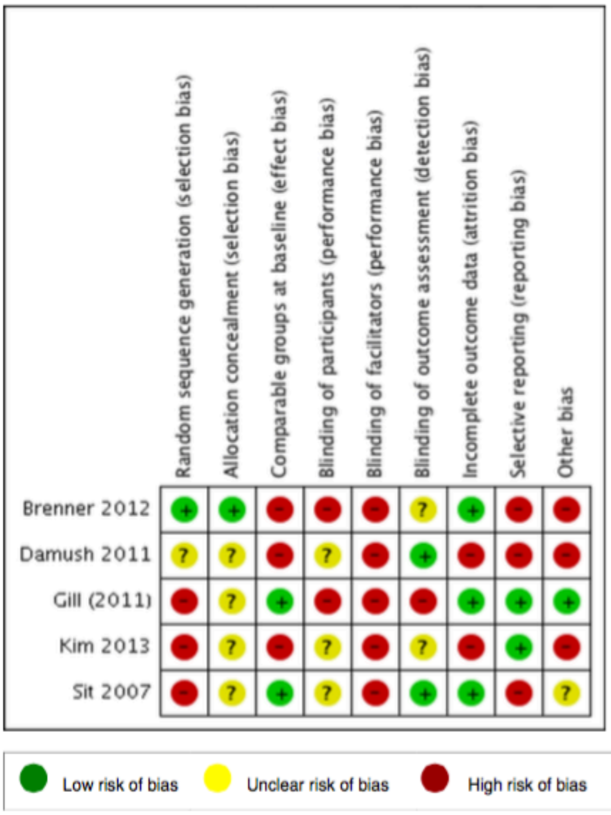

Figure 2 Risk of bias summary - review authors' judgements about each risk of bias item for each included study.

133.0 (range: −4976 to 25,638) in the control group with a significant between-group difference ($T = 692.50$; $P = 0.002$) [58]. An 8-week community-based stroke prevention program with a focus on increasing walking for exercise as one component of a secondary risk prevention program resulted in maintenance of the proportion of individuals that were participating in walking for exercise in the intervention group at 3 months (non-significant decline of 1.8%; $P = 0.975$), while the control group saw a significant decline of 16.9%; $P = 0.021$), resulting

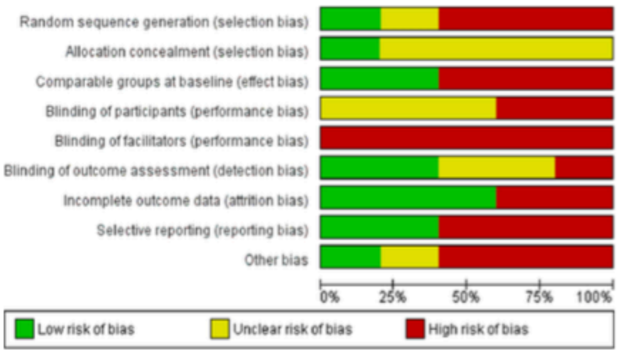

Figure 3 Risk of bias graph - review authors' judgements about each risk of bias item presented as percentages across all included studies.

in a significant between-group difference at 3 months ($P < 0.001$) [59]. The study by Damush and colleagues [56] reported limited data about physical activity outcomes from their *'Stroke Self-management Program'*. We were unable to obtain further data for analysis from the study's authors. From the published results, there does appear to be an average increase of 47.6 min/week in self-reported time spent doing aerobic activity at 3 months in the intervention group and an average decline in the control group of 3 min/week [56]. However, these results should be interpreted with caution given the control group was more active than the intervention group at baseline (107.8 *vs.* 78.9 min/week on average, respectively). Gill and Sullivan's *'Stay Active and Stop Stroke'* program demonstrated limited benefits from this short intervention on the CABS-R Exercise subscale [57]. A significant increase in self-efficacy for exercise was seen in the intervention group at follow-up ($F(1, 11) = 7.33$; $P = 0.02$); however, this did not result in a significant difference between groups. In TBI, Brenner and colleagues reported limited data from the physical activity subscales HPLP-II Physical Activity Subscale and SRAHP Physical Activity and Exercise domain. Further data were unable to be obtained from the authors. The reported program outcomes showed no significant between-group differences [55].

Efficacy and acceptability of remote delivery

No study in this review utilized remote delivery of a self-management program in isolation from face-to-face delivery. Remote delivery via telephone was the predominant form of delivery in two studies [56,58]. Although efficacy of remote delivery in isolation cannot be fully established at this stage, current evidence does support the inclusion of remote delivery modes in self-management programs for individuals following stroke. Acceptability of delivery mode was not formerly assessed in either study. Attrition rates were low in both studies; however, reasons for attrition were not reported.

Program features associated with optimal clinical outcomes and client satisfaction

Due to the heterogeneity of outcome measures, as well as program content and delivery characteristics, a comparison of studies in order to determine features associated with best clinical outcomes is difficult. In addition, there was no analysis of client satisfaction in any of the studies included in this review. The amount of specific physical activity-related program content was not able to be clearly established in four of the five studies included in this review due to physical activity being a subtopic of a larger self-management program [55,56,58,59]. It was also difficult to establish the depth to which content was covered and the extent to which skills were taught and practiced. Education and goal setting were employed in all interventions and did not differentiate studies that obtained more positive results from those that demonstrated less efficacy of intervention. Sit and colleagues [59] were the only authors to implement the concept of individual preferences for both the choice of the risk behavior they wanted to focus on each week, as well as individual preferences for exercise pattern, duration, and pace. This was also the only study to focus on the formation of healthy habits as a part of their behavioral change intervention. Positive intervention results were also seen with the use of planning and scheduling [56,59] and coping strategies [56,58], while mixed success was seen with the implementation of barrier identification skills [55,57,58], problem solving [55-57], and self-monitoring [57-59].

Discussion

This is the first review, to the authors' knowledge, that has attempted to examine the clinical efficacy of self-management programs aimed at improving physical activity levels following ABI. This is an important contemporary issue in health care, and there is a growing body of literature in this area. However, there were a scant number of studies that met our stringent eligibility criteria. Many studies were excluded because they were not randomized or quasi-randomized controlled trials or because they did not utilize a self-management approach or examine physical activity specifically. An alternative approach to a future review in this field would be to include non-randomized studies and applying the GRADE approach to the examination of the quality of the evidence [43]. This may allow for more thorough examination of pragmatic trials conducted in this area.

The studies included in this review had a high risk of potential bias on many parameters. In part, this may be because some were smaller proof of concept studies, as is common in an emerging field. Nonetheless, the high risk of bias does limit interpretation of efficacy for the interventions investigated. With this taken into consideration, the results do show promising trends towards physical activity being enhanced through participation in a self-management program for individuals following stroke. This trend is not currently supported in TBI where the amount of research is even less, as highlighted by Pawlowski and colleagues. Their review of the status of physical activity research for individuals with TBI found only 6% ($n = 4/63$) of studies focused on the evaluation of behavior change intervention, and only 5% ($n = 3/63$) examined dissemination of health promotion programs [18]. More rigorous research is clearly needed in order to establish the efficacy and acceptability of self-management programs in improving physical activity levels for community-dwelling adults with ABI.

It was difficult to synthesize the results of the different self-management programs covered in this review, primarily because of variation in program content and delivery characteristics. Four studies examined self-management programs in which physical activity was only a small component of the overall program, rather than the main focus [55,56,58,59], making it difficult to establish the proportion and duration of the program that was focused on the acquisition of physical activity specific self-management skills in these studies. In the fifth study, although the focus of the program was specifically on physical activity [57], it was significantly shorter than the others at 1 h/week for 3 weeks in duration. In summary, while limited, the available evidence examined in this review indicates benefits in physical activity for stroke survivors of programs consisting of 6 to 8 sessions over 8 to 12 weeks. The evidence indicates that changing behavior related to physical activity is difficult in this population, particularly achieving sustained changes over time [65]. It is possible that too a short program does not allow for the establishment of skills needed for long-term behavior change to occur.

This review has demonstrated that self-management programs for stroke survivors that use a holistic, multifaceted approach offer some benefits in improving physical activity [56,58,59]. However, the concept of a self-management program that focuses on one risk factor, such as physical activity, also warrants further investigation. Sit and colleagues demonstrated positive results with a program that involved participants choosing the risk behavior on which they wanted to focus each week [59]. Such a focus on one self-selected risk factor has also been shown to have good effect on long-term physical activity levels in self-management programs with other populations, such as those with cardiovascular disease [66]. People with ABI often have complex disabilities and face multiple barriers and challenges in the self-management of physical activity. Therefore, a program that specifically targets physical activity may potentially be more effective in establishing long-term behavior change than a program that focuses on simultaneously changing numerous risk factors. Given the significance of physical inactivity to the global burden of chronic disease, this proposal warrants further investigation.

The professional background of the facilitators used in the programs reviewed here is also an issue of interest. The types of health professionals varied greatly between studies. Nurses were most commonly engaged as facilitators, with three of the five studies using at least one nurse in their facilitation team [55,56,58]. The experience and skills of the facilitators to help people increase physical activity following ABI is an important consideration in an analysis of efficacy of self-management programs to increase physical activity. However, this information was not reported in any of the included studies. People with ABI face many unique barriers to engaging in physical activity, such as mobility impairments, pain, fear, and limitations regarding access [4-8]. The experience of the facilitators in regard to changing physical activity behavior is an important factor to consider in any study that aims to increase physical activity levels of individuals with ABI.

The overall conclusions that can currently be drawn regarding efficacy of self-management programs for improving physical activity following ABI are limited. This is primarily because of the heterogeneity of methodological features such as the outcome measures used and how physical activity was operationalized. No study collected objective measures of physical activity such as from accelerometers or other devices. Although Sit and colleagues did have participants log data from pedometers for their own self-monitoring, these data were not reported in the study [59]. All five studies employed different self-report assessments of physical activity, each based on a different construct or aspect of physical activity. For example, one study measured minutes per week spent in aerobic activity [56] while another study examined attitudes and beliefs regarding exercise [57]. Additionally, in three of the five studies, the physical activity outcome was not the primary outcome [56,58,59]. In another study, the physical activity measure was a subscale of the primary outcome measure [55], which limits the power of the study to make conclusions about physical activity. Boger and colleagues have stated that the use of outcome measures which are related, indirect, or proxy indicators of self-management and that have questionable reliability and validity, contributes to an inability to sensitively evaluate the effectiveness of stroke self-management interventions [47]. Thus, in future research, employing objective measures of physical activity along with validated self-report measures that can capture participation in a broad range of physical activities is important and will enable a more rigorous investigation of the efficacy of self-management interventions aimed at in improving physical activity levels.

An additional limitation of this review may come from the common diversity seen in an ABI population. Studies examining both individuals with stroke and those with TBI were included in this review. There are obvious differences between these populations, for example, etiology and average age. There was also limited information regarding the specific mobility or physical activity status of the included participants. This may impact on both the examination of overall efficacy and the ability to translate these results into practice. However, all the participants were community-dwelling adults with the cognitive and communicative ability to participate in a self-management program.

A second objective of this review was to assess the effectiveness and acceptability of self-management programs delivered remotely, that is, via telephone, computer, posted workbooks, and the Internet. The evidence on this question is even more limited and preliminary. Two of the five studies utilized one form of remote delivery, specifically telephone, with both studies showing positive findings in terms of increasing physical activity [56,58]. As outlined above, ABI survivors face many barriers to participate in physical activity and difficulties in accessing self-management programs due to mobility impairments, transport limitations, lack of specialist resources, and cost [4-8]. Remote delivery of interventions may assist in overcoming some of these barriers and access issues [33]; however, research into this area is limited. Dishman and Buckworth conducted a meta-analysis of 127 studies examining the efficacy of interventions delivered via differing modes for increasing physical activity in community, worksite, school, home, and health-care settings. They reported that physical activity programs utilizing mediated delivery methods, such as the Internet, are more effective than those using just face-to-face methods [65]. Although this differs from the findings of Conn *et al.* [67], who found face-to-face delivery produced superior outcomes in healthy adults, a recent Cochrane review by Foster *et al.* [41] has shown consistent evidence to support the effectiveness of remote and web-based interventions for promoting physical activity in generally healthy community-dwelling adult populations. There are also promising results from a number of non-randomized stroke-specific studies utilizing telehealth interventions [68-71], and it is important to note that the acceptability of remote interventions may be examined in more detail in these earlier stage research studies. Further research into the efficacy of remote delivery of self-management programs for ABI survivors, specifically aimed at improving physical activity levels, is therefore warranted given the importance of physical activity and the difficulties of people with ABI report in accessing self-management programs.

This review also aimed to establish which features of self-management interventions were associated with the optimal clinical outcomes and client satisfaction for participants. Although specific content related to physical activity was difficult to quantify, a number of common features were seen across the five studies. For example, education and goal setting were features of all the intervention programs included in this review. This is important because improving health literacy through health education programs helps build the capacity of individuals to seek, access, comprehend, and effectively utilize health information and services [22,72,73]. Goal setting, when combined with improved health literacy, does appear to positively influence patients' perceptions of self-care ability and engagement in rehabilitation following stroke [54]. However, education and goal setting did not differentiate a positive study from one that was less effective. It is difficult to establish whether programs were developed in a way that effectively targeted the level of health literacy of the users to allow for behavior change. Brenner and colleagues report on performing a pilot study of the program used in their study on eight participants with no resulting change to the materials [55], while Damush and colleagues report on developing their program with input from key stakeholders, including veterans with stroke [56]. Other authors report on building programs based on findings from local studies and focus groups [57,59]; however, although this may assist with content development, it does not guarantee that materials were targeted at the correct level of health literacy for users. The complexities of the manner in which these elements were delivered cannot be differentiated with the current evidence. Other program components were inconsistent between studies. These included self-monitoring, teaching coping strategies, planning and scheduling, barrier identification, problem solving, and habit formation.

Three of the five studies based their interventions on recognized psychological theories of behavior change, namely, the transtheoretical model, social cognitive model, and expanded health beliefs model [55-57]. Sit *et al.* did not specify a particular model of behavior change on which their program is based but do discuss the importance of modification of lifestyle habits as a component of behavioral change [59]. Kim and Kim also did not specify any theoretical basis to their interventions but utilized an educational framework with similar behavior change principles to the other studies examined [58]. Utilizing both psychological science and best educational practices can optimize the impact of self-management programs [22], and physical activity programs based on the principles of behavior modification have shown to be more effective than those based on cognitive modification [65,67]. A review of more than 550 pieces of high-quality research by de Silva [29] suggests that it is worthwhile to support self-management of individuals with chronic health conditions, particularly when there is a focus on behavior change and increasing self-efficacy, through approaches such as motivational interviewing and coaching with active goal setting. Future self-management programs aiming to increase physical activity following ABI should continue to adhere to these principles.

Conclusions

The field of self-management of chronic health conditions is rapidly growing, and successes have been demonstrated in a range of conditions, such as depression and chronic pain. The application of this approach for individuals with ABI is emerging. To date, there are a limited number of trials that have specifically investigated the efficacy of self-management to improve physical activity in this population. However, the risk of bias of these studies is generally high, and analysis is limited by heterogeneity in study interventions, methodology, measures, and diversity of the ABI population. Based on the results of this review, the efficacy of self-management programs in increasing physical activity levels in community-dwelling adults following ABI is still unknown. Moreover, the efficacy and acceptability of remotely delivered self-management programs for increasing physical activity levels after ABI is also unknown.

Further research into physical activity following self-management interventions for community-dwelling adults with ABI is required in order to properly establish efficacy and implications for practice. This research should be designed, undertaken, and reported on in a manner that reduces the potential for bias and allows for establishment of efficacy. Remote delivery methods also warrant further research given the potential they offer in regard to improving access, overcoming barriers, and changing health behaviors.

Additional file

Additional file 1: MEDLINE search strategy. Final search strategy used in MEDLINE.

Abbreviations

ABI: Acquired brain injury; CABS-R: Cerebrovascular attitudes and beliefs scale - revised; CENTRAL: Cochrane central register of controlled trials; eHBM: expanded health beliefs model; FASD: Fetal alcohol spectrum disorder; HPLP-II: Health promoting lifestyle practices - II; IPAQ: International physical activity questionnaire; MET: Metabolic equivalent of task; PRISMA: Preferred reporting items for systematic reviews and meta-analyses; SCI-EXPANDED: Science citation index expanded; SCT: Social cognitive theory; SRAHP: Self-rated abilities for health practices; TBI: Traumatic brain injury; TIA: Transient ischaemic attack; TTM: Transtheoretical model; WHO: World health organization.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

TMJ participated in the conception and design, data collection, analysis and interpretation, manuscript writing, and final approval of the manuscript. CMD participated in the conception and design, data collection, analysis and interpretation, manuscript writing and critical revision, and final approval of the manuscript. JMH participated in the conception and design, data analysis and interpretation, manuscript writing and critical revision, and final approval of the manuscript. BFD participated in the conception and design, data analysis and interpretation, critical revision of the manuscript, and final approval of the manuscript. NT participated in the conception and design, interpretation of the data, critical revision of the manuscript, and final approval of the manuscript. All authors read and approved the final manuscript.

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CHAPTER 3

STUDY II – Exploring interest in remotely delivered self-management program aimed at increasing physical activity in community-dwelling adults with acquired brain injury

3.1 Preface

In Chapter 3, the ongoing needs assessment of individuals with ABI is continued through examination of the physical activity status of community-dwelling Australian adults with ABI, and the barriers to physical activity that they experience. Interest in a remotely delivered self-management program specifically focussed on physical activity is also examined.

Ethical approval for this study was granted by the Macquarie University Human Research Ethics Committee (Medical Sciences) and is provided in Appendix 2.

This Chapter consists of the following publication:

Jones, T. M., Dean C. M., Dear B. F., Hush J. M. and Titov N. (2015). "An internet survey of the characteristics and physical activity of community-dwelling Australian adults with acquired brain injury: exploring interest in an internet delivered self-management program focused on physical activity." *Disability & Health Journal*, doi: 10.1016/j.dhjo.2015.08.004

The following conference abstracts also relate to the work conducted in this Chapter:

Jones, T. M., Dean C. M., Hush J. M., Dear B. F. and Titov N. (2014). Is the concept of an internet-based self-management program to increase physical activity acceptable to community-dwelling stroke survivors? *25th Annual Scientific Meeting of the Stroke Society of Australasia*. 30 July – 1 August 2014, Hamilton Island, Queensland, Australia, International Journal of Stroke. 9**:** 35.

Jones, T. M., Dean C. M., Dear B. F., Hush J. M. and Titov N. (2015). Exploring interest in an internet delivered self-management program focused on physical activity after acquired brain injury. *Australian Physiotherapy Association Connect Physiotherapy Conference 2015*. 3-6 October 2015. Gold Coast Exhibition Centre, Queensland, Australia.

3.2 Co-authors' statement

DEPARTMENT OF HEALTH PROFESSIONS | DISCIPLINE OF PHYSIOTHERAPY
Faculty of Medicine and Health Sciences

MACQUARIE University

Co-authors' Statement

As co-authors' of the paper, *An internet survey of the characteristics and physical activity of community-dwelling Australian adults with acquired brain injury: Exploring interest in an internet-delivered self-management program focused on physical activity*, we confirm that Taryn Jones has made the following contributions to this study:

- Conception and design of the research
- Collection and extraction of data
- Analysis and interpretation of the findings
- Drafting and revising of the manuscript
- Critical appraisal of the content

Professor Catherine Dean: C Dean .... Date: 14.09.15

Associate Professor Julia Hush: .... Date: 14.09.15

Dr Blake Dear: .... Date: 14.09.15

Professor Nickolai Titov: .... Date: 14.09.15

3.3 An internet survey of the characteristics and physical activity of community-dwelling Australian adults with acquired brain injury: exploring interest in an internet delivered self-management program focused on physical activity

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Research Paper

An internet survey of the characteristics and physical activity of community-dwelling Australian adults with acquired brain injury: Exploring interest in an internet-delivered self-management program focused on physical activity

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Abstract

Background: Individuals with Acquired Brain Injury (ABI) are more likely to be physically inactive and experience barriers to accessing services to address inactivity. This study was designed to guide the development of an internet-delivered self-management program to increase physical activity after ABI.

Objective: The aims of this study were to examine the current physical activity status of community-dwelling Australian adults with ABI, the barriers to physical activity they experience and to explore interest an internet-delivered self-management program aimed at increasing physical activity.

Methods: An online survey of Australian adults with ABI was used to collect information about demographic characteristics; general health; emotional well-being; mobility and physical activity status, and satisfaction; barriers to physical activity; confidence in overcoming barriers, and; interest in an internet self-management program. Data were analyzed descriptively and correlational analyses examined relationships between variables.

Results: Data were analyzed from 59 respondents. Over half were not satisfied with their current physical activity status. The most frequently reported barriers were pain/discomfort, fatigue and fear, and confidence to overcome these barriers was very low. Interest in an internet-delivered self-management program was high (74%) and not related to the amount of physical activity, satisfaction with physical activity and mobility status or total number of barriers.

Conclusion: Australian adults with ABI are not satisfied with their activity levels and experience barriers in maintaining their physical activity levels. Participants were interested in accessing an internet-delivered self-management program aimed at improving physical activity levels. Therefore such a program warrants development and evaluation.

Keywords: Self-management; Physical activity; Barriers; Stroke; Internet

Acquired Brain Injury (ABI) refers to any damage to the brain that occurred after birth, with common causes being stroke and trauma.[1] ABI is a significant cause of disability globally. Stroke alone causes a loss of 49 million disability-adjusted life years (DALYs) worldwide annually[2] while traumatic brain injury (TBI) is the leading cause of disability in those under the age of 40.[2] Individuals with ABI often have more complex disability than other disability groups.[1] Australians with disability experience significantly poorer health than those without disability,[3] leading to higher likelihood of individuals with ABI not reaching adequate physical activity levels recommended for optimal health.[4]

Improving physical activity levels is an important part of improving the overall health and well-being of those with ABI. However, those with ABI often face numerous barriers to physical activity. A systematic review by Nicholson and

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colleagues included examination of barriers following stroke from four studies, and found a lack of motivation, environmental factors (e.g. transport), health concerns, and stroke impairments were the most commonly reported barriers.[5] Following TBI, Driver and colleagues found a lack of endurance, feelings of self-consciousness, a lack of transportation and a lack of time to be the most common barriers to physical activity.[6] However, these studies primarily focused on barriers to participating in exercise programs specifically and/or accessing community exercise facilities[6–8] whilst others focused on barriers to community participation of which physical activity is only one aspect.[9,10] Given that barriers can vary for different individuals in different situations it is important in the development of a self-management program to identify the barriers to physical activity that are specific to potential users.

There is growing evidence to support the use of self-management programs in many populations, including those with ABI.[11–14] A review by de Silva examining over 550 high quality publications suggests that it is worthwhile to support self-management focused on behavior change and improving self-efficacy.[15] Achieving sustained changes in physical activity behavior over the long term is difficult.[16] However, a systematic review we recently completed examined found favorable physical activity outcomes following self-management interventions for stroke, although risk of bias in these studies was high and overall efficacy remains unclear.[17]

Self-management programs for those with ABI are widely heterogeneous with respect to program content, delivery characteristics, and outcomes, with physical activity typically just one component of a multifaceted intervention.[17] This makes it difficult to establish the depth to which physical activity specific content is covered, and the extent to which skills are taught and practiced. Hence a program that focuses solely on physical activity may potentially be a valuable option for those requiring more support to achieve changes in this area. However, to be effective, self-management programs must be focused on the concerns and barriers of the target population, thus a detailed needs analysis for the specific population is fundamental to the development of a targeted program.[15,18]

The mode of delivery is an important consideration when developing an effective self-management program. Delivery of self-management programs remotely, such as via the Internet or telephone, can be cost-effective and easily accessible, particularly for those who face multiple barriers to accessing optimal health care.[19] Remote delivery methods have been used with success in the delivery of self-management programs in a number of different populations, including chronic pain,[20] anxiety and depression,[21–23] post-traumatic stress disorder (PTSD),[24] arthritis,[25] cerebral palsy,[26] and generic chronic disease populations.[19] A systematic review of remote and web-based interventions for promoting physical activity found consistent evidence to support their effectiveness in supporting healthy, community-dwelling adults to become more physically active.[27] Evidence to support remote delivery of self-management programs for physical activity after ABI is beginning to emerge. Delivery of a self-management program predominantly via telephone has shown evidence to support its use in improving physical activity for individuals following stroke.[28,29] There are also promising results from a number of non-randomized studies showing improved health behaviors and self-efficacy following telehealth interventions for individuals following stroke.[30–33] However, there is a lack of availability of remote-based programs that specifically focus on increasing physical activity after ABI. Before starting to design and develop such programs, however, it is important to assess the level of interest of such a program to individuals in this population.

Therefore, a specific needs analysis of potential users of an internet-delivered self-management program to increase physical activity after ABI was conducted. The aims of this study were:

1. To examine the current physical activity status of community-dwelling adults with ABI and level of satisfaction with this status;
2. To establish the main barriers to physical activity experienced by community-dwelling adults with ABI and the level of confidence in overcoming these barriers;
3. To establish the level of interest in an internet-based self-management program focused specifically on increasing physical activity for adults with ABI.

Methods

Survey design and ethics

The survey was designed using *Qualtrics* software, Version 44426. The survey consisted of 65 items delivered to all participants in the same order. Participants were able to change their responses before submitting the survey. The survey was pilot tested by lay individuals with and without ABI, and questions were subsequently modified to improve comprehension. No formal analyses of internal consistency or validity were conducted.

This study was approved by the Macquarie University Human Research Ethics Committee (Medical Sciences) (Reference number 5201300495). No incentives were offered for participation. Participants were invited to leave their contact details if they were interested in the final results of the study or participating in future research. IP addresses of participants' computers were used to prevent users from repeating the survey. Survey data were collected between August 2013 and March 2014.

Recruitment & administration

Participants were recruited via advertisements listed on websites, social media sites and printed materials from major consumer advocacy groups associated with ABI in Australia, including the National Stroke Foundation and Brain Injury Australia. Email invitations were also distributed via Stroke Support Groups and other professional networks. These advertisements guided participants to a website where they were presented with detailed information about the purpose of the study. Participants were invited, via the website, to consent and commence the survey, or to exit the survey site.

Participants

Participants with an ABI and living in the community in Australia were invited to participate. Participants had to confirm they met the following inclusion criteria: (1) aged 18 years or older; (2) be an Australian resident; (3) have sustained an ABI; (4) be currently living in the community; (5) be able to read and understand written English; and (6) be able to consent to participate independently. Participants were excluded if they were suffering from a degenerative neurological condition. There was no exclusion based on time since injury or on current physical or mobility status.

Measures

All measures were administered online and consisted of questions relating to the following:

Demographics, general health & emotional well-being

We collected data about demographic details, general health status and emotional well-being. The Rural, Remote and Metropolitan Areas (RRMA) classification[34] was used to establish whether participants' residential postcodes were classified as metropolitan areas, or rural or remote areas. Participants' emotional well-being was assessed using the Kessler Psychological Distress Scale (K-10), a brief self-report measure of non-specific psychological distress. Scores are rated on a 5-point Likert scale, and summed to range from 10 to 50. Scores are used to categorize individuals according to their level of psychological distress (10−19: likely to be well; 20−24: likely to have a mild mental disorder; 25−29: likely to have a moderate mental disorder; 30−50: likely to have a severe mental disorder).[35−37] The K-10 has excellent internal consistency (Cronbach's alpha = .92) with an ability to discriminate DSM-IV cases from non-cases. It is used in annual government health surveys in Australia, the US and Canada as well as in the WHO World Mental Health Surveys.[36,37]

Mobility status

The second section of the survey was comprised of items relating to current mobility status. Participants were asked about the level of assistance they require to walk, as well as to indicate the distance and time they can walk, and the number of stairs they can climb, before requiring a rest on an average day. Participants were asked to rate how difficult they found walking on flat ground, and climbing stairs, on an average day on a 5-point Likert scale with the following options: *Very easy; Easy; Neither easy nor difficult; Difficult; Very difficult.* Participants were also asked about current level of satisfaction with their mobility status in regards to walking and stairs on a 5-point Likert scale with the following options: *Very satisfied; Satisfied; Neither satisfied nor dissatisfied; Dissatisfied; Very dissatisfied.*

Physical activity

Participants were asked to report the number of days in the past week in which they had accumulated 30 min or more of moderate physical activity. This was based on current physical activity guidelines where it is recommended adults achieve 30 min or more of physical activity on 5 or more days of the week.[38,39] Moderate physical activity was described to participants as being any activity, planned or incidental, that made them breathe more deeply than normal or to cause them to "*huff and puff*." Similarly to mobility, participants were asked to rate their level of satisfaction with their current physical activity status on a 5-point Likert scale.

Barriers to physical activity

Participants were asked to identify barriers to physical activity they experienced. They were able to select from a list of 17 common barriers. This list was derived by examining the most common barriers reported in the current literature.[5−10] Participants could also opt to select the statement "*None of these statements apply to me*." This list of barriers was derived from previous studies reporting barriers to physical activity or exercise in an ABI population.[6−8,40] Participants were also asked about their level of confidence to overcome these barriers on a 4-point Likert scale with the following options: *Very confident; Fairly confident; Somewhat confident; Not at all confident.*

Interest in an internet-delivered self-management program

Participants were asked whether they would be interested in participating in an online self-management program aimed at improving the ability of people living in the community with an ABI to overcome barriers and increase their levels of physical activity (*Yes or No*). Participants also had the option of leaving qualitative feedback about the type of content they would like to see included in such a program.

Data analysis

The data analysis consisted of four components. These included (1) descriptive and frequency analyses; (2) correlation analyses using Kendall's tau-b to examine nonparametric correlations with amount of physical activity and barriers to physical activity; and (3) analysis of interest

Table 1
Participant demographics

Variable	N	Subcategory	N [%] unless otherwise stated
Age (years) (median [IQR])	59		54.0 [39.0–64.0]
Gender	59	Male	34 [57.6]
		Female	25 [42.4]
Residential RRMA classification	59	Metropolitan	39 [66.1]
		Rural or remote	20 [33.9]
Lives alone	58		14 [24.1]
Highest educational qualification	58	University	26 [44.8]
		Vocational/other certificate	12 [20.7]
		High school	17 [29.3]
		No qualification	3 [5.2]
Cause of ABI	57	Stroke	41 [71.9]
		Trauma	14 [24.6]
		Other	2 [3.5]
Time since injury (median years [IQR])	57		5.0 [1.5–13.0]
Length of acute hospital stay	57	Less than 4 weeks	21 [36.8]
		4–12 weeks	13 [22.8]
		More than 12 weeks	23 [40.4]
Rehabilitation following discharge	57	Yes	47 [82.5]
Currently receiving rehabilitation	56	Yes	19 [33.9]
No of chronic health conditions	58	0	6 [10.3]
		1	24 [41.4]
		2	17 [29.3]
		3+	11 [19.0]
BMI (kg/m^2) (median [IQR])	56		25.4 [22.8–28.0]
K-10 (score 10–50) (median [IQR])	55		18.0 [13.0–25.0]
K-10 analysis	55	Likely to be well	32 [58.2]
		Likely to have a mild mental disorder	9 [16.4]
		Likely to have a moderate mental disorder	5 [9.1]
		Likely to have a severe mental disorder	9 [16.4]
General health perception	57	Excellent	7 [12.3]
		Good	25 [43.9]
		Fair	12 [21.1]
		Poor	1 [1.8]

using chi-square tests for categorical data and independent-samples *t*-tests for continuous data. Additionally, one-way ANOVAs were conducted to assess for differences in the amount of physical activity between groups based on level of satisfaction with physical activity and mobility. All data analysis was conducted using *IBM Statistical Package for Social Sciences (SPSS)* version 21 for Windows. Descriptive results are reported as mean (SD) for normally distributed data, or as median (IQR) for data that is non-parametric. Kendall's tau-b was selected for correlational analyses as this is recommended when non-parametric data is generated from a small data set with a large number of tied ranks.[41]

Results

Eighty participants consented to commence the survey; however, 10 participants did not meet the eligibility criteria: not Australian resident ($n = 4$); had not sustained an ABI ($n = 1$); not community-dwelling ($n = 1$); degenerative neurological condition ($n = 4$). A further 11 participants were excluded on the basis of not completing the eligibility questions ($n = 9$) or not completing any survey data ($n = 2$). The final sample consisted of 59 eligible participants. Four participants submitted incomplete surveys. The data that was received from these participants was included in the analysis.

Participant characteristics

Participant demographics

Participant demographics, general health and emotional well-being are outlined in Table 1. Of note is that K-10 scores indicate that over 40% of the sample displayed distress at a level that makes them likely to have a mild, moderate or severe mental disorder.

Mobility

The participants' mobility status is outlined in Table 2. Most participants (92.7%) were able to walk outside, although the average time and distance participants could walk varied. Similarly, the majority of participants (92.3%) were also able to climb stairs, with 66.7% reporting they could climb a flight of 14 or more stairs without a rest. However, only 22.9% of participants reported finding stair climbing to be '*Easy*' or '*Very easy*.'

Table 2
Mobility status

Variable	N	Subcategory	N [%] unless otherwise stated
Able to walk outside	55		51 [92.7]
Requires assistance from others outside (always or sometimes)	51		17 [33.3]
Uses walking aid outside (always or sometimes)	51		23 [45.1]
Average walking time before requiring rest	52	30 min Or less	28 [53.8]
		More than 30 min	24 [46.2]
Average walking distance before requiring rest	52	500 m or less	28 [53.8]
		More than 500 m	24 [46.2]
Perception of walking ability (flat ground)	52	Very difficult	2 [3.8]
		Difficult	6 [11.5]
		Neither difficult nor easy	21 [40.4]
		Easy	14 [26.9]
		Very easy	9 [17.3]
Able to climb steps or stairs	52		48 [92.3]
Average number of stairs without rest	48	Less than 14	16 [33.3]
		14 or more	32 [66.7]
Requires assistance from others (always or sometimes)	48		16 [33.3]
Requires handrail (always or sometimes)	48		41 [85.4]
Perception of stair climbing ability	48	Very difficult	5 [10.4]
		Difficult	9 [18.8]
		Neither difficult nor easy	23 [47.9]
		Easy	6 [12.5]
		Very easy	5 [10.4]
Satisfaction with mobility status	52	Very satisfied	8 [15.4]
		Satisfied	19 [36.5]
		Neither satisfied nor dissatisfied	13 [25.0]
		Dissatisfied	8 [15.4]
		Very dissatisfied	4 [7.7]

Satisfaction with mobility status was strongly associated with all aspects of mobility including walking time ($\tau_b = -.449$, $p < .001$), walk distance ($\tau_b = -.360$, $p = .001$), perceived walking difficulty ($\tau_b = -.515$, $p < .001$), reported stair climbing ability ($\tau_b = -.340$, $p = .008$), and perceived stair climbing difficulty ($\tau_b = -.438$, $p < .001$). Those who could walk further and longer, climb stairs more easily and perceived less difficulty with their mobility were, in general, more satisfied with their mobility status.

Physical activity

Current physical activity status

Participants' physical activity status is displayed in Fig. 1. Over 44% of participants reported that they are currently performing less than 5 days/week of 30 min moderate physical activity.

The amount of physical activity reported did not have any significant relationship with age ($\tau_b = .140$, $p = .177$), gender ($\tau_b = -.075$, $p = .547$), level of education ($\tau_b = -.029$, $p = .802$), BMI ($\tau_b = -.098$, $p = .344$), or level of emotional distress (K-10) ($\tau_b = -.189$, $p = .071$). There was also no significant relationship between physical activity and mobility status in regards to the time or distance an individual walked before requiring a rest ($\tau_b = .197$, $p = .081$; $\tau_b = .218$, $p = .057$ respectively); stair climbing ability ($\tau_b = .065$, $p = .607$); or reported difficulty with walking or stairs ($\tau_b = .065$, $p = .583$; $\tau_b = .126$, $p = .302$ respectively). However, when grouped according to satisfaction with mobility status, there was a statistically significant difference in the amount of physical activity performed ($F(2,46) = 4.630$, $p = .015$). Bonferroni-adjusted post-hoc tests revealed that the number of days of physical activity was significantly lower in the group that reported they were dissatisfied (mean = 3.78 (SD 1.7), $p = .013$) compared with those who were satisfied with their mobility status (mean = 5.65 (SD 1.7)).

Satisfaction with physical activity status

Over 58% of participants were not satisfied with their current physical activity status. There was a statistically significant difference in the number of days of physical activity reported between individuals with different levels of satisfaction ($F(2,49) = 6.665$, $p = .003$). Those who were satisfied with their level of physical activity reported a significantly higher number of days of physical activity (mean = 5.65 (SD 1.7)) compared with those who reported they were dissatisfied with their activity levels (mean = 3.78 (SD 2.0), Bonferroni-adjusted $p = .004$) and those who were neither satisfied nor dissatisfied (mean = 4.00 (SD 1.7), Bonferroni-adjusted $p = .041$). There was no significant difference between those who reported being dissatisfied and those reporting neither satisfaction nor dissatisfaction (Bonferroni-adjusted $p = 1.00$).

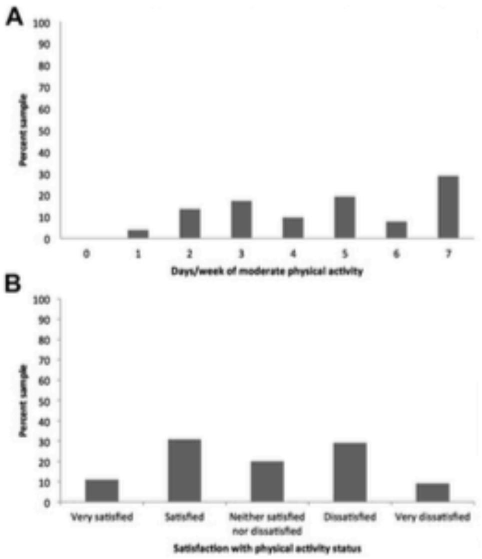

Fig. 1. Current physical activity status. (A) Days/week of moderate physical activity (B) Satisfaction with physical activity status.

Table 3
Barriers to physical activity

Statement	N [%]
Physical activity causes me pain or discomfort	15 [36.6]
I find physical activity is too tiring	12 [29.3]
I am fearful of performing physical activity	11 [26.8]
I do not feel safe enough to be physically active outside my home	10 [24.4]
I am unable to get to a suitable facility/venue to perform physical activity	9 [22.0]
I do not have the time to be more physically active	8 [19.5]
I do not have the money to undertake a physical activity program	8 [19.5]
Physical activity is too difficult for me	8 [19.5]
I am concerned that physical activity will cause me further health problems or injury	8 [19.5]
It is not easy to be physically active in my local neighborhood	7 [17.1]
I have no-one to perform physical activity with	7 [17.1]
I feel that increasing my physical activity adds further burden to my family/friends	6 [14.6]
I have been instructed not to perform physical activity by a health professional	4 [9.8]
I do not know what to do when it comes to physical activity	2 [4.9]
I do not know where there is an appropriate place for me to be physically active	2 [4.9]
I don't feel being physically active helps me	1 [2.4]
Physical activity is boring	1 [2.4]

Barriers

Barriers to physical activity

Frequencies of barriers reported by participants are displayed in Table 3. Over 74% of participants reported at least 1 barrier with pain/discomfort (36.6%), fatigue (29.3%) and fear (26.8%) the most commonly reported barriers. A significant relationship was found between the amount of physical activity participants reported doing weekly and the total number of barriers reported ($\tau_b = -.367$, $p = .001$), with participants reporting no barriers more likely to achieve 5 days or more of 30 min moderate intensity physical activity ($X^2(1) = 6.694$, $p = .008$). The number of barriers reported was also found to be significantly correlated to K-10 score ($\tau_b = .406$, $p < .001$).

When individual barriers were examined there was found to be a significant relationship between the amount of physical activity reported and the barriers of pain/discomfort ($\tau_b = .264$, $p = .033$) and fear ($\tau_b = .254$, $p = .040$), but not with finding physical activity tiring ($\tau_b = .207$, $p = .095$).

Relationships between participant demographics and barriers were also explored. Age and gender were found to have a significant correlation with being unable to get to a suitable venue to engage in physical activity, with those who were older or female more likely to report this as a barrier ($\tau_b = .325$, $p = .004$; $\tau_b = -.305$, $p = .025$ respectively). Female participants were also more likely to report that being a burden to family or friends was a barrier to physical activity ($\tau_b = -.280$, $p = .040$). Being able to get to a suitable venue was not found to have a significant correlation with residential location ($\tau_b = .083$, $p = .541$). However, those who lived in rural/remote areas were more likely to cite cost as a barrier to physical activity ($\tau_b = -.394$, $p = .004$). No other significant correlations were found between demographic characteristics and specific barriers reported.

Confidence to overcome reported barriers to physical activity

Confidence to overcome barriers to physical activity is displayed in Fig. 2. Only 4.9% of participants ($n = 2$) reported being '*Very confident*' in their ability to overcome the barriers reported. Confidence to overcome barriers to physical activity was found to have no significant

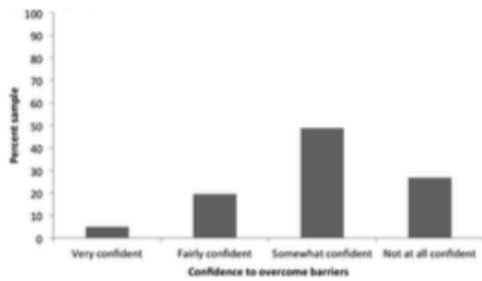

Fig. 2. Reported confidence to overcome barriers.

relationship with the total number of barriers reported (τ_b = .230, p = .082) nor the amount of physical activity reported (τ_b = .030, p = .824). However, a significantly lower level of confidence to overcome barriers was reported by those who could walk for a shorter period of time (τ_b = −.271, p = .042), those who could climb less stairs (τ_b = −.476, p = .001), and those who reported more difficulty with walking on flat ground (τ_b = −.337, p = .017) or with climbing stairs (τ_b = −.459, p = .002). A significantly lower level of confidence to overcome barriers was also reported by those with lower levels of satisfaction with physical activity status (τ_b = .431, p = .001) and with mobility status (τ_b = .309, p = .026).

Interest in an internet-delivered self-management program

Interest in an internet-delivered program aimed at improving their ability to manage their physical activity levels is shown in Fig. 3. Interest in such a program was high, with 74.5% of participants reporting they would be interested in such a program. Interest in the program was not significantly related to the amount of physical activity reported ($t(50)$ = .24, p = .981), level of satisfaction with physical activity status ($X^2(4)$ = 4.474, p = .346) or level of satisfaction with mobility status ($X^2(4)$ = 3.755, p = .440). There was also no significant relationship with the total number of barriers reported ($t(53)$ = .759, p = .451) or confidence to overcome these barriers ($X^2(3)$ = 1.625, p = .654). However, when individual barriers were examined, those who reported that they were fearful of performing physical activity were more likely to be interested in an internet-delivered self-management program ($X^2(1)$ = 4.695, p = .030). When participant demographics were examined, there was no significant relationship between interest and age ($t(53)$ = −.151, p = .880), gender ($X^2(1)$ = .309, p = .578) or residential location ($X^2(1)$ = .048, p = .826). There was, however, a significant relationship between program interest and K-10 scores ($t(46.895)$ = 2.701, p = .010) with those reporting higher levels of distress more likely to be interested in a self-management program.

A number of participants (n = 39; 66%) opted to leave a short comment regarding their preferences for program content. Comments were diverse in content, as shown by the following examples:

> *"Information to keep the body moving as much as possible without too much discomfort − especially as arthritis sets in along with stroke symptoms" (Participant 32).*

> *"Skills to help me be more comfortable and confident with participating in physical activity" (Participant 27).*

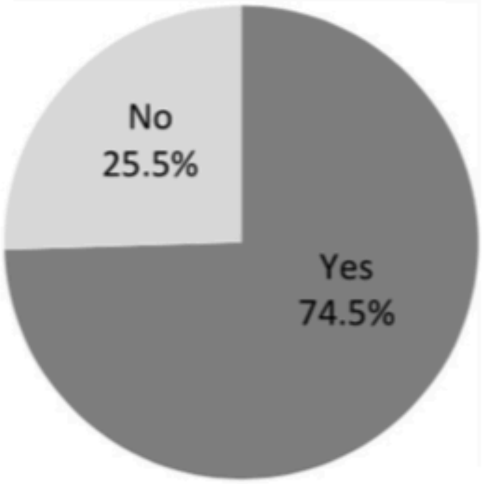

Fig. 3. Interest in Internet-delivered self-management program to increase physical activity following ABI.

> *"... how to increase physical and mental energy levels" (Participant 25).*

> *"Often in rehab we focus on the body without addressing a persons thinking about their situation. Incorporate some thinking skills" (Participant 16).*

> *"... anything to get me motivated to do physical activity and improve my self esteem and confidence ..." (Participant 23).*

> *"A better understanding of physical exercise and it's benefits to me" (Participant 48).*

Discussion

An overwhelming majority (74.5%) of survey participants reported that they would be interested in participating in an Internet-based self-management program aimed at increasing physical activity after ABI. This interest was not influenced by the amount of physical activity participants reported doing; level of satisfaction with physical activity or mobility; total number of barriers reported or confidence to overcome these barriers. This is may reflect the needs of this population, who often feel neglected and isolated,[40] to gain access to more information and services following ABI, regardless of level of ability.

Interest in an internet-delivered self-management program did, however, have a significant association with K-10 scores. Those with higher levels of distress were more likely to find the program acceptable. Remote interventions, such as those delivered by internet, have been shown to be highly acceptable to those with mental health conditions, such as depression and anxiety,[42–46] as well as those with chronic pain.[20] It is likely that those in some psychological distress may find remote-based interventions less threatening and more easily accessible than traditional face-to-face interventions. The most frequently reported barriers – pain/discomfort, fatigue and fear – are also likely to be amenable to an intervention delivered remotely. Self-management programs delivered via the internet in other populations, such as those with chronic pain, have shown improvements in the management of pain and fatigue, as well as increases in confidence.[20,22–24]

Barriers most frequently reported by participants' in this survey differ slightly to those previously reported in other studies of people following stroke and traumatic brain injury. This may be in part because this survey considers all forms of physical activity, both planned and incidental, whilst some other studies have focused more specifically on planned exercise and access to exercise facilities.[7,8] Other studies have also found motivation to be a significant barrier to exercise. In this study, pain and fear were both highly cited barriers to physical activity. The Fogg Behavioral Model highlights that pain and fear contribute significantly to lowering motivation levels, and as such we examined these factors rather than focusing on the overall feeling of motivation in this survey.[47,48]

A limitation in the interpretation of these results is that it is likely that those who are more interested in physical activity after ABI were more likely to have undertaken this survey. Online recruitment makes it difficult to obtain overall response rates, as it is unclear exactly how many people would have seen the study advertised via social media and websites. We also acknowledge that our recruitment strategy resulted in targeting a sample of ABI survivors who are unlikely to be representative of the whole ABI population, with most having sustained a stroke or trauma, and all participants having sufficient cognitive and communication skills to complete the survey. However, the aim of this study was to target potential users of an internet-delivered self-management program to increase physical activity after ABI. Our recruitment strategy reflects this aim. Stroke and trauma are the leading causes of ABI in Australia[1,49] and it is appropriate that they also represent the largest proportion of this sample. There was no also exclusion based on physical ability, and the mobility status of participants shown in Table 2 demonstrates a wide variety of physical ability represented in this survey.

Another limitation of this study is the small sample size. However, it should be noted that this is actually one of the largest published studies examining barriers to physical activity after ABI, and the largest examining an Australian population.[5] This is also the first paper to the authors' knowledge that has specifically examined interest in a self-management program specifically aimed at increasing physical activity after ABI delivered via the Internet. This is significant as remote delivery offers the potential of a cost-effective and accessible treatment approach for a population who are vulnerable to chronic disease and mortality due to low physical activity levels.

Interpretation of these results may also be limited by the use of a customized question asking participants to report on the average number of days/week in which they achieved 30 min or more of moderate intensity physical activity. Although this question was based on current physical activity guidelines,[39] there are limitations when categorizing physical activity in this way. There is also potential for recall bias and reduced accuracy when utilizing a retrospective self-report measure. Adults with ABI from stroke have been found to overestimate the amount of physical activity they perform when self-reports are compared to objective measures.[50] Overestimation of physical activity may have occurred in this survey as the levels of physical activity reported by participants in this study were, in general, higher than is often reported for an ABI population.[51,52] This may indicate even greater need for interventions aimed at increasing physical activity after ABI, particularly given the low level of perceived satisfaction with current physical activity status.

Knowledge of the specific barriers facing this population will be used to inform the content of an internet-delivered self-management program aimed specifically at increasing physical activity after ABI. In order to maximize the relevance of this program to participants it will need to focus on improving the management of pain and fatigue after ABI, enhance skills to improve self-efficacy and reduce levels of fear about physical activity. Improving these factors has the potential to increase the level of physical activity undertaken by this population.

Conclusion

Over half of ABI participants surveyed were not satisfied with their current level of physical activity. Barriers to physical activity included pain/discomfort, fatigue and fear, and confidence to overcome these barriers low. Participants demonstrated a high level of interest an Internet-delivered self-management program aimed at increasing physical activity after ABI. This provides timely and consumer-driven evidence to support the development of such a program.

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Previous publications: All authors have read the manuscript and are happy for the paper to be submitted to *Disability and Health Journal*. This manuscript, or any part of it, has not been published and will not be submitted elsewhere for publication while being considered by the journal. A small subgroup analysis of the stroke participants of this survey was conducted for a poster presentation at the 25th Annual Scientific Meeting of the Stroke Society of Australasia, held on Hamilton Island, Queensland, Australia on 30 July – 1 August 2014. The abstract was published in International Journal of Stroke (9: S1, p35).

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CHAPTER 4

Study III - Systematic development of a remote self-management program for increasing physical activity after acquired brain injury using an Intervention Mapping approach

4.1 Preface

The development of a complex and multifaceted intervention, such as a self-management program aiming to change physical activity behaviour, requires a scholarly and systematic developmental process. The myMoves program, a remotely delivered self-management program, aimed at increasing physical activity and reducing sedentary behaviour in individuals with ABI, underwent a rigorous developmental process using an Intervention mapping framework. This Chapter outlines this developmental process.

A paper based on this Chapter has been submitted for consideration for publication to *Physical Therapy* and is currently under review:

Jones, T. M., Dear B. F., Hush J. M., Titov N. and Dean C. M. (under review). "A remote self-management program for increasing physical activity after acquired brain injury: Systematic development using Intervention Mapping." *Physical Therapy* (submitted 8 July 2015).

The following conference abstract also relates to this Chapter:

Jones T. M., Dean C. M., Dear B. F., Hush J. M. and Titov N. (2015). Design and development of an internet-delivered self-management course to increase physical activity after acquired brain injury. *Stroke 2015, Combined 26th ASM of the Stroke Society of Australasia and 11th Australasian Nursing & Allied Health Stroke Conference SMART STROKES,* Melbourne, Australia. *International Journal of Stroke.* 10(Suppl. 3): 36.

4.2 Co-authors' statement

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Co-authors' Statement

As co-authors' of the paper, *A remote self-management program for increasing physical activity after acquired brain injury: Systematic development using Intervention Mapping*, we confirm that Taryn Jones has made the following contributions to this study:

- Conception and design of the research
- Collection and extraction of data
- Analysis and interpretation of the findings
- Drafting and revising of the manuscript
- Critical appraisal of the content

Professor Catherine Dean: C Dean Date: 14.09.15

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4.3 A remote self-management program for increasing physical activity after acquired brain injury: Systematic development using Intervention Mapping

4.3.1 Abstract

Background

Physical therapy interventions, such as those designed to change physical activity behaviour, are often complex and multi-faceted. In order to facilitate rigorous evaluation and implementation of these complex interventions into clinical practice, the development process must be scholarly, systematic and transparent, with a sound theoretical basis. Intervention Mapping is designed to guide an iterative and problem-focused approach to the development of complex interventions.

Objective

Can a remote self-management program to increase physical activity after acquired brain injury be systematically developed using an Intervention Mapping approach?

Methods

The six steps of Intervention Mapping were followed, including: 1) needs assessment; 2) identification of outcomes, performance objectives and change objectives; 3) selection of theory-based intervention methods and practical applications; 4) organisation of methods and applications into an intervention program; 5) creation of an implementation plan; 6) generation of an evaluation plan.

Results

A needs assessment of the target population was conducted and a review of evidence, both epidemiological and theoretical, was performed. Program outcomes and changes objectives were established, from which theory-based intervention methods and practical applications were selected. These were then organised into a novel intervention program, myMoves, which is designed to help individuals with an acquired brain injury to change their physical activity behaviour, with consideration for how the program can be implemented and evaluated.

Conclusion

Physical therapists can apply the Intervention Mapping framework to develop complex interventions to ensure that the development is scholarly, systematic and thorough; with a sound theoretical basis. This process facilitates translation into clinical practice and allows for greater confidence and transparency when the program efficacy is investigated.

4.3.2 Introduction

Physical therapy has a substantial evidence base to guide practice (Allied Health Evidence 2015). However, physical therapy interventions are commonly complex and multi-faceted in nature and because of this the translation of evidence into practice is a significant challenge. Increasing physical activity and reducing sedentary behaviour is a core aspect of many physical therapy interventions. With the growing burden of chronic disease globally, many of which are caused by modifiable risk factors such as physical inactivity, there is an urgent need for more effective interventions to mediate this public health crisis. However, changing long-term physical activity behaviour is difficult (Dishman and Buckworth 1996) and empowering individuals to change behaviours and self-manage their physical activity often requires complex interventions.

One reason why interventions designed to increase physical activity fail may be that the design, development and implementation have been ineffective (Campbell, Fitzpatrick et al. 2000, Bartholomew, Parcel et al. 2011). The UK Medical Research Council (MRC) has reported that too often there is inadequate development and piloting of interventions, and that the primary effort to conduct treatment efficacy trials misses the opportunity to develop and evaluate the theoretical and practical aspects of intervention (Craig, Dieppe et al. 2008). This can result in less useful interventions that are harder to evaluate and less likely to be implemented (Craig, Dieppe et al. 2008). The UK MRC recommends that complex interventions should include a coherent theoretical basis that clearly underpins the development process, and that this process should be described fully to allow for implementation, replication and robust evaluation (Craig, Dieppe et al. 2008). Physical activity interventions that have an explicit theoretical basis have been shown to have larger effects on behaviour than those that do not (Webb, Joseph et al. 2010, Taylor, Conner et al. 2012).

Physical therapy researchers seldom report on the process of intervention development, particularly in the area of physical activity. The causal chain from determinants of behaviour through to objectives, methods and practical applications is mostly absent from the literature (Bartholomew, Parcel et al. 2011). The result is a lack of information about how interventions are developed, and their theoretical basis; how specific content is covered; and how the method of implementation is designed (Jones, Dean et al. 2015b). When this information about the development of interventions is lacking, interpretation of treatment efficacy is problematic (Campbell, Fitzpatrick et al. 2000). There is also little published about what has, and has not, worked in the development, implementation and evaluation of existing interventions to guide clinical researchers in the development of new interventions. This information is crucial, both in guiding clinical researchers in the development of new interventions, or the adaptation of existing interventions to a different population groups (Craig, Dieppe et al. 2008, Bartholomew, Parcel et al. 2011, Campbell, Fitzpatrick et al. 2000), as well as in the translation of research into clinical practice (Schaalma and Kok 2009).

Intervention Mapping is an established approach used to develop complex health promotion interventions (Bartholomew, Parcel et al. 2011). Developed by a group of US and Dutch health promotion researchers (Kok, Schaalma et al. 2004), its purpose is to provide a framework for effective decision making at each step of intervention development, including the planning, design, implementation and evaluation (Bartholomew, Parcel et al. 2011). It is designed to reflect the complexity of the decision-making process, recognizing this process to be collaborative, iterative and cumulative (Schaalma and Kok 2009). It also allows for practical and political considerations that relate to efficiency, feasibility and ethics (Schaalma and Kok 2009). The construction of the Intervention Mapping framework has been based on the authors experience in developing of complex self-management programs for individuals with cystic fibrosis and asthma (Bartholomew, Parcel et al. 2011, Bartholomew, Parcel et al. 1998, Bartholomew, Parcel et al. 1991). Intervention Mapping has also been used to develop complex health promotion interventions in areas such as AIDS prevention and management; obesity prevention; workplace health; cancer screening; and sexual health (Bartholomew, Parcel et al. 2011). Intervention Mapping consists of six steps, as shown in Figure 4.1, which serve as a blueprint for the design, implementation and evaluation of an intervention based on a foundation of theoretical, empirical and practical information. These steps are presented in a linear manner; however, the process is both iterative and cumulative. Thus, in reality, intervention developers move back and forth between the steps as information is gained (Bartholomew, Parcel et al. 2011).

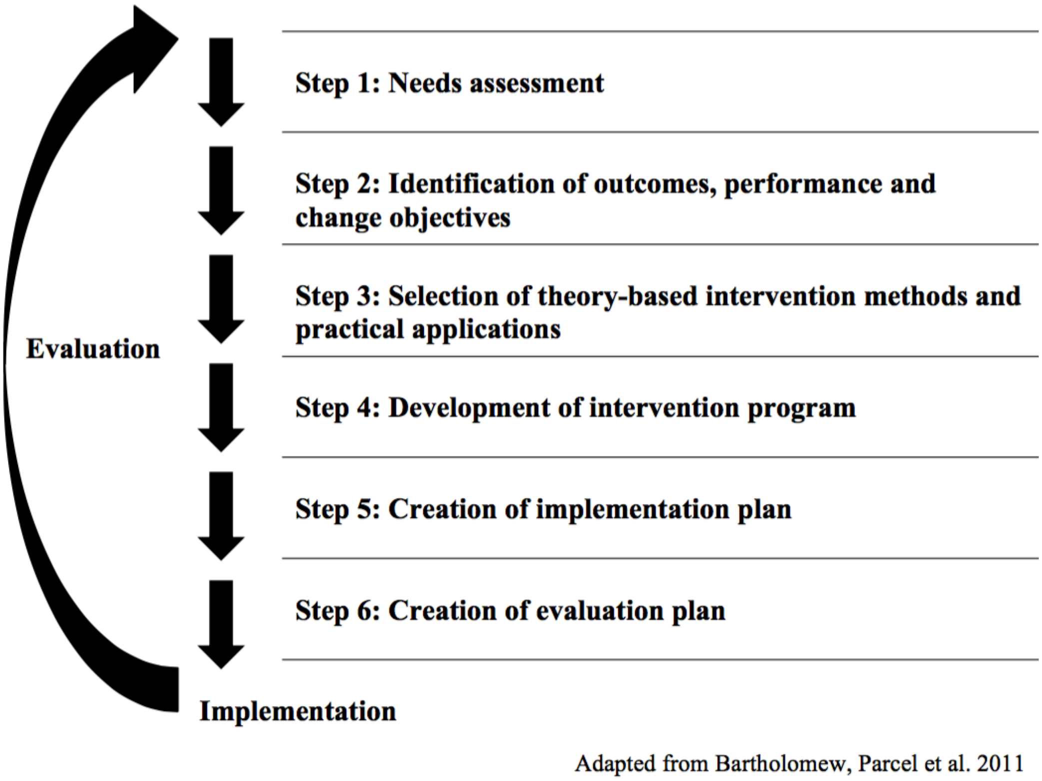


Figure 4.1 Schematic representation of the Intervention Mapping framework

Physical therapists have a responsibility to help individuals and communities change their health behaviour to optimize health and wellbeing. Intervention Mapping offers a systematic and scholarly method to develop, or adapt existing, interventions to enhance efficacy. In this paper we describe the application of Intervention Mapping to the development of an internet-delivered self-management program aimed at increasing physical activity in adults living in the community with an acquired brain injury (ABI). ABI, often caused by stroke or trauma, is a health problem with which physiotherapists commonly intervene to improve health through increasing physical activity. Thus, in this paper, we ask the following question: Can a remote self-management program to increase physical activity after acquired brain injury be systematically developed using an Intervention Mapping approach?

4.3.3 Process of Intervention Development

The Intervention Mapping approach is summarised here as it was applied to the development of the myMoves program, a remotely delivered self-management program aimed at increasing physical activity in community-dwelling adults with ABI. As is typical of the Intervention Mapping approach, we have presented the steps in a linear fashion, however there was movement between the steps to inform iterative changes as needed. Where community participation was required, ethical approval was obtained from Macquarie University Human Research Ethics Committee (Medical Sciences).

Step 1: Needs assessment

The purpose of Step 1 is to assess the health problem that has been identified in more detail, including the related behavioural and environmental conditions and the associated determinants. This process includes both examining the scientific, epidemiological, behavioural and social perspectives of the population of interest, as well as an effort to begin to understand this population. The ultimate product of this needs assessment is a description of the health problem facing our population of interest through the development of a model (Bartholomew, Parcel et al. 2011). This model is based upon the PRECEDE-PROCEED model, which guides planning of a health intervention through a process that starts with a health problem and works backwards in a casual chain to identify determinants of behaviours (Bartholomew, Parcel et al. 2011, Green and Kreuter 2005).

Different health problems and populations of interest will necessitate different modes of needs assessment, often combining both quantitative and qualitative research methods (Bartholomew, Parcel et al. 2011). The myMoves program was initially born from the concept that a remotely delivered self-management program focused on supporting physical activity behaviour change may be of use to individuals living in the community with ABI. This was derived from the clinical expertise of Ms Taryn Jones and Professor Catherine Dean, in developing and delivering physiotherapy services to individuals with ABI; and based on the success of Professor Nickolai Titov and Dr Blake Dear, in providing remotely delivered self-management programs to individuals with a variety of mental health conditions, including chronic pain (Dear, Titov et al. 2013, Dear, Gandy et al. 2015), anxiety and depression (Titov, Andrews et al. 2010, Titov, Dear et al. 2013, Titov, Dear et al. 2014), and post-traumatic stress disorder (Spence, Titov et al. 2011). A team was established to develop this concept into the myMoves program.

The myMoves team consisted of the following members:

- Ms Taryn Jones – a physiotherapist with extensive clinical experience managing individuals with complex neurological and orthopaedic injuries, particularly those with TBI and other forms of ABI;

- Dr Blake Dear – a psychologist with extensive clinical and research experience in developing and testing remotely delivered self-management interventions to individuals with mental health conditions;
- Professor Catherine Dean – a physiotherapist with extensive expereince in providing both clinical and research interventions to individuals following stroke, as well as substantial expereince in developing and delivering educational programs to physiotherapy students;
- Associate Professor Julia Hush – a physiotherapist with clincial expertise in the management of chronic pain;
- Professor Nickolai Titov - a psychologist with extensive clinical experience in working with individuals with neurological impairments, and extensive clinical and research experience in developing and testing remotely delivered self-management interventions to individuals with mental health conditions.

Prior to undergoing an extensive intervention development process to move the myMoves program from a concept to a reality, we needed to know whether this was an intervention that would be of interest to this population, and, if so, what could we learn that could assist us in understanding the needs of this population in greater detail. Therefore, the needs assessment consisted of 1) a literature review of epidemiological literature examining physical activity after ABI; 2) a literature review of theories of behaviour change used to change physical activity behaviour; 3) a literature review of self-management of physical activity after ABI, including a systematic review of the efficacy of current self-management programs; 4) a literature review of remotely-delivered self-management programs; 5) survey of a sample of Australian adults living in the community with an ABI, who would be potential users of the intervention. Much of this information is discussed in detail in the previous chapters of this thesis, however a summary pertaining specifically to this needs assessment is provided here:

Epidemiological evidence

Acquired brain injury (ABI), often caused by stroke or trauma, is a significant public health issue globally. Stroke is one of the greatest causes of disease burden globally (Thrift, Cadilhac et al. 2014), while traumatic brain injury is the world's leading cause of disability in children and young adults (World Health Organization 2006). Individuals with ABI often have more complex disabilities than other groups with disability (O'Rance 2007). Adults with disabilities are more likely to be physically inactive and vulnerable to further non-communicable disease (Centers for Disease Control and Prevention 2014).

Physical activity interventions have been shown to be effective in improving physical, psychosocial and cognitive status after ABI; however, maintaining these improvements once intervention ceases is challenging, and physical activity participation levels after ABI remain low (Grealy, Johnson et al. 1999, Mudge 2009, States, Pappas et al. 2009, Driver, Ede et al. 2012, Driver, Irwin et al. 2012, Ada, Dean et al. 2013, Moore, Hallsworth et al. 2013, Morris, Macgillivray et al. 2014). Individuals with ABI often face many barriers to physical activity, such as mobility impairments, transport difficulties, limited local specialist services, financial costs, concerns regarding safety when being active, and a lack of knowledge about how to be active after an ABI (Hammel, Jones et al. 2006, Damush, Plue et al. 2007, National Stroke Foundation 2007, Rimmer, Wang et al. 2008, Robison, Wiles et al. 2009, Driver, Ede et al. 2012, Nicholson, Sniehotta et al. 2013). Compounding this is the fact that there is a significant shortage of programs targeting long-term promotion of physical activity in those with ABI (Pawlowski, Dixon-Ibarra et al. 2013, Cleveland, Driver et al. 2015).

Review of behaviour change theories used to change physical activity

An extensive review of the literature on behaviour change theories was conducted. There are a number of theories that have been applied commonly to physical activity interventions, including those with ABI. These include Bandura's Social Cognitive Theory (SCT) (Bandura 1986) and the Transtheoretical Model (TTM) (Prochaska and Velicer 1997). A core construct of SCT is self-efficacy, obtained through means such as modelling and mastery. Improving physical activity self-efficacy is a core component of many physical activity interventions, including those for individuals with ABI (Jones, Harris et al. 2005, Driver 2006, Jones, Mandy et al. 2009, Driver, Irwin et al. 2012). The TTM includes self-efficacy as one of its core components but adds a temporal dimension with the stages of change. Stages of change have been used to tailor physical activity interventions based on an individual's readiness to change, with different processes of change being used for the more cognitive stages, as opposed to action based interventions for those further along the readiness scale (Marcus, Banspach et al. 1992, Marcus, Selby et al. 1992, Marcus and Simkin 1993, Morris, Oliver et al. 2012).

The Health Beliefs Model (HBM) is a third theoretical model commonly used to frame interventions that assist individuals to overcome barriers to physical activity and increase the perceived benefits from being more physically active (Becker 1974, Janz and Becker 1984, Kelly, Zyzanski et al. 1991), including those with ABI (Sullivan, White et al. 2008, Gill and Sullivan 2011). A fourth model is the Theory of Planned Behaviour and the Theory of Reasoned Action, which postulates that the intention to be physically active is determined by attitude, subjective norms and perceived behavioural control (Ajzen 1985, Blue 1995, Bartholomew, Parcel et al. 2011).

More recently, there has been emerging interest in the role of habits on a variety of health behaviours including physical activity. Previous attitude-oriented theories have neglected the role of habitual and automated responses in driving behaviour, rather than deliberate and reasoned decision making (Aarts, Verplanken et al. 1998, Eagleman 2011, Lally and Gardner 2013), with theories such as the Fogg Behavioral Model (FBM) (Fogg 2009, Fogg 2011) garnering interest.

Review of self-management programs on physical activity after ABI

Self-management programs have been shown to result in better long-term outcomes for people with chronic diseases, including programs for individuals with ABI, specifically following stroke (Barlow, Wright et al. 2002, Marks, Allegrante et al. 2005, Marks, Allegrante et al. 2005, Cadilhac, Hoffmann et al. 2011, de Silva 2011, Jones and Riazi 2011). Despite this, many people with ABI do not receive, and cannot access, self-management programs. In Australia, the 2014 National Stroke Audit of Rehabilitation Services reported that only 42% of stroke survivors were given any advice about risk factor modification before discharge from hospital, and only 34% were informed about self-management programs (National Stroke Foundation 2014).

Self-management programs are most successful when founded on theories and principles of behaviour change (de Silva 2011). Supporting self-management by empowering and activating people, primarily through developing skills such as problem-solving and decision-making, builds self-efficacy to alter long-term behaviours (Lorig and Holman 2003, de Silva 2011).

We conducted a systematic review examining the efficacy of self-management programs in improving physical activity in community-dwelling adults following ABI (Jones, Dean et al. 2015b). We found only five studies, of variable methodological quality, that met our inclusion criteria (Sit, Yip et al. 2007, Damush, Ofner et al. 2011, Gill and Sullivan 2011, Brenner, Braden et al. 2012, Kim and Kim 2013). Studies were widely heterogeneous with respect to program content and delivery characteristics, and outcomes, although all programs utilised behavioural change principles. Four of the five studies examined interventions in which physical activity was a component of a multifaceted intervention, where the depth to which physical activity specific content was covered, and the extent to which skills were taught and practiced, could not be clearly established (Sit, Yip et al. 2007, Damush, Ofner et al. 2011, Brenner, Braden et al. 2012, Kim and Kim 2013). Three studies showed favourable physical activity outcomes following self-management interventions for stroke, however risk of bias was high and overall efficacy remains unclear (Sit, Yip et al. 2007, Damush, Ofner et al. 2011, Kim and Kim 2013). Although not used in isolation from face-to-face delivery, remote delivery via telephone was the predominant form of delivery in two studies (Damush, Ofner et al. 2011, Kim and Kim 2013) with support for its inclusion in self-management programs for individuals following stroke (Jones, Dean et al. 2015b). This informed us that there is a clear information gap in this area.

Review of remotely delivered self-management programs

Delivery of self-management programs through remote delivery modes, such as the internet or telephone, is becoming increasingly popular. It is seen as a way of increasing accessibility to programs for those who face multiple barriers to accessing optimal health care (Lorig, Ritter et al. 2013), such as cost, mobility restrictions or service availability in rural or remote regions. Self-management programs delivered via the internet, including those developed and evaluated by members of this team (BFD, NT), have been shown to be successful in a variety of populations, such as chronic pain (Dear, Titov et al. 2013, Dear, Gandy et al. 2015), anxiety and depression (Titov, Andrews et al. 2010, Titov, Dear et al. 2013, Titov, Dear et al. 2014), post-traumatic stress disorder (Spence, Titov et al. 2011), arthritis (Lorig, Ritter et al. 2008), and cerebral palsy (Maher, Williams et al. 2010). A Cochrane review examining remote and web-based interventions physical activity has also highlighted the potential of remote delivery methods to change behaviour (Foster, Richards et al. 2013). Although not specifically examining self-management programs, the interventions included in this latter review did include behaviour change strategies commonly seen in self-management programs such as motivational interviewing, coaching, goal setting and self-monitoring. The most effective interventions were found to be those where a tailored approach to the type of physical activity was used and telephone contact to support change in physical activity behaviour was provided (Foster, Richards et al. 2013).

Survey of potential users

An online survey of 59 Australian adults with ABI was used to collect information about demographic characteristics, general health, emotional well-being, mobility and physical activity status, barriers to physical activity, confidence in overcoming barriers, and interest in a self-management program delivered remotely. Over half of those surveyed (58%) were not satisfied with their current physical activity status. The most frequently reported barriers were pain/discomfort, fatigue and fear. Confidence to overcome these barriers was very low. More than 74% of participants stated they would be interested in participating in an internet-delivered self-management program focused on physical activity (Jones, Dean et al. 2015c).

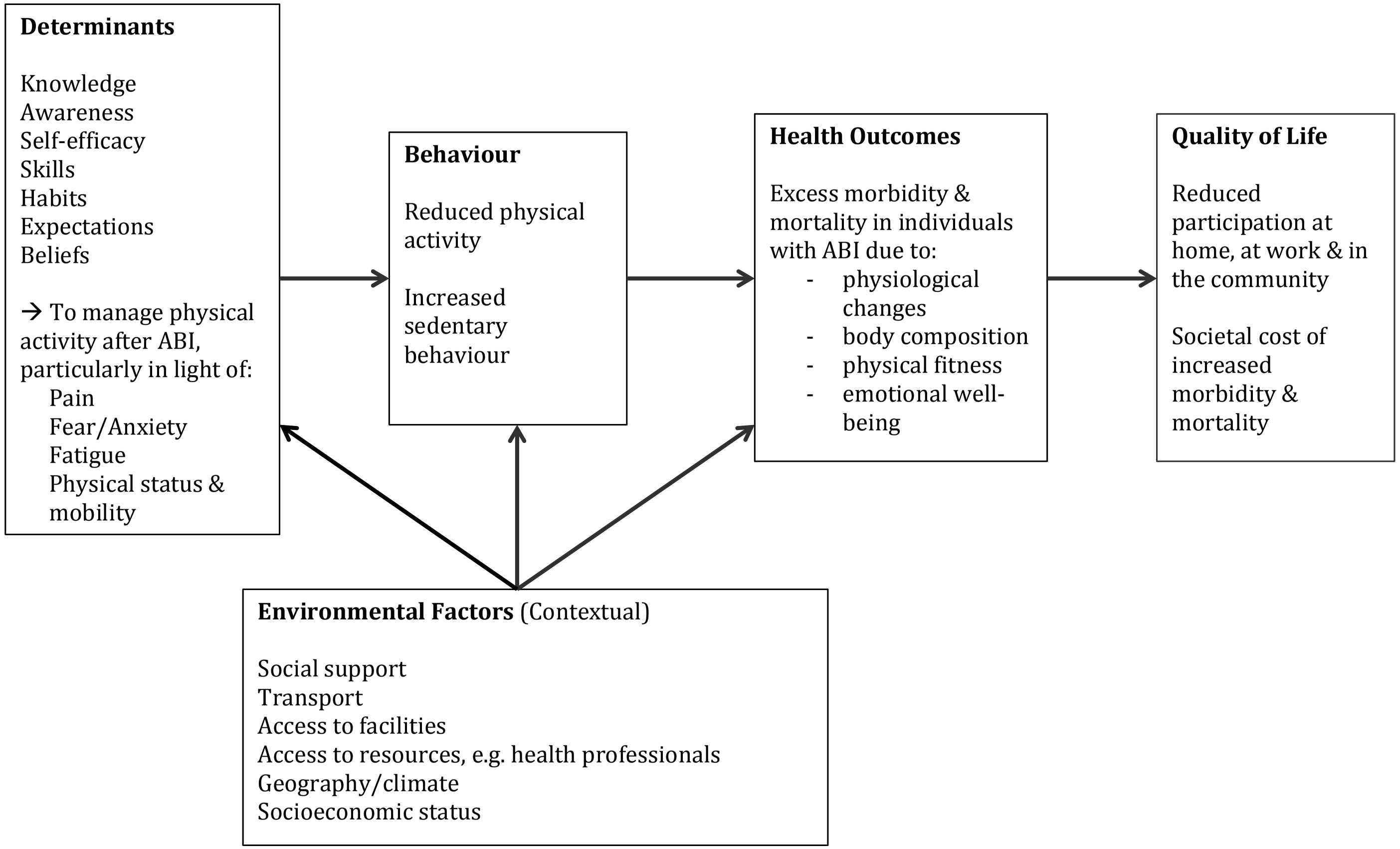
In summary, the needs assessment resulted in greater detail being obtained regarding the difficulties in obtaining sustained improvement in physical activity levels of individuals with ABI (Morris, Macgillivray et al. 2012, Moore, Hallsworth et al. 2013, Driver, Irwin et al. 2012); the shortage of programs available that target long-term promotion of physical activity in those with ABI (Pawlowski, Dixon-Ibarra et al. 2013, Cleveland, Driver et al. 2015); particularly those focusing on improving the self-management of physical activity after ABI (Jones, Dean et al. 2015b); and the importance of building self-management interventions, based on sound theories and principles of behaviour change (de Silva 2011), that improve long-term health outcomes for individuals with ABI (Jones, Dean et al. 2015b, de Silva 2011, Jones and Riazi 2011, Cadilhac, Hoffman et al. 2011). This needs assessment also demonstrated that there were promising results from self-management interventions that have been delivered remotely to individuals with ABI (Jones, Dean et al. 2015b). We established that individuals living in the community with ABI often face many barriers to physical activity, such as mobility impairments, transport difficulties, limited local specialist services, financial costs, concerns regarding safety when being active, and a lack of knowledge about how to be active after an ABI (Nicolson, Sniehotta et al. 2013, Driver, Ede et al. 2012, National Stroke Foundation 2007). Of particular concern to those individuals surveyed by our team was the need to be able to manage their pain and/or discomfort, manage their levels of fatigue, and manage the fear they experienced in regards to being more physically active (Jones, Dean et al. 2015c). There was also a desire by individuals with ABI to have access to a program specifically focused on physical activity, being delivered via remote modes, such as via the internet (Jones, Dean et al. 2015c).

Development of a problem-focused model for intervention development

Information gathered from the needs assessment was used to develop a problem-focused model to establish the behavioural and environmental causes of the health problem, and the key determinants of these causes (Bartholomew, Parcel et al.

2011). The key determinants were derived from all facets of the needs assessment by drawing on information derived from individuals with ABI, through both the survey study and the extensive examination of the literature relating to the experiences of individuals with ABI; and through the examination of the evidence related to underlying behavioural theories relating to physical activity. The results are outlined in Figure 4.2.

Figure 4.2: Determinants of behaviour based on needs assessment



Step 2: Identification of outcomes, performance objectives and change objectives

The purpose of Step 2 of the Intervention Mapping approach is to provide a detailed foundation upon which the intervention will be built by specifying exactly what will change as a result of the intervention (Bartholomew, Parcel et al. 2011). This is achieved by firstly establishing the program outcomes, which were identified as: (1) to increase physical activity, and (2) to reduce sedentary behaviour. These were chosen as they were the primary behaviours identified in Step 1 that were contributing to the poor health outcomes seen in this population. However, broad conceptualizations, such as *increasing physical activity*, do not provide sufficient detail on which to base an intervention. Therefore, the process involved working down from these overall program goals to identify the detailed objectives that would provide clarification upon which to build a complex intervention.

Performance objectives were identified next. These are specific objectives that would need to be performed by the individuals undergoing the intervention in order to achieve the program goals. These performance objectives are then mapped in a table against important and changeable determinants of behaviour, known as change objectives, using information gathered in Step 1. This process was undertaken through a process of knowledge attainment from Step 1, as well as brainstorming and discussion amongst the intervention development team. The result is a detailed matrix of change objectives – the specific actions that would need to occur in order to achieve the performance objectives and program goals (Bartholomew, Parcel et al. 2011), displayed in Table 4.1.

Table 4.1: Change matrix for increasing physical activity (PA) and reducing sedentary behaviour (SB)

Performance objectives	Determinants			
	Knowledge & awareness (KA)	**Skills & self-efficacy (SSE)**	**Outcome expectations & beliefs (OEB)**	**Habits (H)**
1. Participants recognise the importance of being physically active after ABI, and reducing SB				
1.1 Understand the benefits of PA after ABI	*KA1.11* Describe the benefits of PA	*SSE1.11* Express confidence in gaining benefits from PA	*OEB1.11* Expect to gain benefits from being PA *OEB1.12* Believe that participation in PA is safe and beneficial	
1.2 Understand the risks of reduced PA and increased SB	*KA1.21* Describe potential risks of low PA and high SB		*OEB1.21* Expect to reduce risks with increased PA	

2. Participants can build a physically active lifestyle			
2.1 Know the principles involved in PA program development	*KA2.11* Understand contribution of planned and incidental activities to total PA	*SSE2.11* Identify desired planned and incidental PA for own participation	*OEB2.11* Expect that benefits of PA can arise from both planned and incidental PA participation
	KA2.12 Understand FITT formula	*SSE2.12* Express confidence in application of FITT formula to planned and incidental PA	*OEB2.12* Expect that understanding the FITT formula is helpful in the development of a PA program
2.2 Gradually increase PA to desired level	*KA2.21* Understand concept of Scaling Up	*SSE2.21* Express confidence in application of Scaling Up to planned and incidental PA	*OEB2.21* Expect that Scaling Up can be useful in achieving desired PA levels

2.3 Identify and manage barriers to PA	*KA2.31* Describe types of common barriers to PA	*SSE2.31* Be able to confidently identify individual barriers to PA *SSE2.32* Be able to confidently use problem-solving & planning to manage barriers to PA	*OEB2.31* Expect that barriers to PA can be identified and managed with problem-solving and planning skills	*H2.31* Develop routines that assist in managing barriers to PA
2.4 Hold realistic expectations about PA levels	*KA2.41* Describe the difference between realistic expectations, positive thinking and goal setting	*SSE2.41* Be able to confidently recognise and challenge unrealistic expectations	*OEB2.41* Believe that realistic expectations will enhance physical and emotional well-being	
2.5 Develop individually tailored goals	*KA2.51* Understand the role of goal setting in returning to or maintaining different areas of life.	*SSE2.51* Express confidence in setting short & long term goals	*OEB 2.51* Expect that goals can be achieved	*H2.51* Develop habits that enhance success of PA goals

3. Participants can maintain a physically active lifestyle				
3.1 Understand how to manage PA levels over the long term	*KA3.11* Describe the importance of pacing, scaling up and scaling down in managing long-term PA levels.	*SSE3.11* Express confidence in implementing pacing, scaling up and scaling down strategies.	*OEB3.11* Expect that the application of pacing will assist in managing pain and fatigue. *OEB3.12* Expect that scaling up and scaling down can result in greater control of PA over the long-term	*H3.11* Develop habits that maintain PA levels despite fluctuations in motivation
3.2 Identify and manage new barriers to physical activity	*KA3.21* Demonstrate awareness of barriers changing over time	*SSE3.21* Express confidence in identifying new barriers to PA and using problem-solving & planning to manage these	*OEB3.21* Expect that new barriers to PA can be identified and managed with problem-solving and planning skills	*H3.21* Develop routines that assist in identifying new barriers and in managing these

3.3 Implement habits to enhance physical activity over the long-term	*KA3.31* Describe how habits can assist in maintaining long term PA	*SSE3.31* Express confidence in building new habits	*OEB3.31* Expect that habits can enhance PA	*H3.31* Develop habits that enhance PA despite fluctuations in motivation
3.4 Manage lapses in physical activity levels	*KA3.41* Understand common causes for lapses in PA.	*SSE3.41* Express confidence in identifying lapses in PA *SSE3.42* Express confidence in developing and implementing a Relapse Prevention Plan	*OEB3.41* Expect that lapses in PA are normal. *OEB3.42* Expect that lapses in PA do not have to lead to a relapse to a sedentary lifestyle. *OEB3.43* Expect that a Relapse Prevention Plan can manage a PA lapse and guide a return to desired PA levels	*H3.41* Develop habits that mediate the effects of PA lapses.

Step 3: Selection of theory-based intervention methods and practical applications

Step 3 of the Intervention Mapping approach involves identification of relevant theoretical methods that can contribute to achieving behaviour change objectives, and the practical applications that can operationalize these methods (Bartholomew, Parcel et al. 2011). Theoretical methods are defined by the authors of Intervention Mapping to be general techniques or processes for influencing changes in the determinants of behaviours, while practical applications are specific techniques for administering these methods (Bartholomew, Parcel et al. 2011). Therefore, Step 3 provides clear information on how the intervention developers actually expect to cause changes in behaviour with all program components accounted for in this way (Bartholomew, Parcel et al. 2011).

When developing complex interventions it is encouraged that developers break away from the traditional approach of using a single theory, and instead use a variety of theories that consider the complexity of behaviour change. Drawing on multiple theories, allows for different methods to be applied to different aspects of a complex intervention, such as increasing knowledge and awareness, building self-efficacy and establishing new physical activity habits (Bartholomew, Parcel et al. 2011). Therefore, constructs from multiple models of behaviour change have been drawn upon in establishing the theoretical models in Step 3.

In order to ensure all change objectives are covered in this process a new matrix table was generated, focusing on the key determinants of behaviour as the primary organising factors. Appropriate theoretical methods were identified to meet these determinants and change objectives. Practical applications were identified through brainstorming, discussion and creative thinking amongst the intervention development team, developing a range of applications that fit the context and characteristics of program participants (Bartholomew, Parcel et al. 2011). An example of a portion of the matrix table for Step 3 in the myMoves development is shown in Table 4.2, with the full version available in Appendix 3.

Table 4.2: Example of methods and applications for change objectives

Determinants & Change Objectives	Methods	Applications
Knowledge & awareness (KA)		
KA2.11 Understand contribution of planned and incidental activities to total PA *KA2.12* Understand FITT formula *KA2.21* Understand concept of Scaling Up *KA3.11* Describe the importance of pacing, scaling up and scaling down in managing long-term physical activity (PA) levels	Chunking Advance organizers Providing cues Modelling	Detailed concepts are broken into smaller steps with keywords and schematic representations. Course is structured clearly around the *Active Lifestyle Model.* Model is carried through the program with each Lesson showing progress through the model schematically. Keywords are kept consistent throughout course. Keywords are designed for translation into everyday life. Stories demonstrate individuals gaining an understanding and awareness of new information gradually. Stories and examples include individuals having difficulty at times with understanding difficult concepts to maximise effect of modelling.

Step 4: Organisation of methods and applications into an intervention program

Step 4 of the Intervention Mapping approach involves the creative development of the actual intervention program components and materials that are to be delivered to participants. The focus of this step was on the successful translation of the methods and applications outlined in Step 3 in order to achieve the objectives identified in Step 2 (Bartholomew, Parcel et al. 2011). This development process consisted of the following steps:

1. *Creation of a framework for the program*

The framework of the myMoves program was developed through brainstorming sessions within the myMoves team, and refined to ensure it reflected the change objectives outlined in Step 2. These sessions identified four core areas that reflected both the needs of the population as identified in Step 1, and the theoretical methods for underpinning behaviour change, as identified in Step 3. These core areas were: (1) being able to understand and manage physical activity levels; 2) identify and manage barriers to physical activity; (3) identify and challenge any unrealistic expectations held by individuals regarding their level of physical activity; and (4) to be able to build and sustain habits that support physical activity.

Managing activity levels was chosen primarily for the purpose of building physical activity knowledge and awareness, deemed to be a problem in the needs assessment. The FITT (frequency, intensity, time, type) principle, used to identify the components of a physical activity, recommended for individuals with ABI

(Billinger, Boyne et al. 2014), could be introduced here early in the program as a foundation method of establishing and progressing a physical activity program. Managing barriers was chosen as the second core area as the needs assessment established that individuals with ABI report significant barriers to physical activity, thereby requiring the skills to identify, problem-solve and plan in order to manage these barriers. Managing expectations was chosen as a third area as individuals with ABI are experiencing fear, fatigue and pain in relation to physical activity, and are at risk of depression and anxiety. These issues would be the core focus of the skills taught within this area of the program. Finally, managing habits was chosen as a way of introducing skills to normalise physical activity as a part of everyday life, reducing the need for sustaining high levels of motivation. In addition, these four core areas were also chosen as they were deemed to be easy for participants to identify and understand, giving the program simplicity as well as structure.

From these core areas a model was constructed, *The Active Lifestyle Model* shown in Figure 4.3, to provide a visual framework to participants upon which the different aspects of the program could be laid.

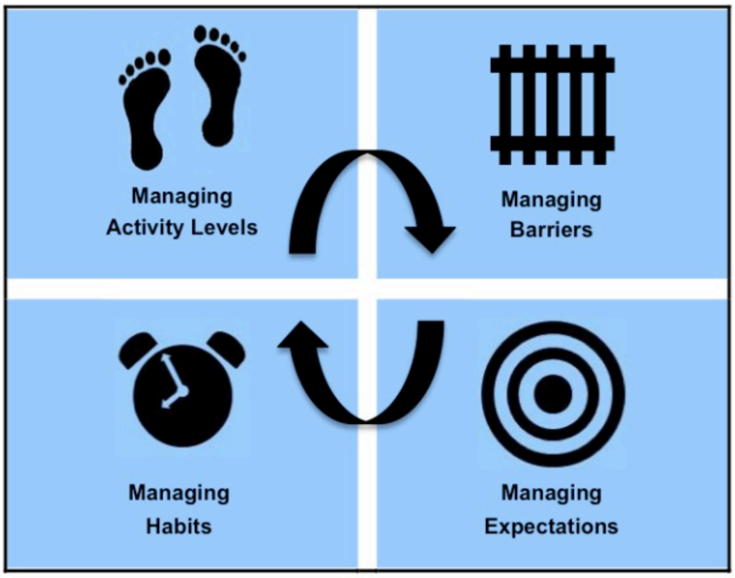


Figure 4.3: The Active Lifestyle Model

2. Identification of the program's scope, sequence and delivery modes

Planning meetings with the team included discussion regarding the program's scope, sequence and delivery modes. Information gained from Step 1 of the Intervention Mapping process, as well as experience of the myMoves team members, namely Dr Dear and Prof Titov, who have successfully developed and tested remote delivery of self-management programs for a variety of mental health conditions and chronic pain (Titov, Andrews et al. 2010, Spence, Titov et al. 2011, Dear, Titov et al. 2013, Titov, Dear et al. 2013, Titov, Dear et al. 2014), informed the decision to provide 6 core Lessons spread over 8 weeks. The sequence of the myMoves program was established through these brainstorming and team planning sessions, with earlier materials providing foundation level information and skills upon which later materials could build. A summary of the programs scope and sequence is shown in Table 4.3.

Table 4.3: myMoves program outline

Timing	Content	Activities	Change objectives addressed	Methods utilised
Week 1	Lesson 1: An Introduction Introductory lesson discussing the importance of physical activity after ABI, common difficulties people with ABI face and addressing any concerns regarding safety. The Active Lifestyle Model is introduced. Concept of planned and incidental physical activity is discussed. The Stories: Chapter 1 Six characters with ABI are introduced, each unique in regards to their current status and experiences. Characters discuss their ABI history and outline the challenges they are facing in becoming more physically active. Participants may identify with one or many of these characters and are encouraged to draw ideas and inspiration from each of them.	DIY Worksheet 1 Activities include: 1. Identification of current difficulties the participant is facing using the Active Lifestyle Model as a framework. 2. Identification of 1 planned and 2 incidental activities to work on over the course.	*KA1.11* Describe the benefits of PA *KA1.21* Describe potential risks of low PA and high SB *KA2.11* Understand contribution of planned and incidental activities to total PA *SSE1.11* Express confidence in gaining benefits from PA *SSE2.11* Identify desired planned and incidental PA for own participation *OEB1.11* Expect to gain benefits from being PA *OEB1.12* Believe that participation in PA is safe and beneficial *OEB1.21* Expect to reduce risks with increased PA *OEB2.11* Expect that benefits of PA can arise from both planned and incidental PA participation	Consciousness raising Persuasive communication Tailoring Chunking Advance organizers Individualization Providing cues Modelling Participation

Week 2	Lesson 2: Managing Activity Levels Introduces the concept of the FITT formula with discussion about it's application to physical activity. Under-Doing or Over-Doing physical activity is discussed with participants encouraged to identify which unhelpful behaviour they tend to use. Strategies of Scaling Up and Pacing are covered with a focus on the management of pain and fatigue. The strategy of Scaling Down is also discussed with examples of appropriate application. The Stories: Chapter 2 Characters discuss their application of Scaling Up and Pacing strategies with varying levels of mastery and success.	DIY Worksheet 2 Activities include: 1. Identification of current strategy (Under-Doing/Over-Doing) and new strategy (Scaling Up/Pacing) for each chosen activity from Week 1. 2. Completion of strategy worksheet (Scaling Up or Pacing) for each chosen activity.	*KA2.11* Understand contribution of planned and incidental activities to total PA *KA2.12* Understand FITT formula *KA2.21* Understand concept of Scaling Up *KA3.11* Describe the importance of pacing, scaling up and scaling down in managing long-term PA levels *SSE2.12* Express confidence in application of FITT formula to planned and incidental PA *SSE2.21* Express confidence in application of Scaling Up to planned and incidental PA *SSE3.11* Express confidence in implementing Pacing, Scaling Up and Scaling Down strategies. *OEB2.12* Expect that understanding the FITT formula is helpful in the development of a PA program *OEB2.21* Expect that Scaling Up can be useful in achieving desired PA levels *OEB3.11* Expect that the application of pacing will assist in managing pain and fatigue. *OEB3.12* Expect that scaling up and scaling down can result in greater control of PA over the long-term	Chunking Persuasive communication Advance organizers Providing cues Modelling Active Learning Guided practice Set tasks on a gradient of difficulty Participation Mastery

Week 3	Lesson 3: Managing Barriers The concept of barriers to physical activity is discussed. The Fogg Behavioral Model is used as a framework to assist participants to identify barriers that affect motivation and those that affect ability. The skills of problem-solving, planning and scheduling are discussed. The Stories: Chapter 3 Characters discuss the barriers to physical activity that they experience, and different strategies they have used to manage them using the skills of problem-solving and planning.	DIY Worksheet 3 Activities include: 1. Completion of Barrier Identification Worksheet to identify current barriers affecting motivation and ability based on Fogg Behavioral Model for each chosen activity 2. Completion of Barrier Problem-Solving Worksheet for each chosen activity 3. Completion of Weekly Planner	*KA2.31* Describe types of common barriers to PA *KA3.21* Demonstrate awareness of barriers changing over time *SSE2.31* Be able to confidently identify individual barriers to PA *SSE2.32* Be able to confidently use problem-solving & planning to manage barriers to PA *SSE3.21* Express confidence in identifying new barriers to PA and using problem-solving & planning to manage these *OEB2.31* Expect that barriers to PA can be identified and managed with problem-solving and planning skills *OEB3.21* Expect that new barriers to PA can be identified and managed with problem-solving and planning skills *H2.31* Develop routines that assist in managing barriers to PA *H3.21* Develop routines that assist in identifying new barriers and in managing these	Consciousness raising Tailoring Chunking Modelling Individualisation Active Learning Guided practice Participation Mastery

Week 4	Lesson 4: Managing Expectations Participants are introduced to the concept of expectations and what can contribute to shaping these expectations. The concept of High and Low Expecttations are introduced, as is the skill of challenging unrealistic expectations. Realistic expectations are compared to positive thinking and goal setting to demonstrate the differences between these concepts. The Stories: Chapter 4 Characters outline the difficulties they have had in managing their expectations. Some characters identify difficulties with expectations that are too high, and others with those that are too low. The different characters demonstrate the application of the skill of challenging these unrealistic expectations with differing levels of mastery.	DIY Worksheet 4 Activities include: 1. Identification of any unrealistic expectations for each chosen activity 2. Completion of a Challenging Expectations Worksheet for any identified unrealistic expectations	*KA2.41* Describe the difference between realistic expectations, positive thinking and goal setting *KA2.51* Understand the role of goal setting in returning to or maintaining different areas of life. *SSE2.41* Be able to confidently recognise and challenge unrealistic expectations *OEB2.41* Believe that realistic expectations will enhance physical and emotional well-being	Consciousness raising Modelling Individualisation Active Learning Guided practice Improving physical and emotional states Belief selection Participation Mastery

Week 5	Lesson 5: Managing Habits The concept of habits is introduced and why habits are useful is discussed, in comparison to the difficulties of making difficult decisions. The concept of the motivation wave is introduced to demonstrate how motivation can fluctuate naturally, with different strategies for times of high and of low motivation discussed. The skill of building habits using the formula of Cue, Activity, Reward is introduced with discussion on finding the right cue, making activities small and easy to enhance habit development, and celebrating successes with either internal or external rewards, with a focus on internal as preferable. The Stories: Chapter 5 Characters discuss their experiences in forming new habits and how this has influenced their levels of physical activity in different ways.	DIY Worksheet 5 Activities include: 1. Identification of appropriate cues and rewards for the desired behaviour, as well as a way of making the activity small and easy 2. Construction of new 'habit formulas' for 1-3 chosen activities for development into habits.	*KA3.31* Describe how habits can assist in maintaining long term PA *SSE3.31* Express confidence in building new habits *OEB3.31* Expect that habits can enhance PA *H2.31* Develop routines that assist in managing barriers to PA *H2.51* Develop habits that enhance success of PA goals *H3.11* Develop habits that maintain PA levels despite fluctuations in motivation *H3.21* Develop routines that assist in identifying new barriers and in managing these *H3.31* Develop habits that enhance PA despite fluctuations in motivation *H3.41* Develop habits that mediate the effects of PA lapses.	Consciousness raising Modelling Implementation Intentions Active Learning Guided practice Cue altering Set tasks on a gradient of difficulty Stimulus control Early commitment Participation Mastery
Week 6	Consolidation Week Participants are encouraged to continue to read through the materials covered in the course and consolidate their learning.	Consolidation Participants are encouraged to continue to practice the skills taught in the course to		Mastery

Week 7	Lesson 6: Keeping it Going The concept of a Lapse in physical activity is introduced and normalised, and shown to be different to a more substantial Relapse to a sedentary lifestyle. The skill of creating a Relapse Prevention Plan is discussed. Goal setting is introduced with the steps of goal setting outlined. The Lesson ends with tips for ongoing improvement and continued behaviour change. The Stories: Chapter 6 Characters discuss their experiences with lapses in their activity levels for different reasons and their subsequent strategies to prevent a substantial relapse. They discuss their goals and plans for the future with ongoing practice of skills and strategies learnt during the course.	DIY Worksheet 6 Activities include: 1. Completion of a Relapse Prevention Plan 2. Completion of a Goal Setting Worksheet	*KA3.41* Understand common causes for lapses in PA. *SSE2.51* Express confidence in setting short & long term goals *SSE3.41* Express confidence in identifying lapses in PA *SSE3.42* Express confidence in developing and implementing a Relapse Prevention Plan *OEB 2.51* Expect that goals can be achieved *OEB3.41* Expect that lapses in PA are normal *OEB3.42* Expect that lapses in PA do not have to lead to a relapse to a sedentary lifestyle. *OEB3.43* Expect that a Relapse Prevention Plan can manage a PA lapse and guide a return to desired PA levels *H2.51* Develop habits that enhance success of PA goals *H3.41* Develop habits that mediate the effects of PA lapses	Consciousness raising Tailoring Modelling Participation Goal setting Individualisation Implementation intentions Planning coping responses Cue altering Stimulus control Early commitment Guided practice Belief selection Mastery
Week 8	Consolidation Week Participants are encouraged to continue to read through the materials covered in the course and consolidate their learning.	Consolidation Participants are encouraged to continue to practice the skills taught in the course to date.		Mastery

The mode of program delivery was decided early in the planning process as myMoves was designed specifically for remote delivery. However, during Step 4, more detailed discussion and planning was undertaken regarding the exact delivery of program materials, and the way participants were to be contacted during the intervention process. This was done in light of both the change objectives outlined in Step 3 and the resources available in terms of budget and time required by program implementers to actually to deliver the intervention effectively. It was decided that all materials would be developed in portable document format (PDF) and delivered via email for initial feasibility testing of the program. All contact with participants was done via email and/or telephone, based on the preferences of the participants. Each participant received an email at the start of each week with materials needed for that week, including their Lesson, Stories, and Worksheet. Each participant would then be contacted at least one additional time later in the week to ensure the program materials were understood, and to clarify any issues. This also allowed the myMoves team to assist participants in tailoring the intervention to their specific situation.

3. Design and development of program materials

The design and development phase of the program materials lasted more than 12 months. For each Lesson a proposed structure was developed, and details were then written and edited until all team members were satisfied that the content met the change objectives outlined for that Lesson. The Stories were designed to reflect the content of each Lesson, and to assist in participants putting the materials into context through modelling of the core knowledge and skills. Each

Worksheet was developed to build participant skills and self-efficacy and enable individual customization of the program. Samples of the myMoves program materials, including excerpts from a Lesson, profiles of the cases portrayed in the Stories, an excerpt from a chapter of the Stories and an example of a Worksheet are located in Appendix 4.

The aesthetics of the materials was created and refined over the development phase through lengthy team discussions. The aesthetics of the program were seen as very important in delivering the right balance to reflect reassurance and professionalism whilst also being uplifting and inspiring. All additions to the program text, such as graphs and charts, were carefully designed to ensure consistency across all materials, and to maximize the translational impact of messages and skills. All images were carefully selected to portray the relevant emotion for each message to maximize engagement at all times.

4. *Revision of draft materials into the final product*

Each member of the myMoves team revised draft materials iteratively. Once this process was completed, the materials were then given to five lay people, who provided feedback from which materials were revised to form the final intervention program to be used in the initial testing phase.

Step 5: Creation of an implementation plan

The purpose of this step was to ensure that, during the development of the program, there was consideration of how the program could be adopted, implemented and sustained over time (Bartholomew, Parcel et al. 2011). Consideration of the pragmatics of the intervention are paramount to ensuring it will be translated into practice if effective (Glasgow 2013). Because of the novelty of this program, the focus of this step was to plan for the initial testing of the program's feasibility and acceptability. This has included:

1. Identification and liaison with potential program adopters

Program adopters include not only potential participants, but also organisations that have access to potential participants (Bartholomew, Parcel et al. 2011). This included the National Stroke Foundation, Brain Injury Australia, The NSW Stroke Recovery Association, Brain Injury NSW and other organisations working with individuals with ABI in Australia. These organisations are able to reach potential participants through social media sites, websites, email and print materials. Potential participants could also be reached directly through email, social media and word of mouth.

2. Development of a website to assist in the adoption and implementation of the intervention

A website was designed and developed to provide both a source of information about the myMoves program and a point of contact with myMoves team members (Appendix 5). It was also designed to provide an application platform for potential participants who can then be contacted by a member of the myMoves team. This was done by liaison with relevant technical support staff at Macquarie University.

3. Planning for program implementation and sustainability

Implementation for initial testing was planned as being provided predominantly by one member of the myMoves team (TJ), an experienced physiotherapist. An implementation support plan was built to ensure additional support, both by experienced physiotherapists and/or psychologists could be provided as needed. A plan was designed to ensure information regarding implementation requirements would be collected at the time of initial testing to inform a more detailed implementation plan, to ensure program implementation and sustainability requirements were met.

Step 6: Generation of an evaluation plan

The purpose of Step 6 of the Intervention Mapping approach is to ensure that the evaluation plan answers the question of whether the intervention is successful in achieving its goals and objectives (Bartholomew, Parcel et al. 2011). However, as the myMoves program is a new intervention, the initial evaluation plan was focused on assessing the programs feasibility and acceptability. This included assessment of the feasibility of the intervention itself, as well as the feasibility of assessing physical activity remotely. This will ensure that ongoing evaluation plans incorporate measures that are pragmatic and feasible to collect in busy, real-world settings (Glasgow 2013). Therefore an evaluation plan was developed that incorporated different methods of assessment. These included objective physical activity monitoring, questionnaire based measures and telephone interviews. To ensure effective objective physical activity monitoring could occur we posted activPAL™ and Actigraph GT3XE monitors to participants. An *Activity Monitor Guide* (Appendix 6) package was designed for participants that included clear and concise information on how to apply and care for the monitors during the evaluation periods. Questionnaire-based measures were evaluated using *Qualtrics* software, enabling distribution and digital data collection via the internet. Separate *Qualtrics* surveys were designed for analysis of course satisfaction and acceptability; and for questionnaires analysing program objectives.

The evaluation plan included the timing of measures for the initial testing phase, with measurements taken in the week immediately prior to commencing the intervention program, the week immediately after completing the final week of the program, and three months after completion of the intervention program. Each physical activity monitoring phase spanned 7 days, with telephone interviews conducted twice during each of these weeks. Evaluation of program satisfaction and acceptability was undertaken in the immediate post-program evaluation period. The feasibility of the different forms of program evaluation informed a detailed evaluation plan for further efficacy testing of the program.

4.3.4 Discussion

Intervention Mapping is a useful framework that can be applied to the development of complex physical therapy interventions, such as those aimed at supporting the self-management of physical activity. This framework guides intervention developers through a scholarly and systematic process that considers fully both the theoretical foundations upon which to build an intervention, as well as the practical aspects of the intervention, which is more likely to lead to translational of the intervention from a developmental and research space to a real-world setting (Craig, Dieppe et al. 2008, Bartholomew, Parcel et al. 2011, Glasgow 2013).

Often physical therapy interventions are developed and tested for efficacy without consideration of the steps outlined in the Intervention Mapping approach (Campbell, Fitzpatrick et al. 2000, Craig, Dieppe et al. 2008, Bartholomew, Parcel et al. 2011). However, the full evaluation of efficacy cannot occur without adequate transparency of the developmental process. If an intervention is found to be ineffective, we cannot be sure as to whether this is a fault in the process of development, which with improvement or alteration may alter the outcomes. Examination of the results of each step of the Intervention Mapping process could aid in more thorough reflection on the efficacy of an intervention. For example, if an intervention is found to be ineffective or only provides a mild-moderate level of efficacy, a thorough review of the outcomes of each step of the developmental process could assist in highlighting areas where improvement or alteration may alter the outcomes (Bartholomew, Parcel et al. 2011). Additionally, without adequate consideration of an implementation plan, we cannot be confident that the program will be adopted, implemented and sustained in the future (Bartholomew, Parcel et al. 2011, Glasgow 2013). Efficacy of an intervention may be established, but may never be adopted or implemented successfully in the future, or may require extensive resources that prevent sustainability (Glasgow 2013). The process of Intervention Mapping encourages a problem-driven approach to develop ‘real-world’ solutions that are backed by theory and empirical evidence (Bartholomew, Parcel et al. 2011, Glasgow 2013).

Intervention Mapping also offers potential benefits to those beyond the development team. It can provide a scholarly framework that clearly articulates the developmental process to others, therefore allowing for more transparency in the design and evaluation of these interventions (Bartholomew, Parcel et al. 2011). This may aid clinicians in assessing the suitability of an intervention to their specific setting and/or population, or in assessing what changes may need to occur to the intervention in order to enhance its suitability. When adapting evidence-based programs to new settings and/or populations there may be a requirement to make changes to the practical application, delivery strategies or cultural elements of the program, whilst identifying and retaining the essential elements of the original program that are important for efficacy (Bartholomew, Parcel et al. 2011). Dissemination of greater detail regarding the development of complex interventions offers clinicians more information on which to base their decisions regarding the implementation of these interventions.

The Intervention Mapping approach is not meant to be a recipe that is simply repeated in the same manner for each new intervention. Rather it is a framework, within which each step allows for adaptation to the differing requirements of the specific population, setting and nature of the intervention (Bartholomew, Parcel et al. 2011, Bartholomew, Parcel et al. 1998). When conducted in full, developing an intervention using Intervention Mapping can be a lengthy process. It requires health professionals to expand their skills in understanding the importance of the underlying theoretical foundations for the interventions, in more fully considering the pragmatics involved in implementing the intervention, and in the creative process involved with developing a complex intervention in a manner that is simple for stakeholders to engage with. However, physical therapy interventions often necessitate complexity due to the nature of the populations and settings within which we operate, and the behaviours we are aiming to influence. We also operate in a diverse range of settings, which may require flexibility in our interventions are applied (Craig, Dieppe et al. 2008). Therefore, in designing interventions that are effective for the individuals with whom we work and in the different setting within where we work, it is important that we give significant consideration to the developmental process or we may risk producing interventions that are either ineffective, or are not translatable to real-world settings (Craig, Dieppe et al. 2008, Bartholomew, Parcel et al. 2011, Bartholomew, Parcel et al. 1998). Intervention Mapping is a framework with which physical therapists and other health professionals can utilize a problem-driven approach to the development of real-world solutions that are backed by theory and empirical evidence (Bartholomew, Parcel et al. 2011).

Intervention Mapping is not the only framework that is available to aid in the development and/or evaluation of complex health interventions. There are other models, such as the Behaviour Change Wheel (Michie, van Stralen et al 2011); the multiphase optimization strategy, or MOST as it is known (Collins, Murphy et al. 2005); and the RE-AIM evaluation model, examining the reach, efficacy, adoption, implementation and maintenance of complex health interventions (Glasgow, Vogt et al. 1999). We chose Intervention Mapping as it was developed through experience in designing self-management interventions, which was similar to the intervention we were aiming to develop, and it offered a framework with which was constructed from experience in the development of self-management programs, considered both the theoretical and pragmatic aspects of the intervention, and allowed for continued development of the intervention in an iterative manner (Bartholomew, Parcel et al. 2011). We believe it offers a useful framework to physical therapists considering the development of a complex physical therapy intervention. However, it is important that developers consider a framework that best suits their needs (Craig, Dieppe et al. 2008).

The myMoves program development described in this paper is yet to be tested for efficacy, but is an example of how the Intervention Mapping process can be applied to the development of a new physical therapy intervention. However, it is important to emphasize the iterative nature of the Intervention Mapping process. One limitation in the initial developmental process is the limited input from stakeholders, particularly the individuals with ABI themselves. Although a survey study was conducted as part of the needs assessment, health professionals predominantly conducted the development of the myMoves program. Further engagement of stakeholders in ongoing iterations of the myMoves program will be important in continuing to enhance the development, and evaluation of the myMoves program (Boger, Ellis et al. 2015, Ellis, Boger et al. 2015, Drum, Peterson et al. 2009). In order to facilitate this process, the initial testing of the myMoves program involves gaining both quantitative and qualitative feedback from participants that can be used to improve future iterations of the program.

4.3.5 Conclusion

Physical therapists can apply Intervention Mapping to the development of complex interventions to ensure that the development of such interventions is systematic and rigorous, enabling confidence in the results of efficacy testing and transparency in their translation.

CHAPTER 5

Study IV – Feasibility and acceptability of a remotely delivered self-management program targeting physical activity after acquired brain injury

5.1 Preface

The Chapter presents the findings of a study conducted to test the feasibility and acceptability of the myMoves program, a remotely delivered self-management program focussed specifically on improving physical activity, to individuals with ABI living in the Australian community. Methods and detailed results are presented for both primary outcomes of feasibility and acceptability; as well as secondary outcomes of objective physical activity and sedentary behaviour, physical activity self-efficacy, psychological distress and participation.

A paper based on this Chapter has been submitted for consideration for publication to *Physical Therapy* and is currently under review:

Jones T. M., Dear B. F., Hush J. M., Titov N. and Dean C. M. (under review). " The myMoves Program: A feasibility trial of a remotely delivered self-management program for increasing physical activity among community-dwelling adults with acquired brain injury." *Physical Therapy* (submitted 13 September 2015).

5.2 Co-authors' statement

DEPARTMENT OF HEALTH PROFESSIONS | DISCIPLINE OF PHYSIOTHERAPY
Faculty of Medicine and Health Sciences

MACQUARIE University

Co-authors' Statement

As co-authors' of the paper, *The myMoves Program: A feasibility and acceptability trial of a remotely delivered self-management program for increasing physical activity among community-dwelling adults with acquired brain injury*, we confirm that Taryn Jones has made the following contributions to this study:

- Conception and design of the research
- Collection and extraction of data
- Analysis and interpretation of the findings
- Drafting and revising of the manuscript
- Critical appraisal of the content

Professor Catherine Dean: .... Date: 14·09·15

Associate Professor Julia Hush: .... Date: 14·09·15

Dr Blake Dear: .... Date: 14.09.15

Professor Nickolai Titov: .... Date: 14.09.15

Ethical approval for this study was provided by the Macquarie University Human Research Ethics Committee (Medical Sciences) and is provided in Appendix 7.

5.3 The myMoves Program: A feasibility and acceptability trial of a remotely delivered self-management program to increase physical activity in community-dwelling adults with acquired brain injury

5.3.1 Abstract

Background

Individuals living with acquired brain injury (ABI) are more likely to be physically inactive and highly sedentary, which increases their risk of morbidity and mortality. However, many adults with ABI experience barriers to participation in effective physical activity interventions. Remotely delivered self-management programs focussed on teaching patients how to improve and maintain their physical activity levels have the potential to improve the overall health of adults with ABI.

Objective

To explore the acceptability and feasibility of a remotely delivered self-management program aimed at increasing physical activity and reducing sedentary behaviour among community dwelling adults with ABI.

Methods

The myMoves program comprises 6 modules delivered over 8 weeks via email. Participants were provided with regular weekly contact with an experienced physiotherapist via email and telephone. Outcomes were assessed using online questionnaires and physical activity monitors. Data were collected prior to program commencement, immediately post-program and 3-months later (follow-up). The primary outcomes were feasibility (adherence, attrition, clinician time, accessibility and adverse events) and acceptability (satisfaction, worthiness of time and recommendation) of the myMoves program.

Results

Twenty-four participants commenced the program, with outcomes collected from 23 and 22 participants post-program and 3-months follow-up, respectively. The program required very little clinician contact time with an average of 32.8 minutes (SD 22.8) per participant. Acceptability was very high, with more than 95% being either *very satisfied* or *satisfied* with the myMoves program and stating that it was worth their time. All participants stated they would recommend the program to others with ABI.

Conclusion

A remotely delivered self-management program aimed at increasing physical activity is feasible and acceptable for adults with ABI. Thus, further large-scale efficacy trials are warranted.

5.3.2 Introduction

Acquired brain injury (ABI) is a significant public health issue globally. ABI refers to any damage to the brain that has occurred after birth, with the most common causes being stroke and trauma (O'Rance 2007). Globally, there are an estimated 9 million new stroke survivors per year (Wolfe 2000) resulting in an estimated loss of 49 million disability-adjusted life years (DALYs) annually (World Health Organization 2006). Traumatic brain injury (TBI) is the leading cause of disability in people under the age of 40 years globally (World Health Organization 2006), with approximately 5.3 million people in America and 7.7 million people in Europe living with a TBI-related disability (Roozenbeek, Maas et al. 2013).

Disability following ABI is often complex (O'Rance 2007), and levels of physical activity following ABI are typically low. Over half of those with stroke do not reach the recommended physical activity levels for optimal health and wellbeing (Rand, Eng et al. 2009, Hornnes, Larsen et al. 2010), and individuals 3 years post-stroke spend an average of 73% (range 31-100%) of their day sitting or lying (Kunkel, Fitton et al. 2015). Following TBI individuals spend less than 50 minutes per week being physically active (Driver 2008, Driver, Ede et al. 2012). This increases the risk of these individuals experiencing chronic disease or death (Blair, Kampert et al. 1996, Lee and Skerrett 2001, Macera and Powell 2001, Warburton, Nicol et al. 2006, Haskell, Blair et al. 2009, World Health Organization 2010, Gulsvik, Thelle et al. 2012). In comparison to age-matched populations, individuals with ABI overall have reduced health and wellness (Braden, Cuthbert et al. 2012), are at higher risk of a future stroke (Hardie, Hankey et al. 2004, Gall, Dewey et al. 2009, Chen, Kang et al. 2011) and other chronic diseases (O'Rance 2007), and have a mortality risk twice that of the normal population (Hardie, Hankey et al. 2003, Anderson, Carter et al. 2004).

Individuals with ABI can experience the same benefits of physical activity as their healthy counterparts (Gordon, Gulanick et al. 2004), and increasing self-management of physical activity can reduce the risk of further morbidity and mortality (World Health Organization 2005). However individuals with ABI face many barriers to increasing physical activity levels (Driver, Ede et al. 2012, Nicholson, Sniehotta et al. 2013, Jones, Dean et al. 2015c). Accessing services aimed at increasing physical activity is made difficult by transportation limitations, mobility limitations, and time restrictions (Driver, Ede et al. 2012, Nicholson, Sniehotta et al. 2013). Managing physical activity is also made difficult by ongoing pain, fatigue and fear (Jones, Dean et al. 2015c). Despite this, ABI is often a lower priority for research and services than many other conditions (Thrift, Cadilhac et al. 2014) and there is a significant lack of physical activity promotion programs targeting those with ABI (Pawlowski, Dixon-Ibarra et al. 2013, Cleveland, Driver et al. 2015).

The potential of remotely delivered physical activity interventions, that is, interventions without face-to-face contact with a clinician, has been demonstrated (Foster, Richards et al. 2013). However, following ABI there are limited interventions delivered remotely that target self-management of physical activity (Jones, Dean et al. 2015b). Current examples that have been examined for individuals after stroke include telephone support given in conjunction with a face-to-face self-management intervention tested in two randomized controlled trials (Damush, Ofner et al. 2011, Kim and Kim 2013), and telehealth interventions evaluated in three non-randomized studies for individuals (Huijbregts, McEwen et al. 2009, Taylor, Cameron et al. 2009, Taylor, Stone et al. 2012, Jaglal, Haroun et al. 2013). However, interest in a remotely delivered self-management program aimed at increasing physical activity specifically within an Australian community-dwelling ABI population is high; therefore development and initial evaluation of such a program was warranted (Jones, Dean et al. 2015c).

The primary aim of this study was to examine the feasibility and acceptability of a remotely delivered self-management program, myMoves, aimed at increasing levels of physical activity in community-dwelling adults with ABI. Secondary aims were to examine changes in the level of physical activity and sedentary behaviour, physical activity self-efficacy, levels of psychological distress, and participation levels following participation in the myMoves program.

5.3.3 Methods

Design

An open trial design was employed comparing baseline measures with those taken immediately following intervention and at 3-months follow-up. This study was approved by the Macquarie University Human Research Ethics Committee (Medical Sciences) (Reference number 5201400830) and registered on the Australian and New Zealand Clinical Trials Registry (Trial ID ACTRN12615000072516).

Participants and recruitment

Participant recruitment was commenced online and completed via telephone interview. Potential applicants were directed to an online application form, including a participant information and consent form, via advertisements listed on the websites, social media sites and in printed materials from the major consumer groups associated with ABI in Australia, including the National Stroke Foundation and Brain Injury Australia. Email invitations were also extended to participants from an earlier survey study conducted to examine potential interest in this program (Jones, Dean et al. 2015c), as well as via stroke support groups and other professional networks.

In order to be eligible for the myMoves program, participants had to meet the following inclusion criteria: (1) aged 18 years or over; (2) have sustained an ABI; (3) be currently living in the Australian community; (4) be able to walk at least 50m outside without assistance from another person; (5) have regular access to the Internet; (6) to be able to read and understand written English; (7) have been seen by their treating medical practitioner within the past 3 months. This final criterion was to ensure participants had received a recent medical review before commencing a remotely delivered physical activity intervention. Exclusion criteria are (1) individuals scoring 30/40 or higher on the Kessler Psychological Distress Scale (K-10); (2) individuals scoring less than 14/17 on the Telephone Assessed Mental State (TAMS); (3) pregnant women; (4) those suffering from a neurodegenerative condition; (5) those having undergone surgical intervention within the last 6 months; (6) those having undergone treatment for cancer within the last 5 years.

Applicants who provided consent and confirmed they met all online eligibility criteria were then interviewed over the telephone, during which time eligibility criteria were confirmed and the TAMS was administered. The TAMS is a brief assessment of attention, orientation, and memory; and correlates strongly with the Mini Mental State Examination (ρ = 0.81) (Lanksa, Schmitt et al. 1993). As participants were required to read, understand and apply a significant amount of material over the duration of the myMoves program a high cut point was deemed necessary for this intervention. At this time further detailed information about the program was given and applicants were given the opportunity to ask questions before confirming their consent to participate.

Intervention

The myMoves program is a remotely delivered self-management program aimed at increasing physical activity after ABI. A comprehensive description of the development of the myMoves program, using an Intervention Mapping framework, is presented in Chapter 4 (Jones, Dear et al. under review). A summary of the myMoves program is shown in Table 5.1. In brief, the myMoves program consists of six modules delivered over eight weeks. It was constructed around a framework called *The Active Lifestyle Model*, which consists of four key areas to achieve a physically active lifestyle – Managing Activity Levels, Managing Barriers, Managing Expectations and Managing Habits. Each module is made up of the following components: (1) A Lesson detailing the core content for that module, (2) Case Stories that cover six individuals with ABI who are followed throughout the program, and (3) A Worksheet with Do-It-Yourself (DIY) tasks aimed at building the skills covered in the Lesson for that module. Additional resources of interest, including information on strengthening activities and remaining active during winter, were also delivered over the study period.

Table 5.1: myMoves program summary

Timing	Content
Week 1	**Lesson 1: An Introduction** This introductory lesson discusses the importance of physical activity after ABI, common difficulties people with ABI face and addressing any concerns regarding safety. The Active Lifestyle Model is introduced. Concept of planned and incidental physical activity is discussed. Case Stories are introduced and DIY activities involve identification of current difficulties in managing physical activity and identification of 1 planned and 2 incidental activities to work on over the program.
Week 2	**Lesson 2: Managing Activity Levels** This lesson introduces the concept of the FITT formula with discussion about it's application to physical activity. Under-Doing or Over-Doing physical activity is discussed with participants encouraged to identify which unhelpful behaviour they tend to use. Strategies of Scaling Up and Pacing are covered with a focus on the management of pain and fatigue. The strategy of Scaling Down is also discussed with examples of appropriate application. Case Stories assist with examples of application of these concepts to real life situations. DIY tasks focus on building the skills of Scaling Up and Pacing strategies.
Week 3	**Lesson 3: Managing Barriers** The concept of barriers to physical activity is discussed. The Fogg Behavioral Model is used as a framework to assist participants to identify barriers that affect motivation and those that affect ability. The skills of problem-solving, planning and scheduling are discussed, with DIY tasks focused on practice of these skills. Case Stories outline various barriers experienced and strategies to overcome them.
Week 4	**Lesson 4: Managing Expectations** Participants are introduced to the concept of expectations and what can contribute to shaping these expectations. The concept of High and Low Expectations are introduced, as is the skill of challenging unrealistic expectations. Realistic expectations are compared to positive thinking and goal setting to demonstrate the differences between these concepts. The Case Stories outline various difficulties experienced in managing their expectations. DIY tasks assist in building the skills of challenging unrealistic expectations.

Week 5	**Lesson 5: Managing Habits** The concept of habits is introduced and why habits are useful is discussed, in comparison to the difficulties of making difficult decisions. The concept of the motivation wave is introduced to demonstrate how motivation can fluctuate naturally, with different strategies for times of high and of low motivation discussed. The skill of building habits using the formula of Cue, Activity, Reward is introduced with discussion on finding the right cue, making activities small and easy to enhance habit development, and celebrating successes with either internal or external rewards, with a focus on internal as preferable. Case Stories outline experiences in forming new habits and the influence of habits on physical activity. DIY tasks help individuals to work through the process of building new habits.
Week 6	**Consolidation Week** Participants are encouraged to continue to read through the materials covered in the course, practice skills and consolidate their learning.
Week 7	**Lesson 6: Keeping it Going** The concept of a Lapse in physical activity is introduced and normalised. The skill of creating a Relapse Prevention Plan is discussed. Goal setting is introduced with the steps of goal setting outlined. The Lesson ends with tips for ongoing improvement and continued behaviour change. Case Stories discuss experiences with lapses in their activity levels for different reasons and their subsequent strategies to prevent a substantial relapse. Goals and plans for the future are also discussed. DIY tasks include development of a Relapse Prevention Plan and setting of goals for the future.
Week 8	**Consolidation Week** Participants are encouraged to continue to read through the materials covered in the course, practice skills and consolidate their learning.

All materials were delivered in portable document format (PDF) via email. Prior to commencing the program, participants received a detailed *myMoves Program Guide* showing the important dates for the myMoves Program (example in Appendix 8). During the program each participant received an email at the start of each week with materials needed for that week, including their Lesson, Stories and Worksheet. Each participant was then contacted at least one additional time later in the week via email or telephone to ensure the program materials were understood, to clarify any issues, and to assist participants in tailoring the intervention to their specific situation. The first author, a physiotherapist with over 10 years experience working with individuals with ABI, provided all clinical and administrative contact with the participants, including initial interviews, email and telephone contact.

Data collection

Data were collected from participants at three time points: (1) the week prior to starting the program (i.e., pre-program), (2) the week immediately following completion of the program (i.e., post-program), and (3) a week 3 months from the date of completion of the program (i.e. follow-up). All data collected via questionnaires were administered online using Qualtrics software, Version 62626 (Copyright © 2015 Qualtrics, Provo, UT). Physical activity monitors were sent to participants via Express Post, with detailed instructions on how to apply and care for the devices (Appendix 6). The monitors were then returned to the research team via post upon completion of the data collection period. Data on instances and time of contact with participants, and any adverse events were logged directly by researchers onto a spreadsheet that was password protected.

Demographics and participant characteristics

We collected data about demographic details, participant characteristics, mobility status, and general health. The Australian Statistical Geographical Classification (ASGC) was used to establish the Remoteness Area (RA) for each participant's residential address. This classification system divides Australia into classes of remoteness based on access to services (Australian Bureau of Statistics 2011). Participants were classified as residing in one of 5 areas: RA1 – major city, RA2 – inner regional area, RA3 – outer regional area, RA4 – remote area, RA5 – very remote area (Australian Bureau of Statistics 2011, Department of Health 2015). Participants were asked about the level of assistance they require to walk, as well as indicating the distance and time they can walk on an average day before requiring a rest. Participants were asked to rate their current level of satisfaction with their mobility status a 5-point Likert scale with the following options: *very satisfied; satisfied; neither satisfied nor dissatisfied; dissatisfied; very dissatisfied*. Participants were also asked to rate their perceived level of general health from one of the following options: *very good*, *good*, *neither good nor poor*, *poor*, *very poor*.

Primary outcomes

Feasibility

Feasibility was examined by collecting data regarding five key factors: i) adherence to the intervention - examined via participant reported feedback as to which Lessons were completed during the 8-week program time frame; ii) attrition from the study; iii) clinician time spent per participant – examined via data collected on all contact events with participants, including emails (both to individuals and to the group) and telephone calls; iv) accessibility – examined via successful acquisition of program materials as well as successful access to and use of outcome data collection tools, including physical activity monitors, by participants and v) reporting of any adverse events.

Acceptability

Acceptability was assessed immediately following the myMoves program using the Program Satisfaction Questionnaire (PSQ), a purpose built questionnaire examining satisfaction with the myMoves program. The PSQ is modelled from those used extensively by Macquarie University's eCentreClinic in remote self-management programs for a variety of clinical populations (Dear, Titov et al. 2011, Titov, Dear et al. 2011, Wootton, Titov et al. 2011, Dear, Titov et al. 2013, Titov, Dear et al. 2014, Dear, Gandy et al. 2015). Participants are asked to rate their overall satisfaction with the myMoves program on a 5-point Likert scale with the following options: *very satisfied; satisfied; neither satisfied nor dissatisfied; dissatisfied; very dissatisfied*. Participants were also asked whether they felt the myMoves program was worth their time (*yes* or *no*), and whether they felt confident in recommending the myMoves program to others with an ABI (*yes* or *no*). Participants were also invited to leave qualitative comments about the program.

Secondary outcomes

Physical activity

Objective physical activity data were collected from two physical activity-monitoring devices, activPAL3™ (PAL Technologies Ltd, Glasgow, UK) and the Actigraph GTX3 (Actigraph, Penascola, FL) worn by participants for 7 consecutive days. The activPAL3™ is a small lightweight (15 g) tri-axial accelerometer and inclinometer worn attached to the anterior thigh. This device is worn with a waterproof dressing allowing for continuous 24 hour recording. The activPAL3™ directly measures posture, allowing for accurate representation of sedentary time, i.e. time spent sitting or lying, as well as time spent standing and stepping (Kozey-Keadle, Libertine et al. 2011, PAL Technologies Ltd 2015). The activPAL™ is also accurate in quantifying step count at a variety of walking speeds (Grant, Dall et al. 2008), and has been used in people with ABI (English, Healy et al. 2015).

The Actigraph GTX3 is also a lightweight (27g) tri-axial accelerometer worn on an elasticised belt above the hip of the least-affected or dominant side. The Actigraph GT3X measures and records time-varying accelerations which are related to the intensity of the participants physical activity during that period (Santos-Lozano, Santin-Medeiros et al. 2013). Participants were instructed to remove the device for showering or any water based activities. Participants were encouraged to wear the device to bed, however were allowed to remove the device if sleeping with the device in situ was uncomfortable. The Actigraph GTX3 has been shown to be a valid in classifying physical activity intensity in individuals with a brain injury (Tweedy and Trost 2005).

For this study three objective physical activity outcomes were collected and analysed. Average daily step count and average daily time spent sitting/lying, were extracted from activPAL3™ data. Average daily time spent in moderate to vigorous physical activity (MVPA) was extracted from the Actigraph GTX3 data.

We determined a clinically important improvement in average daily time spent sitting/lying to be a reduction of 30 minutes or more from the time recorded before the program commenced. We classified individuals recording a time within 30 minutes of pre-program time in either direction as remaining the same. Similarly, for average daily step count and average daily time spent in MVPA we determined a clinically important improvement to be an increase of 10% or more from amounts recorded before the program commenced, while those staying the same recorded amounts within 10% of pre-program measures in either direction.

In addition to these objective physical activity measures, participants were also asked to rate their level of satisfaction with their physical activity status on a 5-point Likert scale with the following options: *very satisfied; satisfied; neither satisfied nor dissatisfied; dissatisfied; very dissatisfied*.

Physical activity self-efficacy

Self-efficacy is a core component of self-management programs following ABI (Jones and Riazi 2011). Self-efficacy has been found to be reduced in individuals with ABI (Pang, Eng et al. 2007, Jones and Riazi 2011, Korpershoek, van der Bijl et al. 2011) and therefore warrants inclusion as an outcome measure within this study). Physical activity self-efficacy was calculated using a 10-item scale adapted from the Spinal Cord Injury (SCI) Exercise Self-Efficacy Scale (ESES). This scale was developed by Kroll and colleagues (2007) when existing self-efficacy scales were found to be too generic or too specific, not suitable for those with a SCI, or not well developed and evaluated. Items for this scale were extracted from existing instruments; and refined using input from clinical and survey experts, as well as consumers, to form a scale consisting of 10 items (Kroll, Kehn et al. 2007). The scale instructs participants to indicate on a 4-point rating scale (*1 = not at all true, 2 = rarely true, 3 = moderately true, 4 = always true*) how confident they are in carrying out regular physical activities. These items were then summed to give a total between 10-40, with a higher score indicative of greater self-efficacy. The SCI ESES has been found to have a high level of internal consistency within a SCI population with a Cronbach's alpha of .9269, and high construct validity with a statistically significant correlation between the SCI ESES and the Generalised Self Efficacy Scale (Spearman RHO = 0.316, $p < 0.05$, $n = 53$, 2-sided) (Kroll, Kehn et al. 2007).

The working definition for the SCI ESES was to measure the confidence of individuals with SCI to plan and carry out physical activities and/or exercise based on their own volition (Kroll, Kehn et al. 2007). As this working definition closely matched the aligned with the operationalisation of self-efficacy we were aiming to capture in the ABI population we chose to use this scale with only minor adaptions. The adaptations consisted of replacing the term "*exercise*" with the term "*physical activity*" or "*physically active*" as appropriate; and in one question, to remove the words "*spinal cord*" to leave the term "*injury*".

In addition to this 10-item physical activity self-efficacy scale, participants were also asked a single item question as part of the PSQ collected at the post-program time point only. This question asked participants to rate their overall confidence to manage their physical activity in comparison to before the myMoves program by selecting from the following options: *much higher, higher, about the same, lower, much lower.*

Participants were also asked to select any barriers to physical activity they were experiencing from a list of 17 common barriers to physical activity experienced by individuals with ABI. This list was used in a previous survey of community-dwelling adults with ABI (Jones, Dean et al. 2015c). Included in the list was an option to select "*I don't experience any barriers to physical activity*" or an "*other*" option where participants could outline any barriers not listed. Participants were also asked to rate their overall confidence in overcoming barriers to physical activity by selecting from the following options: *very confident, confident, neither confident nor not confident, mostly not confident, not at all confident.*

Psychological Distress

Psychological distress has been shown to high amongst individuals with ABI (Jones, Dean et al. 2015c, Hackett and Pickles 2014 Hart, Brenner et al. 2011, Tang, Lau et al. 2013), and therefore warrants examination within this study. Participants' psychological distress was assessed using the Kessler Psychological Distress Scale (K-10), a brief self-report measure of non-specific psychological distress (Andrews and Slade 2001, Kessler, Andrews et al. 2002, Australian Bureau of Statistics 2012). This scale includes 10 items rated on a 5-point Likert scale (*1=none of the time, 2=a little of the time, 3=some of the time, 4=most of the time, 5=all of the time*). Items are summed to give a total ranging from 10 to 50. Scores are used to categorize individuals according to their level of psychological distress (10-15: low distress; 16-21: moderate distress; 22-29: high distress; 30-50: very high distress). The K-10 has excellent internal consistency (Cronbach's α = 0.92) with an ability to discriminate DSM-IV cases from non-cases. It is used extensively in Australia, North America, and by the WHO (Andrews and Slade 2001, Kessler, Andrews et al. 2002, Australian Bureau of Statistics 2012).

Participation

Individuals with ABI demonstrate reduced participation in home, work and community activities; and reduced satisfaction and QOL (Ponsford, Olver et al. 1995, Pound, Gompertz et al. 1998, Sturm, Dewey et al. 2002, Colantonio, Ratcliff et al. 2004, Hartman-Maeir, Soroker et al. 2007, Wise, Mathews-Dalton et al. 2010, Braden, Cuthbert et al. 2012), and is an important outcome to consider within this study. Participation was measured using the modified Reintegration to Normal

Living Index (mRNLI) (Miller, Clemson et al. 2011). This is a global functional status measure that assesses how well people return to normal living patterns following disease or injury. Participants are asked to rank 11 items on a 4-point scale with the following options: (*0=does not describe me or my situation, 1=sometimes describes me or my situation, 2=mostly describes me or my situation, 3=fully describes me or my situation*) to give a total ranging from 0-33. Items can also be categorized into items describing Daily Functioning (items 1 to 7) or Personal Integration (items 8 to 11). The mRNLI has been found to have good construct validity and internal consistency (Cronbach's α = 0.80), and test-retest reliability (intraclass correlation coefficient (3,1) = 0.83, p=.0001) in a community-dwelling adult population (Miller, Clemson et al. 2011). Participants were also asked to rate their satisfaction with their level of participation on a 5-point Likert scale with the following options: *very satisfied; satisfied; neither satisfied nor dissatisfied; dissatisfied; very dissatisfied*.

Data Analysis

Objective physical activity data from the activPAL3™ were downloaded using the manufacturers software (activPAL3™ version 7.2.32). A weekly summary was saved from which time spent sitting/lying, and step counts were extracted for each full day of recording. Actigraph data were processed using the ActiLife software (version 6.8.2). Non-wear validation was performed using the algorithm by Choi and colleagues (2011). Cut-points for physical activity intensity were based on the *Freedson VM3* equation by Sasaki and colleagues (2011), where

MVPA is categorised as 2690 *VM3* counts/min or higher, which equates to 3.00 MET or higher.

Descriptive statistics were used to characterise participants' demographic data and to evaluate feasibility and acceptability. Secondary outcome data were presented as means (SD) for continuous measures. As a preliminary feasibility study, paired sample t-tests were used to calculate the mean difference (MD) (95% confidence interval (CI)) between post program and follow-up outcomes relative to pre-program measures using *IBM Statistical Package for Social Sciences (SPSS)* version 22 for Macintosh (IBM Corp 2013). Number (%) of participants were presented for categorical data and mean risk difference (MRD) (95% CI) were calculated using a confidence interval calculator (Herbert 2013) to examine proportional changes for post-program and follow-up outcomes relative to pre-program measures.

5.3.4 Results

Participants

The flow of participants through the study is outlined in Figure 5.1. Demographic data are presented in Table 5.2 and participant characteristics in Table 5.3. Participants from four Australian states were involved in this study, with two thirds of participants residing in a major city. There were no participants from remote areas in this study, however 2 participants did travel to remote areas of Australia during the course of the study, whilst a third participant travelled overseas for work.

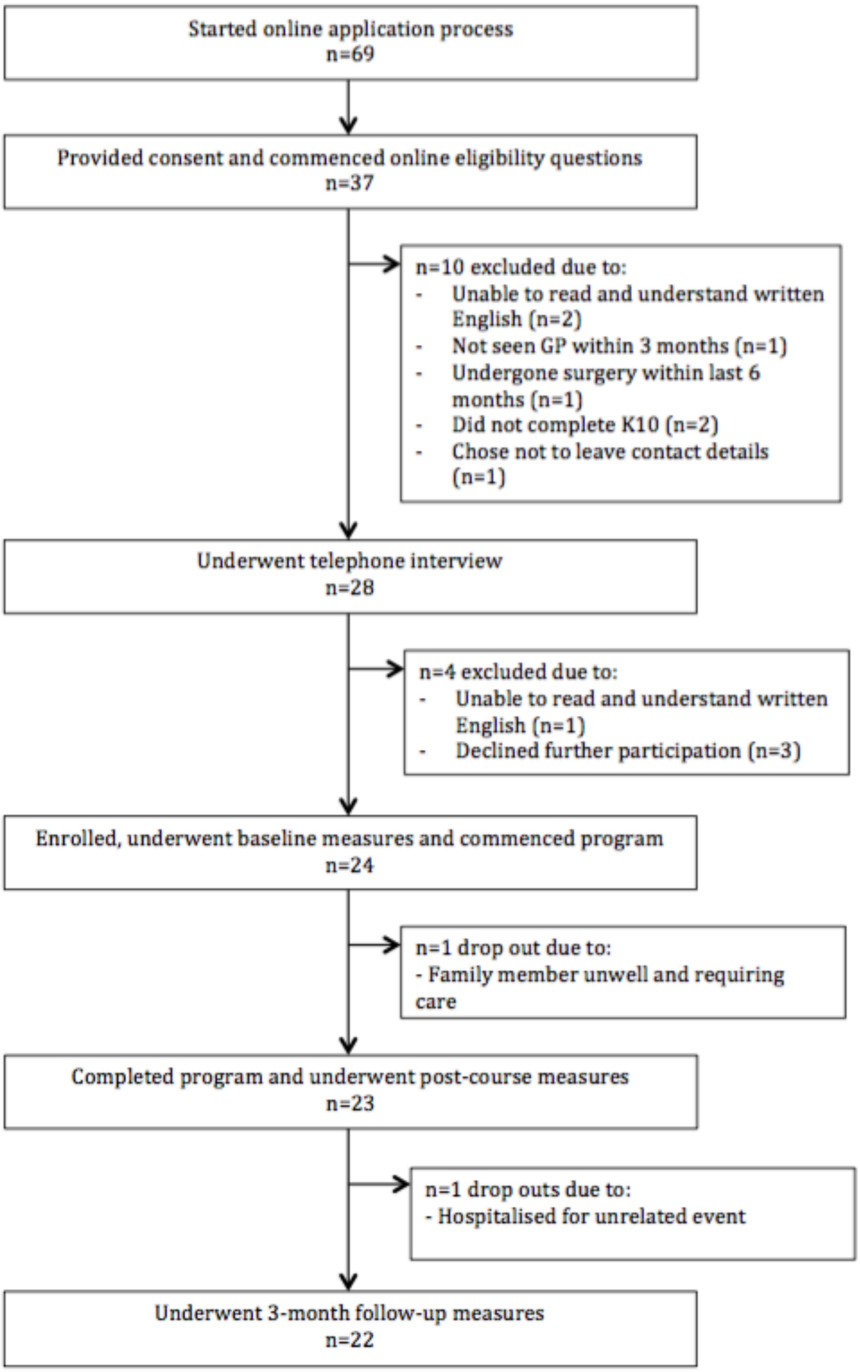


Figure 5.1: Participant flow

Table 5.2: ABI and demographic characteristics of participants

Characteristic	n (%) unless otherwise stated
Age (mean years (SD))	51.13 (16.52)
Gender	
Male	10 (41.7)
Cause of ABI	
Stroke	20 (83.3)
TBI	4 (16.7)
Time since ABI (years) median (IQR 25%-75%)	4.42 (1.35 – 7.44)
Length of inpatient stay after ABI	
Less than 1 week	3 (12.5)
1 – 4 weeks	2 (8.3)
4 – 8 weeks	10 (41.7)
8 – 12 weeks	5 (20.8)
12 – 16 weeks	4 (16.7)
Lives alone	1 (4.2)
Residential Locality (ASGC_RA)	
Major city (RA1)	16 (66.7)
Inner regional area (RA2)	7 (29.2)
Outer regional area (RA3)	1 (4.2)
Remote area (RA4)	0 (0)
Very remote area (RA5)	0 (0)
Education	
University	15 (62.5)
Vocational/Trade/TAFE	4 (16.7)
High school	5 (20.8)
No qualification/high school not completed	0 (0)
Work status	
Full time paid	2 (8.3)
Part time paid	4 (16.7)
Casual	2 (8.3)
Registered sick/disabled	5 (20.8)
Retired	9 (37.5)
Unemployed	2 (8.3)
Study status	
Full time	0 (0)
Part time	4 (16.7)

Table 5.3: Participant characteristics

Characteristics	n (%)
Use of mobility aid	
Indoors	8 (33.3)
Outdoors	8 (33.3)
Average length of walking without a rest	
Less than 10 minutes	6 (25.0)
10 – 30 minutes	8 (33.4)
30 – 60 minutes	5 (20.8)
More than 60 minutes	5 (20.8)
Average walking distance without a rest	
Less than 250m	10 (41.7)
250 – 500m	1 (4.2)
500m – 2km	6 (25.0)
More than 2 km	7 (29.2)
Satisfaction with mobility status	
Very satisfied	3 (12.5)
Satisfied	4 (16.7)
Neither satisfied nor dissatisfied	5 (20.8)
Dissatisfied	10 (41.7)
Very dissatisfied	2 (8.3)
Perception of general health	
Very good	3 (12.5)
Good	13 (54.2)
Neither good nor poor	6 (25.0)
Poor	2 (8.3)
Very poor	0 (0)

Feasibility and Acceptability

Adherence and attrition

Participants completed 5.6 of 6 lessons (SD=1.2) on average immediately post program. Post program data and 3-month follow up self-reported data were collected from 95.8% (23/24) and 91.7% (22/24) of participants respectively. Objective physical activity data were retrieved from at least one device from 95.8% (23/24) participants post program, and 83.3% (20/24) at 3-month follow-up.

Clinician Time

In total, over the entire study duration, there was an average of 55.9 (SD 14.8) instances of contact per participant, with an average time spent of 218.0 minutes (SD 56.6) per participant, including sending and reading emails, and making telephone calls. The mean total clinician time per participant during the 8-week program was 32.8 minutes (SD=22.8). Of this time, phone calls averaged 0.7 (SD1.0) instances and 9.4 minutes (SD16.2) of clinician time per participant, while emails averaged 15.5 (SD5.9) instances and 23.4 minutes (SD11.0) per participant.

Accessibility

All participants received the program materials via email, and were able to access the online data collection tools. All activity monitors were received by participants and returned to the researchers. Participants appropriately donned all activity monitor devices, either independently or with the assistance of a family member. There was only one occasion of a technical device failure during the 3-month follow-up data collection period.

Adverse events

No adverse events occurred as a result of the myMoves program. A number of participants (n=5) reported minor skin irritation from the adhesive waterproof dressing used to attach the activPAL3™ device; however, this was relieved when hypoallergenic tape was applied beneath the device and waterproof dressing. One participant was unable to wear the activPAL3™ due to known skin sensitivity to adhesive tapes.

Program Satisfaction

Participants reported a high level of overall satisfaction with the program, with 95.7% (22/23) being either *very satisfied* or *satisfied*. Most participants also reported the program was *worth their time* (95.7%, 22/23) and all participants (100%, 23/23) reported they would *recommend the course* to others.

Examples of qualitative feedback from participants include:

"I am very impressed with the help myMoves has done, and will do for me. I will look back on my notes to keep going." (Participant 2)

I liked the… "fact that it is delivered online and can be worked through at own pace" (Participant 12)

"Gave me belief in myself – to know what is best" (Participant 3)

I liked…"reading people's stories and being able to identify" (Participant 21)

"It made me think about what I actually do each day" (Participant 9)

"It works! It makes sense!" (Participant 11)

Secondary outcomes

Levels of physical activity

Physical activity outcomes are outlined in Table 5.4. In comparison to pre-program, change in average daily step count was an increase of 287 steps (95% CI -160 to 733) post-program and an increase of 132 steps (95 % CI -503 to 767) three months later. Participants had reduced their average time spent sitting/lying per day by an average of 24 minutes post program (MD -0.4 hours/day, 95% CI -0.9 to 0.1) and by 12 minutes three months later (MD –0.2

hours/day, 95% CI -0.7 to 0.4). Given the wide variability in physical activity levels at baseline it is interesting to note that 91% (n=20) of participants had maintained or increased their average daily step count immediately after the program and 65% (n=13) 3 months later. Similarly, the percentage of participants who had maintained or reduced daily sitting/lying time by 30min or more was 82% (n=18) post-program and 80% (n=16) 3 months later.

The group mean for average daily time spent in MVPA remained above 30 minutes/day for all measures, however there was a reduction in average time spent in MVPA of 8 minutes post-program (95% CI 14 to 2), and an ongoing reduction of 4.5 minutes (95 % CI -12 to 3) 3 months later. However, despite this mean reduction, immediately post-program 30% (n=7) of participants either maintained or increased their time spent in MVPA by 10% or more, whilst 3 months later this had increased to 50% (n=10).

Overall, as shown in Table 5.5, satisfaction with physical activity levels increased significantly immediately following the program. Post program, 27% more participants were *very satisfied* or *satisfied* with their level of physical activity compared with before the program (risk difference 0.27, 95% CI 0.00 to 0.49). At follow-up this had reduced to 10% (risk difference 0. 10, 95% CI -0.14 to 0.35).

Table 5.4: Secondary continuous outcomes –Mean (SD) and range of secondary outcomes and mean difference (95% CI) at post-program and 3-month follow-up relative to pre-program measure. Number (%) of participants who improved or maintained physical activity outcomes at post and follow-up measures

Outcome	Measures			Difference between measures	
	Pre	Post	Follow-up	Post minus pre	Follow-up minus pre
Physical activity					
Steps (steps/day)	5598 (2722) 912 to 11313 (n=23)	5816 (2682) 1077 to 11203 (n=22)	5571 (2606) 950 to 10995 (n=20)	287 (-160 to 733) (n=22)	132 (-503 to 767) (n=20)
Improved (>10% increase) n (%) Maintained (±10%) n (%)		9 (41) 11 (50)	7 (35) 6 (30)		
Sitting/lying time (hours/day)	19.6 (1.9) 14.6 to 23.4 (n=23)	19.2 (1.9) 12.9 to 22.4 (n=22)	19.4 (2.0) 13.1 to 23.4 (n=20)	-0.4 (-0.9 to 0.1) (n=22)	-0.2 (-0.7 to 0.4) (n=20)
Improved (>30 min reduction) n (%) Maintained (±30 min) n (%)		11 (50) 7 (32)	7 (35) 9 (45)		
Time in MVPA (minutes/day)	42 (32) 4 to 105 (n=24)	35 (26) 3 to 86 (n=23)	36 (28) 2 to 96 (n=20)	-8 (-14 to -2) (n=23)	-4.5 (-12 to 3) (n=20)
Improved (>10% increase) n (%) Maintained (±10%) n (%)		7 (30) 0 (0)	7 (35) 3 (15)		
Physical activity self-efficacy					
Total score (10-40)	29.6 (5.1) 18 to 38 (n=24)	31.7 (4.1) 24 to 38 (n=23)	30.6 (3.5) 25 to 40 (n=22)	2.1 (-0.2 to 4.3) (n=23)	1.0 (-1.4 to 3.4) (n=22)
Psychological distress					
K10 score (10-50)	19.2 (5.4) 12 to 34 (n=24)	17.0 (6.1) 10 to 37 (n=23)	17.4 (5.5) 10 to 30 (n=21)	-2.3 (-3.9 to -0.7) (n=23)	-1.4 (-3.3 to 0.4) (n=21)
Participation (mRNLI)					
Daily Functioning score (0-21)	13.0 (4.4) 7 to 20 (n=24)	14.6 (4.4) 4 to 20 (n=23)	15.1 (2.8) 9 to 19 (n=21)	1.5 (0.1 to 2.9) (n=23)	1.5 (-0.2 to 3.2) (n=21)
Personal Integration score (0-12)	7.6 (2.6) 1 to 12 (n=24)	8.5 (2.5) 0 to 12 (n=23)	8.1 (2.0) 5 to 12 (n=21)	0.9 (0.0 to 1.7) (n=23)	0.1 (-0.6 to 0.9) (n=21)
Total mRNLI score (0-33)	20.7 (5.8) 10 to 30 (n=24)	23.1 (6.1) 4 to 32 (n=23)	23.1 (4.0) 14 to 29 (n=21)	2.6 (0.4 to 4.3) (n=23)	1.6 (-0.3 to 3.6) (n=21)

Abbreviations MVPA: moderate/vigorous physical activity; mRNLI=modified reintegration to normal living index. Shaded comparisons significant at p<0.05

Table 5.5: Secondary categorical outcomes - Number (%) of participants for categorical outcomes and mean (95% CI) risk difference immediately post program and 3 months later relative to the pre measure

Outcome	Measures: Pre (n=24)	Measures: Post (n=23)	Measures: Follow-up (n=22)	Differences between measures: Post minus Pre	Differences between measures: Follow-up minus Pre
Satisfaction with physical activity					
Very Satisfied or Satisfied	5 (20.8)	11(47.8)	7(31.8)	0.27 (0.00 to 0.49)	0.10 (-0.14 to 0.35)
Very Satisfied	0 (0)	1 (4.3)	0 (0)		
Satisfied	5 (20.8)	10 (43.5)	7 (31.8)		
Neither satisfied nor dissatisfied	2 (8.3)	6 (26.1)	9 (40.9)		
Dissatisfied	12 (50.0)	5 (21.7)	6 (27.3)		
Very dissatisfied	5 (20.8)	1 (4.3)	0 (0)		
Confidence to overcome barriers to PA					
Very Confident or Confident	18 (75.0)	20(87.0)	12 (57.1)	0.12 (-0.11 to 0.34)	-0.20 (-0.44 to 0.07)
Very Confident	4 (16.7)	7 (30.4)	5 (23.8)		
Confident	14 (58.3)	13 (56.5)	7 (33.3)		
Neither confident nor not confident	4 (16.7)	2 (8.7)	7 (33.3)		
Mostly not confident	2 (8.3)	0 (0)	2 (9.5)		
Not confident at all	0 (0)	1 (4.3)	0 (0)		
Psychological distress category*					
Low distress	5 (20.8)	9 (39.1)	10 (47.6)	0.18 (-0.08 to 0.41)	0.27 (-0.01 to 0.50)
Moderate distress	12 (50.0)	11 (47.8)	7 (33.3)		
High distress	5 (20.8)	2 (8.7)	3 (14.3)		
Very high distress	2 (8.3)	1 (4.3)	1 (4.8)		
Satisfaction with participation*					
Very Satisfied or Satisfied	12 (50.0)	17(73.9)	14(66.7)	0.24 (-0.07 to 0.47)	0.13 (-0.14 to 0.39)
Very satisfied	0 (0)	2 (8.7)	0 (0)		
Satisfied	12 (50.0)	15 (65.2)	14 (66.7)		
Neither satisfied nor dissatisfied	10 (41.7)	4 (17.4)	7 (33.3)		
Dissatisfied	2 (8.3)	2 (8.7)	0 (0)		
Very dissatisfied	0 (0)	0 (0)	0 (0)		

*Follow-up measures n=21.

Physical activity self-efficacy

Total physical activity self-efficacy scale scores are shown in Table 5.4. In comparison to pre-program scores, physical activity self-efficacy increased by 2.1 points (95% CI -0.2 to 4.3) post-program and by 1 point (95% CI -1.4 to 3.4) 3 months later. Additionally, in a single item question in the PSQ, 82.6% (n=19) of participants reported that their overall confidence to manage their physical activity was *much higher* or *higher* than prior to commencing the myMoves program.

The most common barriers to physical activity reported by participants before the program were fatigue (n=9, 37.5%), and pain or discomfort (n=8, 33.3%). At both post-program and follow-up testing, fatigue as a barrier had reduced to a smaller proportion of participants (n=5; 20.8% and 22.7% respectively). Pain and discomfort as a barrier was reduced to 4 participants (16.7%) at post-program testing, and only 3 participants (13.6%) at follow-up. A lack of time and having no one to perform physical activity with became slightly bigger concerns at 3-month follow-up (both: n=5, 22.7%), compared with to pre-program (both: n=3, 12.5%). Confidence in overcoming physical activity barriers was more likely to be improved immediately following the myMoves program, as shown in Table 5.5, however this was not sustained at 3-month follow-up.

Psychological distress

Psychological distress as measured by the K10 is shown in Table 5.4. There was a statistically significant reduction in psychological distress immediately after the myMoves program (p=0.006), with participants demonstrating a reduced psychological distress of an average of 2.3 points (95% CI 0.7 to 3.9). Three months later there was a smaller, non-significant reduction of an average of 1.4 points (95% CI -0.4 to 3.3). Compared with pre-program, post program 18% more participants scored in the low distress category (risk difference 0.18, 95% CI -0.08 to 0.41) (Table 5.5). Three months later this had increased to 27% more participants (risk difference 0.27 95%CI -0.01 to 0.50).

Participation

As shown in Table 5.4, there was a statistically significant improvement in participation immediately after the program, as measured by the mRNLI with an average increase of 2.6 points (95% CI 0.4 to 4.3, p=0.021). Significant improvement was also found on both the Daily Functioning subscale (p=0.041) and Personal Integration subscale (p=0.045). Three months later, although no longer statistically significant, mean scores for all participation measures remained increased from baseline. Compared with before the program, 24% more participants were *very satisfied* or *satisfied* with their participation post program and 13% at follow-up (Table 5.5).

5.3.5 Discussion

The primary aim of this study was to assess the feasibility and acceptability of a remotely delivered program aimed at improving self-management of physical activity after ABI. Overall, the program showed high levels of acceptability despite participants averaging just 32.8 minutes (SD 22.8) of clinician contact time during the 8-week myMoves program. The program was delivered successfully using remote technology, including both internet and telephone, as well as utilising postal services for objective measurement of physical activity levels. The program allowed the research team to successfully engage with and evaluate outcomes from participants spread over four different states of Australia, from both metropolitan and regional areas, with no adverse events.

There are a number of limitations of this study to note. Firstly, as this study was focussed on feasibility and acceptability primarily, the trial design utilised was a single group, open trial design. This design of this trial is not one in which efficacy of the myMoves program in regards to physical activity and sedentary behaviour can be established. There was no control group comparison and the sample size was not powered for detection of changes in physical activity measures.

Secondly, participants displayed a high level of heterogeneity in regards to demographics, mobility, physical activity, psychological distress, and participation status. In combination with the small sample size and the lack of a control group for comparison, this heterogeneity makes it difficult to detect statistically significant changes in outcome measures. However, this heterogeneity is representative of an ABI population; and feasibility and acceptability of the myMoves program was demonstrated despite this variability. We also derived clinically meaningful cut points for the objective physical activity measures using either a 10% change for stepping and MVPA, or a change of 30 minutes or more in time spent sitting/lying, based on our clinical expertise. We operationalised these cut points to assist in making meaningful interpretations of data from individuals with a high level of variation in their physical activity status. However, these cut points have not been tested for validity, and further investigation of what may warrant a meaningful change to all stakeholders, including individuals with ABI, caregivers and health professionals is warranted.

Thirdly, although the myMoves program runs for 8 weeks, contact with participants continues beyond this time. Particularly notable was the contact time via telephone. During the 8-week program the number of phone calls to participants averaged only 0.7 (SD 1.0) per participant with an average length of 9.4 minutes (SD 16.2). Outside this intervention period the average number of phone calls per participant was 4.8 (SD 1.3) with an average duration of 133.9 minutes (SD 43.9). The contact time beyond the myMoves program is predominantly administrative and research oriented in nature, with particular emphasis on the delivery, application and monitoring of physical activity devices. However, it was felt pertinent to include this time within the data presented in this study, as any ongoing contact is likely to have some level of clinical effect. It is important to note these variations when considering assessment of efficacy or translation of the myMoves program into clinical practice. However, it is also important to recognise that 133.9 minutes is not a substantial amount of time when spread over approximately 4 months, which includes time before the program commenced, 3-month follow-up and time post follow-up when participants are returning activity monitors and exiting the study. When divided over 16 weeks, 133.9 minutes equates to only an average of 8.4 minutes per participant per week. This figure does appear to be feasible, and is likely to reduce further in future iterations of the myMoves program, with the experience gained from this study in remote monitoring of physical activity using accelerometers and associated streamlining of the administrative and evaluative processes.

Despite these limitations, in general data from secondary outcomes suggest that the myMoves program is a promising intervention, particularly regarding psychological distress, participation, and participant satisfaction with physical activity. Two of the three physical activity measures (step count and time spent sitting/lying), while not statistically significant, demonstrated movement in the right direction; while the third (MVPA) despite demonstrating a small reduction still resulted in 50% of participants showing improved or maintained levels at 3-month follow-up. Given the program was focussed predominantly on changing physical activity behaviour slowly over time, and participants were actively encouraged to take small steps toward building sustainable physical activity habits, these results are promising. However, further examination in a randomised trial design and adequately powered to detect clinically important differences in physical activity outcomes is needed to explore the efficacy of the myMoves program in improving physical activity and reducing sedentary behaviour. Our feasibility data suggests that utilising step count and time spent sitting/lying would be worthwhile primary outcome measures for efficacy testing. In order to detect a 10% treatment difference in steps per day at a two-sided 0.05 significance level, given the standard deviation of the proportion of change in average steps per day was 24%, and with 80% power, we need a total sample of 184 participants. Allowing for 15% attrition, we would need to recruit 212 participants (i.e. 106 for the intervention group and 106 for the waitlist control group) to ensure we have adequate power to detect both primary physical activity outcomes as this sample will allow us to detect a 26 min reduction in sitting/lying time (Schoenfeld 2010). Given that feasibility of the myMoves program has been demonstrated and acceptability was very high, a future randomised controlled trial is warranted.

5.3.6 Conclusion

This study demonstrates that a remotely delivered self-management program, myMoves, aimed at increasing physical activity after ABI is feasible, both in regards to program delivery and evaluation. The program demonstrated a high level of acceptability amongst participants and further investigation of efficacy within a larger scale randomised controlled trial is warranted.

CHAPTER 6

Study V: Iterative review of a remotely delivered self-management program to increase physical activity in community-dwelling adults with acquired brain injury

6.1 Preface

This Chapter involves the examination of both quantitative and qualitative participant feedback, which has been combined with information gained from Study IV, to inform an iterative review of the myMoves program. In line with the Intervention Mapping framework for the development of a complex health intervention, this review presents recommendations for revisions to the myMoves program, as well as outlining plans for future evaluation for efficacy.

6.2 Iterative review of a remotely delivered self-management program for community-dwelling adults using Intervention Mapping

6.2.1 Introduction

Intervention Mapping consists of six steps that serve as a framework for the design, development and evaluation of a complex and multifaceted health intervention (Bartholomew, Parcel et al. 2011). These six steps are 1) needs assessment; 2) identification of outcomes, performance objectives and change objectives; 3) selection of theory-based intervention methods and practical applications; 4) organisation of methods and applications into an intervention program; 5) creation of an implementation plan; 6) generation of an evaluation plan. These steps are presented in a linear manner; however, the process is both iterative and cumulative. Thus, in reality, intervention developers move back and forth between the steps as information is gained to achieve iterative improvements (Bartholomew, Parcel et al. 2011).

The Intervention Mapping framework has been used to guide the development of myMoves, a remotely delivered self-management program aimed specifically at improving physical activity in community-dwelling Australian adults with acquired brain injury (ABI). This program, by its nature is both complex and multifaceted. The UK Medical Research Council (MRC) recommends interventions of this nature undergo pilot testing, including both quantitative and qualitative methods, to assess procedures for their acceptability and feasibility, as well as gaining information to assist in estimating likely rates of recruitment and retention of subjects, and the calculation of appropriate sample sizes (Craig, Dieppe et al. 2008). Information from this early testing phase can be used to further enhance an intervention in an iterative manner, as per the Intervention Mapping process.

The myMoves program underwent pilot testing, from which important information in regards to both feasibility and acceptability was collected from participants. This information can now be examined to allow for iterative review of the myMoves program in order to more fully inform a future efficacy trial of this program. Therefore, this review will examine quantitative and qualitative feedback from participants regarding specific aspects of the myMoves program, including program content, support from researchers and timing. Based on this feedback, in conjunction with the results of the feasibility and acceptability study (Study IV) presented in Chapter 5 of this Thesis, an iterative review of the myMoves program will be conducted, and plans for efficacy testing will be outlined.

6.2.2 Methods

Design

We used an open trial design with primary outcomes for iterative review taken immediately following the intervention period. This study was approved by the Macquarie University Human Research Ethics Committee (Medical Sciences) (Reference number 5201400830) and registered on the Australian and New

Zealand Clinical Trials Registry (Trial ID ACTRN12615000072516). This registration process was completed after initial trial applications commenced, but prior to any baseline data collection or commencing the intervention.

Data collection

The primary data collection time point for feedback from participants was the week immediately following completion of the 8-week program. All online data were collected via questionnaires administered using Qualtrics software, Version 62626 (Copyright © 2015 Qualtrics, Provo, UT). Data were also collected to record time spent contacting participants, including sending and receiving emails (individual and group) and telephone calls. Data on instances and time of contact with participants, and any adverse events or concerns from participants were logged directly by researchers onto a spreadsheet that was password protected.

Participant feedback

Both quantitative and qualitative feedback from participants was collected primarily using a purpose built online questionnaire, the Program Satisfaction Questionnaire (PSQ). The PSQ is modelled from those used extensively by Macquarie University's eCentreClinic in remote self-management programs for a variety of clinical populations (Dear, Titov et al. 2011, Titov, Dear et al. 2011, Wootton, Titov et al. 2011, Dear, Titov et al. 2013, Titov, Dear et al. 2014, Dear, Gandy et al. 2015). Participants are asked to rate their overall satisfaction with the myMoves program, as well as their satisfaction with program materials, on a 5-point Likert scale with the following options: *very satisfied; satisfied; neither satisfied nor dissatisfied; dissatisfied; very dissatisfied*. Participants were also asked whether they felt the myMoves program was worth their time (*yes* or *no*), and whether they felt confident in recommending the myMoves program to others with an ABI (*yes* or *no*); as well as whether they found the timing of the myMoves program to be satisfactory, or whether it progressed too quickly or too slowly.

In order to gain more specific feedback relating to each specific module participants were asked to rate how helpful they found each of the Lessons covered in the myMoves program on a 5-point Likert scale with the following options: *very helpful, helpful, neither helpful nor unhelpful, unhelpful or very unhelpful.* If participants had not completed that module at the time of completing the questionnaire they were asked to select *not applicable*. Participants were then asked to select from a list of all skills taught in the myMoves course those that they had used to assist them to manage their physical activity levels over the myMoves program, and to rate these selected skills in regards to their helpfulness using the same 5-point Likert scale used previously.

Participants were also invited to leave qualitative comments about the program. In order to guide these comments participants were asked the following questions:

1. What did you NOT LIKE about the myMoves program? How would you suggest that we change or modify this for future participants?
2. What did you MOST LIKE about the myMoves program? Is there anything we can do to make this more useful?

Data analysis

Descriptive statistics were used to evaluate quantitative data, with mean (standard deviation (SD)) presented for continuous measures and number (%) of participants presented for categorical data. All quantitative data analysis was conducted using *IBM Statistical Package for Social Sciences (SPSS)* version 22 for Macintosh (IBM Corp 2013). Qualitative feedback was collated for each question. Given the small sample size and limited depth of the qualitative feedback, a simple qualitative analysis was conducted. Examination of the comments was conducted by one investigator (TMJ), with statements grouped according to similarity of themes contained within each statement. A second investigator (CMD) assessed the outcomes of the thematic analysis to ensure concordance. Any disagreement was discussed between the investigators and a resolution found. The resulting themes are presented and discussed with examples.

6.2.3 Quantitative and qualitative participant feedback

Twenty-three of the 24 participants who commenced the myMoves program completed the PSQ. Participant demographics and characteristics have been presented previously, with details outlined in Tables 5.2 and 5.3.

Quantitative participant feedback

Overall, participants were highly satisfied with the myMoves program, with 95.7% of participants stating they were *very satisfied* or *satisfied*. Similarly, 95.7% of participants reported being *very satisfied* or *satisfied* with the quality of the myMoves program materials. Most participants (95.7%) reported that the myMoves program was worth their time, while all participants (100%) reported feeling confident in recommending the myMoves program to others. In regards to the timing of the program, the majority of participants (82.6%) reported finding the timing of the program to be satisfactory, while 4 participants (17.4%) reported finding the program progressed too quickly.

Data relating to the perceived helpfulness of each Lesson is presented in Table 6.1. Most participants completed each of the Lessons. The vast majority of participants (73.9% to 87.0%) found each Lesson either *very helpful* or *helpful*. Data regarding the use of skills taught during the myMoves course, and the perceived helpfulness of these skills, are presented in Table 6.2. The skills used by most participants were planning and goals setting (both 65.2%), followed by scaling up and barrier identification (56.5%), and pacing (52.2%). The skills employed least were relapse prevention planning (13.0%) and scaling down (17.4%). Overall, when participants did utilise a skill they found it *very helpful* or *helpful* in nearly all cases.

Table 6.1: Number (%) of participant reported helpfulness of each Lesson of the myMoves program

Level of helpfulness	Lesson 1: An Introduction	Lesson 2: Managing Activity Levels	Lesson 3: Managing Barriers	Lesson 4: Managing Expectations	Lesson 5: Managing Habits	Lesson 6: Keeping It Going
Very helpful	9 (39.1)	10 (43.5)	9 (39.1)	9 (39.1)	9 (39.1)	9 (39.1)
Helpful	9 (39.1)	10 (43.5)	9 (39.1)	9 (39.1)	9 (39.1)	8 (34.8)
Neither helpful nor unhelpful	4 (17.4)	2 (8.7)	2 (8.7)	2 (8.7)	2 (8.7)	2 (8.7)
Unhelpful	0 (0)	0 (0)	1 (4.3)	0 (0)	1 (4.3)	1 (4.3)
Very unhelpful	1 (4.3)	1 (4.3)	0 (0)	1 (4.3)	0 (0)	0 (0)
Not applicable	0 (0)	0 (0)	2 (8.7)	2 (8.7)	2 (8.7)	3 (13.0)

Table 6.2: Number (%) of participants using skills taught during the myMoves program to assist management of physical activity and perceived helpfulness of skills taught

Skill	Using skill n(%)	Finds skill *very helpful* or *helpful* n(%)
Scaling up	13 (56.5)	13 (100.0)
Pacing	12 (52.2)	12 (100.0)
Scaling down	4 (17.4)	4 (100.0)
Identifying barriers	13 (56.5)	13 (100.0)
Problem-solving	7 (30.4)	7 (100.0)
Planning	15 (65.2)	15 (100.0)
Challenging unrealistic expectations	8 (34.8)	8 (100.0)
Habit formulation	10 (43.5)	8 (80.0)
Relapse prevention planning	3 (13.0)	3 (100.0)
Goal setting	15 (65.2)	14 (93.3)

Qualitative participant feedback

Areas requiring improvement

Feedback in regards to what participants did not like about the myMoves program and what improvements could be made was received from 7 (30.4%) participants. This feedback covered two main themes; namely receiving feedback, and the complexity and volume of information covered within the program.

Feedback

Three participants made comments relating to the feedback received during the program. One participant stated that they would like "*more feedback from program coordinators*". Similarly, a second participant felt more human interaction would be beneficial as the "*human rewards are missing*". A third participant felt that feedback after the initial physical activity monitor assessments in regards to suggestions on "*what to increase or changes to routine to consider*" would be helpful.

Complexity and volume of information

Four participants made comments in regards to the complexity and/or volume of information given during the myMoves program. Two participants commented on the fatigue and "*mental exhaustion*" they experienced from having to read and understand the program content. A third participant reported finding the amount of information a "*bit overwhelming*" whilst a fourth participant reported problems due to having a "*short attention span*", and suggested less content would be preferable. One participant suggested that having the program accompanied by audio-visual materials might be helpful.

Areas of greatest benefit

Feedback into what participants most liked about the myMoves program was received from 18 participants. Comments were more diverse than for the previous question, however three common themes were identified.

Feedback by phone

Four participants found that the feedback they received over the phone was particularly useful, particularly in assisting with the understanding of the program content. One participant stated "*speaking on the phone…made it much easier to understand the content…I could relate to it more and visualise what I have to do*"; whilst another stated that the "*personal contact*" and "*encouragement to solve a problem*" were what they most liked.

Stories

Three participants reported that reading the case stories of individuals with ABI was what they most like about the myMoves program. In general this was because they were "*able to identify*" with the individuals in the stories, with one participant recommending to "*widen this input*".

Confidence

A number of participants reported that they most liked that the myMoves program had improved their confidence in being physically active. One participant reported realising that they were not going hurt themselves during physical activity like previously thought, whilst another stated that the program gave them "*belief in myself – to know what is best*". This was particularly related to being physically active away from a structured health care setting, a sentiment echoed by another participant who stated that they found "*ceasing structured outpatient rehab to being on my own hard*", however the myMoves program gave him the "*help to structure*" a home program.

6.2.4 Iterative review of myMoves program

Based on the results of the feasibility and acceptability trial of the myMoves program (Study IV), and the participant feedback presented in this study, there was a very high level of satisfaction with myMoves program. However, in order to further improve the program the following iterative changes to the myMoves program are recommended:

1. *Reduce the length and complexity of the Lessons* – all Lessons will be reviewed for length and complexity, and adjustments made to the materials to ensure key messages are delivered in the simplest and clearest manner.
2. *Improvements to skill training* – skills with <50% of participant uptake will be reviewed to ensure delivery of the key components required to build these skills are delivered in an optimal manner to maximise participant uptake.

3. *Increase contact with participants via telephone* – the support offered via telephone is noted to be of importance to a number of participants. During Study IV, participants received an average of just 0.7 (SD 1.0) instances of contact with the clinician via the telephone during the 8-week myMoves program; amounting to average clinician contact time of 9.4 minutes (SD 16.2) per participant. The majority of clinician contact was via email, with an average 15.5 (SD 5.9) instances of clinician contact, amounting to an average of 23.4 minutes (SD 11.0). Given that total clinician contact time was an average of 32.8 minutes (SD 22.8) per participant over the 8-week myMoves program, it appears feasible to increase contact time with participants over the telephone. It would be recommended, based on participant feedback, that the telephone be used more regularly during the myMoves program, rather than using email as the default option for participant contact. However, it is still recommended that participant's preference for contact be the major consideration.
4. *Provide individualised feedback based on initial pre-program measurements of physical activity* – participants were provided with individualised feedback regarding the results from physical activity monitoring at the end of the program (see example in Appendix 9). It may be beneficial to provide this earlier in the program, after pre-program testing, to both raise awareness of their objective level of physical activity, and to assist in individualising activity plans and goals. This strategy has also been utilised successfully during a face-to-face self-management program for individuals with stroke (Preston 2015).

6.2.5 Plan for future efficacy testing

The myMoves program has been shown to be both feasible and acceptable to individuals with ABI. This remotely delivered self-management program should now undergo testing in a trial design format that allows for examination of efficacy. In order to do this, a Phase II wait-listed randomised controlled trial design can be utilised. Utilising a wait-list control group has a number of potential benefits. Firstly, it is likely to improve recruitment, as all participants will receive the intervention. It is also likely to ensure that all participants are equally interested and motivated to participate in the trial, including undertaking the accompanying outcome measurements involved. This should assist in reducing trial attrition. Finally, a wait-list control group is also reflective of the way this type of intervention is likely to be delivered in a real-world setting, increasing the translation of results to clinical services beyond a research setting. This trial design has been employed to examine other remotely delivered self-management programs of a similar format for individuals with depression, anxiety and chronic pain (Titov, Dear et al. 2011, Dear, Titov et al. 2013).

The myMoves program was focussed predominantly on changing physical activity behaviour slowly over time, and participants were actively encouraged to take small steps toward building sustainable physical activity habits. Participants are encouraged to initially increase their levels of light activity and reduce their sedentary activities, and then focus on increasing MVPA. Therefore, for efficacy testing we intend to have two primary outcomes, average time spent sitting and lying per day and average steps per day with the primary endpoint to be the end of the intervention period, whilst MVPA will be collected as a secondary outcome measure. We have used the feasibility data to ascertain the sample size required to ensure the Phase II trial is adequately powered to detect changes in these two primary outcomes. In order to detect a 30 min treatment difference in sitting and lying time per day at a two-sided 0.05 significance level, with 80% power we need a total sample of 146 participants. This is based on the feasibility data that the standard deviation of the change in sitting and lying time per day was 64 min. However, given the standard deviation of the proportion of change in average steps per day was 24%, in order to detect a 10% treatment difference in steps per day at a two-sided 0.05 significance level with 80% power, we need a total sample of 184 participants. Allowing for 15% attrition, we therefore intend to recruit 212 participants (i.e. 106 for the intervention group and 106 for the waitlist control group) to ensure we have adequate power to detect both primary physical activity outcomes. This increased sample will allow us to detect a 26 min reduction in sitting/lying time (Schoenfeld 2010). We are confident that this sample size target is feasible given the establishment of the Australian Stroke Clinical Registry (Australian Stroke Clinical Registry 2009), and our ongoing links with the National Stroke Foundation and Brain Injury Australia.

The primary time point for the RCT will be immediately following the intervention period. This will capture the efficacy of the program in establishing improvements in physical activity behaviours in the short term. However, given that the focus of the intervention is also on sustaining physical activity levels over time, or improving them further, secondary time points will be at 3 months and 12 months following the intervention. This will allow for the examination of the longer term efficacy of the myMoves program for individuals with ABI.

6.2.6 Discussion

The Intervention Mapping framework utilised for the development of the myMoves program consists of six steps, which although presented linearly, are both iterative and cumulative, allowing for movement back and forth between the steps as new information is gained. The undertaking of a pilot study assessing feasibility and acceptability of a complex intervention, such as the myMoves program, provides valuable information that can be fed back into the development process. This brief iterative review provides an outline of how the myMoves program can be further improved based on participant feedback, both of a quantitative and qualitative nature.

The iterations outlined in this review predominantly involve reviewing Step 4, the development of program materials. Recommended changes to program materials to reduce the complexity and volume of information participants need to read and understand will be particularly important. Improving the uptake of important skills, such as problem-solving, challenging unrealistic expectations and habit formulation, through improvements to the program content, will also be a focus of iterative changes to the program. It was noted from Study IV that the barriers to physical activity changed over time. There was a reduction over the study period in the number of participants reporting some reported barriers, such as pain and fatigue; whilst there was an increase in the number of people reporting other barriers, such as time and having no one to be physically active with. The uptake of skills, such as problem-solving, are important for the myMoves program to improve an individuals ability to manage their physical activity over the long term in the face of change, such as with a change in barriers. However, it should be noted that, although there was a lower reported uptake of some skills, such as scaling down and relapse prevention planning, this is probably due to the fact that feedback regarding the use of these skills was sought immediately following the 8-week program, during which time participants have likely focused more on increasing activity levels, rather than reducing them, or on planning for relapses in the future. It may also, then, be important to gain further iterative feedback from future participants at times of follow-up in addition to post-program time points.

Reviewing Step 5, the implementation plan, will be important to consider the planned additional telephone communication as part of this iterative review. Ensuring participants' preferences for contact and support are considered, it is recommended that the implementation plan be altered to reflect telephone support each week to be the 'default' option, rather than email.

However, in making these iterative changes as per the Intervention Mapping framework, it should be recognised that, overall, the myMoves program had a very high level of acceptability and was feasible to deliver in its current format. Iterative changes, therefore, are likely to be minimal and aimed at further enhancing the program, rather than dramatically altering it from its current form.

Finally, Step 6, the evaluation plan, has been enhanced greatly by the pilot testing that has informed plans for a randomised controlled trial to test the myMoves program for efficacy. A wait-listed control group will be utilised as a control group, with the aim of evaluating whether the myMoves program leads to changes in physical activity and sedentary behaviour over both the immediate 8-week program, as well as at 3-month and 12-month follow-up time periods.

6.2.7 Conclusion

In conclusion, a brief iterative review of the myMoves program has been conducted based on the feasibility and acceptability outcomes received as part of Study IV, and the quantitative and qualitative feedback received from participants. As a result, minor improvements to the program will be made, particularly at Steps 4 and 5 of the Intervention Mapping process. The evaluation plan, Step 6, has been further enhanced by the information gained from this review and Study IV, with the plan updated to reflect future evaluation of efficacy.

CHAPTER 7

Discussion and concluding remarks

7.1 Preface

The primary aim of this thesis was to develop a remotely delivered self-management program focused on increasing physical activity in community-dwelling adults with ABI. This was achieved through undertaking a systematic and scholarly process of intervention development using an Intervention Mapping framework, including a comprehensive needs assessment which included a systematic review of the efficacy of self-management programs on physical activity after ABI, and a survey of a sample of community-dwelling adults with ABI. This chapter will summarise the main findings of the studies presented in this thesis, whilst considering the limitations of this work. Implications, both clinically and in regards to future research, will be discussed.

7.2 Summary of findings

7.2.1. Study I

Study I provided the first systematic review of the efficacy of self-management programs on physical activity specifically in community-dwelling adults with ABI (Jones, Dean et al. 2015b). Only five studies met the eligibility criteria for inclusion in this review (Sit, Yip et al. 2007, Damush, Ofner et al. 2011, Gill and Sullivan 2011, Brenner, Braden et al. 2012, Kim and Kim 2013), and, overall, the studies displayed a high risk of bias. The studies also displayed a high level of heterogeneity in regards to intervention, methodology, outcome measures and sample population; with physical activity included only as a small component in a larger, holistic program in four of the five studies (Sit, Yip et al. 2007, Damush, Ofner et al. 2011, Brenner, Braden et al. 2012, Kim and Kim 2013). For this reason, a meta-analysis could not be conducted. Therefore, to date, the efficacy of self-management programs in increasing physical activity levels in community-dwelling adults following ABI remains unclear. However, this review did demonstrate favourable physical activity outcomes from three of the five included studies (Sit, Yip et al. 2007, Damush, Ofner et al. 2011, Kim and Kim 2013), with two of these studies including remote, as well as face-to-face, delivery (Damush, Ofner et al. 2011, Kim and Kim 2013). This review also suggested there are physical activity benefits for stroke survivors who complete programs with a dosage of 6 to 8 sessions over 8 to 12 weeks (Jones, Dean et al. 2015b). The evidence also indicates that outcomes of self-management programs are optimised when there is a focus on behaviour change and increasing self-efficacy (de Silva 2011, Jones and Riazi 2011). Nonetheless, this review revealed that there is a significant knowledge gap in this area, despite the potential that self-management programs, particularly those developed on sound behaviour change principles, and utilising remote delivery, may offer to individuals living in the community with ABI

7.2.2 Study II

Study II consisted of an online survey of 59 Australian adults living in the community with ABI. The aim was to examine the characteristics, physical activity status and barriers to physical activity experienced by these individuals. Interest in a remotely delivered self-management program designed to increase physical activity was also explored. It was found that a high number of participants (44%) reported they were currently not meeting physical activity guidelines and over 58% of participants were not satisfied with their physical activity status. The most frequently reported barriers to physical activity were pain/discomfort (37%), fatigue (29%) and fear (27%). Participants reported their confidence to overcome these barriers was very low. Also of note was that over 40% of participants displayed some level of psychological distress, with over 16% displaying high levels of distress. However, interest in an internet-delivered self-management program aimed specifically at improving physical activity was high (74%) and provided evidence from a sample of potential participants that a remotely delivered self-management program warranted development.

7.2.3 Study III

The aim of Study III was to develop a multifaceted self-management program aimed at increasing physical activity in adults living in the community with an ABI, using an Intervention Mapping framework. Intervention Mapping process consists of six steps that guide design, implementation and evaluation based on sound theoretical principles and practical information. The steps are presented linearly, however the process is both iterative and cumulative allowing movement back and forth between the steps as information is gained. Study III outlines the work that was undertaken through these steps to develop the myMoves program.

The first step was a needs assessment. This consisted of a review of the epidemiological evidence regarding physical activity after ABI, and a review of behaviour change theories that have been used for physical activity interventions. These results were combined with information gained from Studies I and II. This resulted in a problem-focused model on which to build the myMoves program. Step 2 involved identifying the exact objectives for change that the program would need to achieve in order to meet the overall program outcomes of increasing physical activity and reducing sedentary behaviour in individuals with ABI. Step 3 then outlined the appropriate theoretical methods and practical applications to be utilised in the program to achieve these change objectives.

Information from these first three steps informed the development of the program framework, the *Active Lifestyle Model*, as well as the sequence, scope and program materials that are outlined in Step 4. The program was developed as six modules delivered over eight weeks via email, with each module consisting of a Lesson, a chapter of the Stories and a worksheet. Each module was accompanied by contact from a physiotherapist later in the week by email and/or telephone to check on the participant's progress and provide individualised support. Steps 5 and 6 outline the implementation and evaluation plans for the initial testing of the program for its feasibility and acceptability, which were undertaken as Study IV of this thesis. In summary, Study III demonstrated that Intervention Mapping could be applied as a framework for the comprehensive, scholarly and systematic development for this complex physiotherapy intervention: a self-management program aimed at increasing physical activity in individuals with ABI.

7.2.4 Study IV

The primary aim of Study IV was to examine the feasibility and acceptability of myMoves, a remotely delivered self-management program aimed at increasing levels of physical activity in community-dwelling adults with ABI. An open trial design was employed with data collected prior to program commencement, immediately post-program and at 3-months follow-up. Twenty-four participants commenced the program, predominantly individuals with stroke (83%). Adherence was high and attrition low, with outcomes collected from 23 participants post-program, and 22 at 3-months follow-up. An average of 5.6 (SD 1.2) modules were completed by participants with no significant adverse events reported. Participants reported high levels of acceptability with 95.7% being *very satisfied* or *satisfied* with the program despite an average clinician contact time of only 32.8 (SD=22.8) minutes over the 8-week program. Overall, with both administrative and clinical contact time combined, participants received an average of 3.6 hours (mean 218 minutes; SD 56.6 minutes) of clinician contact over an average of 56 (SD 14.8) instances of contact per participant extending from the application stage, to just beyond the 3-month follow-up. Remote methods of data collection were also successful and acceptable.

Data from secondary outcomes suggest that the myMoves program is a promising intervention. Statistically significant improvements in psychological distress and participation were demonstrated immediately after the program. Participant satisfaction with physical activity was also substantially higher on completion of the program. The majority of participants either maintained or improved their average daily step count, and maintained or reduced their average daily time spent sitting or lying both immediately after the program and at 3-month follow-up, Study IV demonstrates that myMoves, a remotely delivered self-management program focused specifically on physical activity after ABI, is both feasible and highly acceptable, and warrants future testing to evaluate efficacy in a randomised controlled trial.

7.2.5 Study V

An iterative review of the myMoves program was conducted using quantitative and qualitative participant feedback, as well as the results from feasibility and acceptability testing in Study IV. As a result of this review, four key revisions will be made to the myMoves program. These are, to: 1) reduce the length and complexity of the Lessons, 2) simplify the training and application of skills with <50% participant uptake, 3) increase telephone contact with participants, and 4) provide participants with individualised feedback based on initial pre-program measurements of physical activity. The evaluation plan of the myMoves program has also been enhanced to reflect future efficacy testing.

7.3 Implications of the Thesis

Above all, the work conducted in this Thesis has resulted in the development of an innovative, remotely delivered self-management program for individuals living with ABI who have difficulty managing their physical activity. This program has been shown to be feasible to deliver and highly acceptable to individuals with ABI. Although efficacy in regards to increasing physical activity and reducing sedentary behaviour over the long term is not yet established, the work presented in this Thesis has demonstrated positive results from preliminary testing that potentially offers both clinicians and individuals with ABI an alternative to, or augmentation of, traditional face-to-face physical activity interventions that is both feasible and safe.

This work presented in this Thesis has also resulted in a number of other implications for physiotherapy practice and individuals with ABI. These are briefly discussed in this section and compared with current evidence.

Self-management programs targeting physical activity behaviour could be beneficial for individuals with ABI

This work presented in this Thesis, in particular Study I, has shown that there are limited studies examining the impact of self-management programs on physical activity after ABI, particularly those that focus specifically on physical activity in isolation from other risk factors. Yet, as shown in Study II there is a high level of dissatisfaction amongst individuals with ABI in regards to their physical activity status, and a high level of interest in a program that could potentially address this concern. Despite this there is a significant shortage of programs specifically targeting long-term promotion of physical activity in those with ABI (Pawlowski, Dixon-Ibarra et al. 2013, Cleveland, Driver et al. 2015). A previous systematic review by Jones and Riazi (2011) found emerging evidence of benefit from programs that target self-management based on self-efficacy principles for individuals after stroke. A subsequent systematic review by Lennon and colleagues (2013) examining self-management programs for individuals after stroke provided supporting evidence.. However neither of these reviews specifically examined the effect of self-management programs on physical activity (Jones and Riazi 2011, Lennon 2013). In response, Study I of this Thesis provided the first systematic review examining the efficacy of self-management programs specifically on physical activity following ABI.

Physical activity, when included in self-management programs, is often included as only a small component of a larger, holistic self-management program (Jones, Dean et al. 2015b). However, in other clinical populations, such as those that have had a cardiovascular event, a program that focuses on a single risk factor at a time, such as physical activity, has been shown to be beneficial to individuals physical activity scores (Neubeck, Freedman et al. 2011). This work presented in this Thesis provides preliminary evidence to support the use of a self-management program, built on a strong foundation of behaviour change principles, which focuses specifically on physical activity after ABI.

Remotely delivered self-management programs for individuals with ABI are feasible and acceptable

The work presented in this Thesis has demonstrated the potential of, and interest in, remote modes of delivery of self-management programs targeting physical activity after ABI, whilst also demonstrating the feasibility and acceptability of this type of program to individuals with ABI. Remote delivery of self-management programs has been shown to be effective in other conditions, such as depression, anxiety and chronic pain (Johnston, Titov et al. 2011, Titov, Dear et al. 2011, Dear, Titov et al. 2013). There is consistent evidence to support the effectiveness of remote and web-based interventions for increasing physical activity in generally healthy community-dwelling adult populations (Foster, Richards et al. 2013). There have also been promising results from a number of non-randomized stroke-specific studies utilising telehealth interventions (Huijbregts, McEwen et al. 2009, Taylor, Cameron et al. 2009, Jaglal, Haroun et al. 2013). However, this work presented in this Thesis provides the first example of a self-management program specifically targeting physical activity in individuals with ABI that is delivered in a wholly remote manner. The findings presented in this Thesis, in particular those of Study IV, demonstrate both the feasibility and acceptability of remote delivery of a self-management program to this population.

Collection of outcome measures from individuals with ABI can be undertaken remotely

This work presented in this Thesis, in particular Study IV, provides the first example, to the author's knowledge, of a study examining physical activity that has collected objective physical activity data from individuals with ABI in a wholly remote manner. Objective physical activity data was collected from two different physical activity monitors, the activPAL3™ (PAL Technologies Ltd, Glasgow, UK) and the Actigraph GTX3 (Actigraph, Penascola, FL). Information required to correctly initialise the devices was collected remotely via an online survey using Qualtrics software, Version 62626 (Copyright © 2015 Qualtrics, Provo, UT). The devices were sent to participants via an Express Post parcel. Included in the parcel were the dressings needed to apply the activPAL3™ to the anterior thigh and a detailed *Activity Monitor Guide* (Appendix 6). This guide included both written instructions and photographs of how to correctly wear and care for the devices. All devices were successfully received and returned by participants at each of the three time points. All participants were able to correctly wear both devices, either independently or with the assistance of a family member. Similarly, all participant-reported outcomes were collected successfully in a wholly remote manner using internet-based survey software. This study, therefore, demonstrates the feasibility of collecting outcome data, including objective physical activity data, in individuals with ABI through wholly remote means. Remote collection of outcome measures may provide clinicians with an additional method of following clients up over time, or of overcoming barriers related to accessing therapy or assessment, such as those of distance or transport.

Pain, fatigue, and fear are common barriers to physical activity in individuals with ABI

Individuals living with ABI face many barriers to increasing physical activity levels (Driver, Ede et al. 2012, Nicholson, Sniehotta et al. 2013). Study II of this Thesis examined barriers to physical activity from a sample of adults living in the Australian community with ABI. Interestingly, the most commonly reported barriers to physical activity in this study were pain and/or discomfort (37%), fatigue (29%), and fear of performing physical activity (27%). Nearly one quarter of participants (24%) also reported not feeling safe enough to be active outside their home. Study IV reinforced these findings with fatigue, and pain and/or discomfort again being the most commonly cited barriers to physical activity (38% and 33% respectively).

A systematic review by Nicholson and colleagues (2013) examined barriers from four studies of individuals with stroke and found a lack of motivation, environmental factors (e.g. transport), health concerns and stroke impairments to be the most commonly reported barriers to physical activity. Driver and colleagues (2012) examined barriers to physical activity after TBI, and found a lack of endurance, feelings of self-consciousness, a lack of transport, and a lack of time to be most common. There are some differences between the barriers reported in previous studies and the work presented in this Thesis. This is likely due to a more specific focus on planned exercise in many of these previous studies, as opposed to more general physical activity examined in this Thesis. However, the lack of endurance reported in the study by Driver and colleagues (2012) is in line with the fatigue reported as a barrier in this Thesis. These findings are also consistent with epidemiological evidence that reports fatigue is a significant post ABI sequelae up to 75-80% of individuals after stroke and TBI (Michael, Allen et al. 2006, van de Port, Kwakkel et al. 2007, Hoang, Salle et al. 2012, White, Gray et al. 2012, Cantor, Gordon et al. 2013, Miller, Combs et al. 2013, Wu, Mead et al. 2015).

Pain is also not an unexpected barrier to physical activity given that chronic pain is reported in the literature to be apparent in up to nearly half of those individuals with stroke (Appelros 2006, Lundstrom, Smits et al. 2009, Hansen, Marcussen et al. 2012) and 73% of those after TBI (Hoffman, Pagulayan et al. 2007, Nampiaparampil 2008, Sullivan-Singh, Sawyer et al. 2014). The Fogg Behavioral Model stipulates that pain and fear are contributors to overall levels of motivation (Fogg 2009, Fogg 2011), and may, therefore, have been strongly associated with the overall lack of motivation reported by Nicholson and colleagues (2013). Based on the findings of this Thesis, it is particularly important for clinicians to assess individuals with ABI in regards to pain, fatigue and fear, as these may be associated with higher risk of physical inactivity and sedentary behaviour. The findings of this Thesis also demonstrate the potential of a self-management program to ameliorate barriers to physical activity through the building of knowledge and skills, such as problem-solving and planning with a reduction in both fatigue and pain as a barrier to physical activity demonstrated in Study IV immediately after the program and at 3-month follow-up.

Psychological distress is common after ABI and has the potential to be reduced through a self-management program targeting physical activity

Studies reported within this Thesis have demonstrated that psychological distress is common after ABI. Study II found that over 40% of participants reported some level of psychological distress, with over 16% reporting this distress to be in the high level. Individuals with a higher level of distress were also more likely to report a higher number of barriers to physical activity. Study IV found that just under 80% of participants reported moderate to very high levels of psychological distress. These findings are in line with current research that indicates depression and anxiety to be common emotional sequelae of ABI (Hart, Brenner et al. 2011, Tang, Lau et al. 2013, Hackett and Pickles 2014) and reinforce how important examination of psychological wellbeing is for individuals undertaking physical activity interventions following ABI.

The findings presented in this Thesis also indicate the potential of self-management programs targeting physical activity in reducing levels of psychological distress. Study IV found a significant reduction in psychological distress as measured on the K-10 immediately after the myMoves program. Although not statistically significant, the outcomes following the myMoves program showed that participants were 18% (95% CI -8% to 41%) more likely to show low (as opposed to moderate to very high), levels of distress immediately after the program, and 27% (95% CI -1% to 50%) more likely to show low levels of distress 3 months later. Given the benefits of physical activity on emotional wellbeing (Teychenne, Ball et al. 2008), engaging individuals with ABI in interventions that target improvements in long term physical activity is important. Additionally, given the findings of Study II, which indicated that individuals with higher levels of distress were more likely to show interest in a remotely delivered self-management program targeting physical activity, a program delivered in this remote manner may offer clinicians another method of assisting individuals with ABI to benefit from improving their levels of physical activity.

Development of a complex physical activity intervention can be undertaken in a scholarly and systematic way

Changing long-term physical activity behaviour is difficult (Dishman and Buckworth 1996) and empowering individuals to change behaviours and self-manage their physical activity requires complex and multifaceted interventions. Physical activity interventions are rarely developed in a scholarly and systematic way prior to evaluation of treatment effects in randomised controlled trials. There is also a lack of information about how interventions are developed, and their theoretical basis; how specific content is covered; and how the method of implementation is designed (Jones, Dean et al. 2015b). The work presented in this Thesis provides an example of a complex and multifaceted intervention that has been developed based on a coherent theoretical and practical foundation through an extensive scholarly and systematic development process, using an Intervention Mapping framework (Bartholomew, Parcel et al. 2011, Jones, Dear et al. under review). Furthermore, the findings of this Thesis indicate that this intervention is acceptable to the target population, as well as being feasible to translate to clinical practice.

7.4 Limitations of the Thesis

Although the work undertaken for this Thesis has provided a significant contribution to the field of health research, and in particular physiotherapy, there are a number of limitations of this work to be considered. Firstly, the efficacy of self-management programs to improve physical activity in individuals with ABI remains unknown. As established in Study I, very few high quality studies evaluating treatment effectiveness have been conducted. Existing trials have a high risk of bias and are highly heterogeneous with respect to interventions, methodology, outcome measures and samples. Physical activity has been typically assessed as only a small component of larger holistic self-management programs. There is also insufficient information about whether interventions were developed based on a coherent theoretical foundation. The work presented in this Thesis aimed to ensure development of a self-management program aimed at improving physical activity was undertaken in a rigorous, scholarly and systematic manner. Evaluation of the effects of this program remains to be tested in a randomised controlled trial.

Secondly, there is a relatively small and selective sample of participants studied across all the included studies. The participants across all studies were required to have sufficient cognition and language skills to be able to read and understand written English. This somewhat limits generalisation of the results of these studies to a larger ABI population. However, the sample of 59 in Study II does represent one of the largest surveys of individuals with ABI in regards to barriers to physical activity. A small sample is also useful in establishing the initial feasibility and acceptability of a program, such as that undertaken in Study IV, and assists in developing a more comprehensive implementation and evaluation plan for efficacy testing, as demonstrated in Study V. In this case, the heterogeneity of the small sample is representative of a typical ABI population and shows that the program is feasible and acceptable to a diverse range of individuals with ABI.

Thirdly, the myMoves program has been developed with limited consumer input. This has predominantly been derived from information gathered in Study II. It is recognised that it is important to engage stakeholders in all aspects of the development of complex health interventions (Drum, Peterson et al. 2009, Boger, Ellis et al. 2015). This should include consumers, caregivers, health professionals and those involved with commissioning health services (Boger, Ellis et al. 2015). The Intervention Mapping framework does advocate for stakeholder input through all six steps of the intervention development process (Bartholomew, Parcel et al. 2011), and it is recognised as a limitation that there was not greater engagement of stakeholders in the development of this program to date. However, the development of the myMoves program is iterative in nature. Study V has compiled input from stakeholders that will be used to enhance future iterations of the myMoves program, and future development will aim to increase this input further.

A fourth limitation of this thesis is that the myMoves program is focused on individuals with ABI who have high levels of cognition; and are able to read, understand and apply the content taught in the myMoves program. In it's current format the myMoves program excludes those individuals who have poor cognitive ability, aphasia, poor health literacy skills, or are unable to read and understand English. These individuals are likely to be at the greatest risk of morbidity and mortality from physical inactivity and are currently unable to benefit from this intervention. However, it should be noted that, it is likely unrealistic to expect an intervention of this nature to be the right intervention for every individual with ABI. Rather, it represents an option to those for whom remotely delivered programs with minimal clinician support are appropriate.

Finally, one limitation of developing a complex and multifaceted intervention is that identifying which components of the program work most effectively, and which require further improvement, is difficult. Study I demonstrated the difficulties in identifying and quantifying specific content related to physical activity and differentiating the complexities of the manner in which these elements were delivered. However, the work presented in this Thesis demonstrates approaches to overcome these limitations. Study III outlined a scholarly and systematic intervention development process that aimed to both develop a program that meets the theoretical and pragmatic requirements of an effective complex and multifaceted intervention, and reported this development process in a transparent and comprehensive manner. Study IV demonstrated the myMoves program to be both feasible and acceptable to participants, while Study V examined quantitative and qualitative feedback from participants in conjunction with the findings from Study IV to produce an iterative review of the myMoves program as well as outlining plans for future efficacy testing.

7.5 Future directions for research

The body of work included in this Thesis signposts exciting new directions for future research. Specific research opportunities are outlined below.

Gain a more thorough understanding of the components of self-management programs for individuals with ABI that enhance physical activity outcomes

Although components of self-management programs to enhance physical activity outcomes were examined as part of Study I of this Thesis, the small number of trials included in this review limited the conclusions that could be drawn from this. There were a number of trials that were excluded from this review, because they were not randomized controlled trials. Given that this area of research is an emerging field, it is not uncommon for interventions to undergo early pilot testing, as seen in Study IV. Information from these excluded studies may provide beneficial information for optimising the physical activity outcomes of a self-management intervention for individuals with ABI. An alternative approach to a future review in this field would be to include non-randomised studies and apply the GRADE approach to the examination of the quality of the evidence (Higgins and Green 2011). This may allow for more thorough examination of pragmatic trials conducted in this area and provide useful information that can be employed to further enhance the myMoves program.

Test for efficacy of a remotely delivered self-management program that focuses specifically on physical activity for individuals with ABI

Individuals with ABI are often physically inactive and highly sedentary (Driver 2008, Rand, Eng et al. 2009, Hornnes, Larsen et al. 2010, Kunkel, Fitton et al. 2015), making them more vulnerable to morbidity and mortality from chronic disease (Anderson, Carter et al. 2004, Hardie, Hankey et al. 2004, Gall, Dewey et al. 2009, Chen and Rimmer 2011, Braden, Cuthbert et al. 2012). Self-management programs have the potential to improve the health and wellbeing of individuals living with chronic health conditions and disability, particularly when built upon behaviour change principles and focused on improving self-efficacy (de Silva 2011, Jones and Riazi 2011). However, the findings presented in this Thesis demonstrate that efficacy of self-management programs on physical activity in individuals with ABI, although promising, is as yet unestablished.

Given the complexity and multifaceted nature of self-management programs it is important that these programs undergo adequate development and pilot testing prior to efficacy testing (Craig, Dieppe et al. 2008, Bartholomew, Parcel et al. 2011). This work presented in this Thesis has resulted in the development of a complex intervention program based on a coherent theoretical foundation and developed with the needs of the target population in mind. Pilot testing has been undertaken with feasibility and acceptability established, and an iterative review of the program has been conducted. It has been demonstrated that further testing of the myMoves program in a randomised controlled trial format to allows for examination of efficacy is warranted.

In considering efficacy evaluation, it is also important to recognise that the myMoves program has been developed with the underlying principles of building self-management skills in order to improve management of physical activity over both the short and the long term. Therefore, in evaluating efficacy of this program it will be important to include both short and long-term time points for measurement.

Develop a remotely delivered self-management program that focuses specifically on physical activity for the caregivers of individuals with ABI

Future iterations of the myMoves program should consider ways of developing a program that improves access for those individuals currently unable to access this intervention. One method likely to expand the access of the myMoves program may be to develop an iteration of the myMoves program for the caregivers of individuals with ABI. Such a program has the potential to benefit both the caregiver and the individual with ABI. Caregivers have a high level of physical inactivity (Australian Bureau of Statistics 2012), and therefore could benefit from a self-management program that offered support to overcome barriers to physical activity experienced by caregivers themselves. The involvement of caregivers in such a program also has the potential of increasing the social support offered to the individual with ABI. Improving social support has been associated with improved levels of physical activity (Driver 2005).

Further examine the psychological determinants of physical activity behaviour in individuals with ABI

The work presented in this Thesis provides useful information regarding psychological determinants of physical activity following ABI, such as self-efficacy, and barriers to physical activity experienced by individuals with ABI. However, the extent to which psychological determinants relate to successful self-management in still unknown (Boger, Ellis et al. 2015). Jones and Riazi (2011) have recognised the importance of self-efficacy as an important variable associated with a variety of outcomes following stroke, however the relationship of self-efficacy to physical activity specifically is yet to be established for individuals after ABI. In order for a program to be most effective, it is important for the program to be targeted towards objectives requiring change. Further information regarding the most important psychological determinants in regards to influencing physical activity after ABI would be useful in informing the development of effective interventions to assist individuals to change their physical activity behaviour. This certainly warrants further investigation.

Investigate the role of habits

The role of habits has been gaining importance in the application of physical activity interventions (Gardner 2011). However, the relationship of habits to physical activity behaviour has not been closely examined in individuals after ABI. Gaining further insight into the significance of habits to physical activity behaviour after ABI, and the optimal way of establishing habits in order to optimise physical activity behaviour, would be a valuable direction for future research.

Assess health professional attitudes to supporting self-management of physical activity in individuals with ABI

Much of the research to date has examined the role of the individual with ABI in managing their physical activity behaviour. Other external barriers to optimise physical activity levels tend to focus on environmental factors, such as a lack of transport, services or facilities available to enhance physical activity opportunities. However, a key role in supporting self-management in individuals with ABI is that of the health professional. The health professional most commonly, and most ideally placed, to support self-management of physical activity after ABI, is a physiotherapist. However, health professionals, such as physiotherapists, often do not possess adequate training in the skills required to support self-management and assist with behaviour change (Jones, Livingstone et al. 2013). Individuals with stroke have reported that physiotherapy, even when conducted in the home, is not particularly supportive for the development of self-management skills or competencies, and often find there is a lack of empathy and support for building the skills to manage emotionally after a stroke (Satink, Cup et al. 2014). There often remains a disconnect between the goals of the physiotherapist and those of the individual with ABI. In a systematic review of self-management outcomes conducted by Boger and colleagues (2015), twenty different self-management outcomes were identified as being important to the patient and eight to the health professional, of which only two of these outcomes were identified by both groups. For example, patient motivation was selected by health professionals as being important for successful self-management, but not by patients (Boger, Ellis et al. 2015). In order to optimise self-management of physical activity over the long term it is imperative that the attitudes and behaviours of key health professionals involved in this clinical partnership, such as physiotherapists, are examined more closely.

7.6 Conclusions

Individuals living with ABI are often physically inactive and highly sedentary, making them vulnerable to future chronic disease and early mortality. Despite the benefits to health and wellbeing from engagement in regular physical activity, individuals with ABI often face many barriers to physical activity. Previous studies have shown environmental barriers, such as difficulty accessing transport, costs and a lack of available services and facilities to individuals in the community to be common barriers to physical activity (Driver, Ede et al. 2012, Nicholson, Sniehotta et al. 2013). The work presented in this Thesis has shown that other common barriers to physical activity in individuals with ABI include pain/discomfort, fatigue and fear. These barriers are all potentially amenable to a remotely delivered self-management program.

Despite the significance of physical inactivity and ABI globally, the work presented in this Thesis has demonstrated the limited number of studies examining self-management on physical activity in individuals with ABI, with efficacy remaining unclear. Self-management programs have been shown to be worthwhile for individuals with chronic disease and disability when founded on behaviour change theory and the principles of self-efficacy. Therefore, a comprehensive scholarly and systematic approach to the development of a self-management program specifically focused on physical activity and delivered remotely to individuals with

ABI was developed using an Intervention Mapping framework. This process led to the development of the myMoves Program.

The work presented in this Thesis demonstrates that the myMoves Program is both feasible to deliver remotely to individuals with ABI living in the Australian community who are able to read and comprehend written English. The program was also found to be highly acceptable to participants. Secondary outcomes, including psychological distress and participation, in a small sample appear promising. However, in order to examine the efficacy of the myMoves Program on physical activity and sedentary behaviour, future testing in a randomised controlled trial is required.

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Appendices

Appendix 1: Systematic review search strategies

Medline search strategy

1. exp Self Care/
2. exp health education/ or exp patient education as topic/
3. exp consumer participation/ or exp patient participation/
4. exp health communication/ or exp health promotion/
5. exp Self Concept/ or exp Self Efficacy/
6. (self adj care*).mp.
7. (self adj manage*).mp.
8. (patient adj educat*).mp.
9. (self adj monitor*).mp.
10. (self adj efficacy).mp.
11. (self adj concept).mp.
12. ((consumer or patient) adj participat*).mp.
13. ((consumer or patient) adj inform*).mp.
14. (health adj educat*).mp.
15. (health adj promot*).mp.
16. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15
17. exp Motor Activity/
18. exp "activities of daily living"/ or exp leisure activities/ or exp recreation/
19. exp gait/ or exp locomotion/ or exp walking/
20. exp sports/ or exp physical fitness/
21. exp Exercise/ or exp Exercise Therapy/
22. exp Health Behavior/
23. (physical adj activity).mp.
24. (leisure or recreation*).mp.
25. (sport* or fit* or exercis*).mp.
26. (walk* or ambulat* or mobil* or locomotion or gait).mp.
27. 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26
28. 16 and 27
29. exp brain damage, chronic/ or exp brain injuries/ or exp cerebrovascular disorders/
30. (brain adj (injur* or damage)).mp.
31. stroke*.mp.
32. (cerebrovascular adj accident*).mp.
33. exp Stroke/
34. 29 or 30 or 31 or 32 or 33
35. 28 and 34
36. Randomized controlled trial.pt.
37. random*.mp.
38. trial*.mp.
39. control*.mp.
40. controlled clinical trial.pt.
41. placebo*.mp.
42. (intervention adj group*).mp.
43. (treatment adj group*).mp.
44. 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43
45. 35 and 44
46. limit 45 to humans
47. remove duplicates from 46

Embase Search Strategy

1. exp self care/
2. exp health education/
3. exp patient education/
4. exp patient decision making/
5. exp patient participation/
6. exp medical information/
7. exp self concept/
8. (self adj care*).mp.
9. (self adj manage*).mp.
10. (patient adj educat*).mp.
11. (self adj monitor*).mp.
12. (self adj efficacy).mp.
13. (self adj concept).mp.
14. ((consumer or patient) adj participat*).mp.
15. ((consumer or patient) adj inform*).mp.
16. (health adj educat*).mp.
17. (health adj promot*).mp.
18. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17
19. exp physical activity/
20. exp motor activity/
21. exp recreation/ or exp leisure/
22. exp daily life activity/
23. exp sport/
24. exp exercise/
25. exp locomotion/
26. exp fitness/
27. exp physical mobility/
28. exp health behavior/
29. (physical adj activity).mp.
30. (leisure or recreation*).mp.
31. (sport* or fit* or exercis*).mp.
32. (walk* or ambulat* or mobil* or locomotion or gait).mp.
33. 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32
34. 18 and 33
35. exp brain injury/
36. exp cerebrovascular accident/
37. (brain adj (injur* or damage)).mp.
38. (cerebrovascular adj accident*).mp.
39. stroke*.mp.
40. 35 or 36 or 37 or 38 or 39
41. 34 and 40
42. random*.mp.
43. trial*.mp.
44. control*.mp.
45. placebo*.mp.
46. (intervention adj group*).mp.
47. (treatment adj group*).mp.
48. 42 or 43 or 44 or 45 or 46 or 47
49. 41 and 48
50. limit 49 to human
51. remove duplicates from 50

CINAHL search strategy

S14 S11 AND S12 Limiters - Exclude MEDLINE records; Human
S13 S11 AND S12
S12 TX random* OR TX control* OR TX trial OR TX intervention group* OR TX treatment group* OR experimental group*
S11 S7 AND S10
S10 S8 OR S9
S9 TX brain injur* OR TX brain damage OR TX stroke OR TX cerebrovascular accident
S8 (MH "Brain Injuries+") OR (MH "Brain Damage, Chronic+") OR (MH "Cerebrovascular Disorders+")
S7 S3 AND S6
S6 S4 OR S5
S5 TX physical activit* OR TX leisure OR TX recreation* OR TX walk* OR TX activities of daily living OR TX sport OR exercis* OR participat* 228,374
S4 (MH "Physical Activity") OR (MH "Leisure Activities+") OR (MH "Activities of Daily Living+") OR (MH "Sports+")
S3 S1 OR S2
S2 TX self manag* OR TX self care* OR TX patient educat* OR TX self efficacy OR TX self concept OR TX patient participation OR TX concumer participation OR TX health promot*
S1 (MH "Self Care+") OR (MH "Consumer Participation") OR (MH "Health Education+") OR (MH "Health Promotion+") OR (MH "Preventive Health Care+") OR (MH "Self Concept+")

PsycINFO search strategy

1. exp self management/
2. exp health education/ or exp client education/ or exp health knowledge/ or exp health literacy/ or exp health promotion/
3. exp client participation/
4. (self adj care*).mp.
5. (self adj manage*).mp.
6. exp self efficacy/ or exp self confidence/ or exp self perception/
7. (patient adj educat*).mp.
8. ((consumer or patient) adj participat*).mp.
9. ((consumer or patient) adj inform*).mp.
10. (self adj efficacy).mp.
11. (self adj concept).mp.
12. (health adj educat*).mp.
13. (health adj promot*).mp.
14. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13
15. exp physical activity/ or exp active living/ or exp activity level/ or exp health behavior/ or exp locomotion/ or exp physical fitness/
16. exp recreation/ or exp leisure time/ or exp sports/
17. exp walking/
18. (physical adj activity).mp.
19. (leisure or recreation*).mp.
20. (sport* or fit* or exercis*).mp.
21. (walk* or ambulat* or mobil* or locomotion or gait).mp.
22. 15 or 16 or 17 or 18 or 19 or 20 or 21
23. 14 and 22
24. exp brain damage/ or exp cerebrovascular accidents/
25. (brain adj (injur* or damage)).mp.
26. stroke*.mp.
27. (cerebrovascular adj accident*).mp.
28. 24 or 25 or 26 or 27
29. 23 and 28
30. random*.mp.
31. control*.mp.
32. trial*.mp.
33. (intervention adj group*).mp.
34. (treatment adj group*).mp.
35. 30 or 31 or 32 or 33 or 34
36. 29 and 35
37. limit 36 to human
38. remove duplicates from 37

AMED search strategy

1. exp self care/
2. exp Health education/
3. exp health promotion/
4. exp patient participation/
5. exp self concept/
6. exp prevention/
7. (self adj care*).mp.
8. (self adj manage*).mp.
9. (patient adj educat*).mp.
10. (self adj monitor*).mp.
11. (self adj efficacy).mp.
12. (self adj concept).mp.
13. ((consumer or patient) adj participat*).mp.
14. ((consumer or patient) adj inform*).mp.
15. (health adj educat*).mp.
16. (health adj promot*).mp.
17. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16
18. exp "activities of daily living"/ or exp exercise/ or exp independent living/ or exp leisure activities/ or exp physical fitness/ or exp sports/
19. exp locomotion/ or exp motor activity/
20. exp health behavior/
21. (physical adj activity).mp.
22. (leisure or recreation*).mp.
23. (sport* or fit* or exercis*).mp.
24. (walk* or ambulat* or mobil* or locomotion or gait).mp.
25. 18 or 19 or 20 or 21 or 22 or 23 or 24
26. 17 and 25
27. exp brain injuries/
28. exp cerebrovascular disorders/
29. (brain adj (injur* or damage)).mp.
30. stroke*.mp.
31. (cerebrovascular adj accident*).mp.
32. 27 or 28 or 29 or 30 or 31
33. 26 and 32
34. random*.mp.
35. trial*.mp.
36. control*.mp.
37. placebo*.mp.
38. (intervention adj group*).mp.
39. (treatment adj group*).mp.
40. 34 or 35 or 36 or 37 or 38 or 39
41. 33 and 40

Cochrane Central Register of Controlled Trials (CENTRAL) search strategy

ID	Search	Hits
#1	physical* activ*	16274
#2	self-manage*	2061
#3	#1 and #2	424
#4	brain injur*	2933
#5	stroke	29167
#6	#4 or #5	31397
#7	#3 and #6	95
#8	#7 in Trials	3

PEDro search strategy

Two search strategies applied to get an "OR" effect

Physical* activ* AND neurology AND clinical trial

Self-manage* AND neurology AND clinical trial

Science Citation Index Expanded (SCI-EXPANDED) search strategy

#7 #5 AND #6
DocType=All document types; Language=All languages;
#6 TS=(random* OR trail* OR control* OR placebo* OR intervention OR allocat* OR assign* OR blind*)
DocType=All document types; Language=All languages;
#5 #3 AND #4
DocType=All document types; Language=All languages;
#4 TS=(brain injur* OR brain damage OR stroke OR cerebrovascular accident OR cerebrovascular disorder*)
DocType=All document types; Language=All languages;
#3 #1 AND #2
DocType=All document types; Language=All languages;
#2 TS=(physical activity OR motor activity OR leisure OR recreation OR sport OR exercise OR walk* OR fitness)
DocType=All document types; Language=All languages;
#1 TS=(self management OR self care OR patient education OR self efficacy OR patient participation OR consumer participation OR health promotion)
DocType=All document types; Language=All languages;

Appendix 2: Ethical approval for Study II

From: "Ethics Secretariat" <ethics.secretariat@mq.edu.au> Date: 27 August 2013 10:21:14 AM AEST To: "A/Prof Catherine Dean" <catherine.dean@mq.edu.au> Cc: "Dr Blake Dear" <blake.dear@mq.edu.au>, "Dr Julia Hush" <julia.hush@mq.edu.au> Subject: Approved- Ethics application- Dean (Ref No: 5201300495)

Dear Associate Professor Dean

RE: "Survey of physical activity in community dwelling adults following Acquired Brain Injury (ABI)" (REF: 5201300495)

Thank you for your email dated 08 August 2013 responding to the issues raised by the Macquarie University Human Research Ethics Committee (HREC (Medical Sciences)).

The HREC (Medical Sciences) is fully constituted and operates in accordance with the National Health and Medical Research Council's National Statement on Ethical Conduct in Human Research (2007) (the National Statement) and the CPMP/ICH Note for Guidance on Good Clinical Practice.

I am pleased to advise that the above project has been granted ethical and scientific approval, effective 27 August 2013. This research meets the requirements of the National Statement which is available at the following website:

http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/e72.pdf

This letter constitutes ethical approval only. In order to ensure that your research conforms to the governance requirements of MQ/MUH you must contact the Research Administration Coordinator on 9812 3516 before commencing research at this site.

The following documentation has been reviewed and approved by the HREC (Medical Sciences):

1. Macquarie University Ethics Application Form (v2.2- May 2013)

2. Macquarie University Participant Information Sheet and Consent

Form-Physical Activity following Acquired Brain Injury (ABI) (v 2.0, dated 08/08/2013)

3. Questionnaire to be used (no version, undated)

4. Recruitment Advertisement- "Have you had a stroke or a brain injury?"

(no version, undated)

Please note the following standard requirements of approval:

1. The approval of this project is conditional upon your continuing compliance with the National Statement. It is the responsibility of the Principal Investigator to ensure that the protocol complies with the HREC-approval and that a copy of this letter is forwarded to all project personnel.

2. The National Statement sets out that researchers have a "significant responsibility in monitoring, as they are in the best position to observe any adverse events or unexpected outcomes. They should report such events or outcomes promptly to the relevant institution/s and ethical review body/ies, and take prompt steps to deal with any unexpected risks" (5.5.3).

Please notify the Committee within 72 hours of any serious adverse events or Suspected Unexpected Serious Adverse Reactions or of any unforeseen events that affect the continued ethical acceptability of the project.

3. Approval will be for a period of five (5) years subject to the provision of annual reports. NB. If you complete the work earlier than you had planned you must submit a Final Report as soon as the work is completed. If the project has been discontinued or not commenced for any reason, you are also required to submit a Final Report for the project. Progress reports and Final Reports are available at the following website:

http://www.research.mq.edu.au/for/researchers/how_to_obtain_ethics_approval/

human_research_ethics/forms

4. If the project has run for more than five (5) years you cannot renew approval for the project. You will need to complete and submit a Final Report and submit a new application for the project. (The five year limit on renewal of approvals allows the Committee to fully re-review research in an environment where legislation, guidelines and requirements are continually changing, for example, new child protection and privacy laws).

5. All amendments to the project must be reviewed and approved by the Committee before implementation. Please complete and submit a Request for Amendment Form available at the following website:

http://www.research.mq.edu.au/for/researchers/how_to_obtain_ethics_approval/

human_research_ethics/forms

6. At all times you are responsible for the ethical conduct of your research in accordance with the guidelines established by the Hospital and University. This information is available at the following websites:

http://www.mq.edu.au/policy/
http://www.research.mq.edu.au/for/researchers/how_to_obtain_ethics_approval/

human_research_ethics/policy

If you will be applying for or have applied for internal or external funding for the above project it is your responsibility to provide the Macquarie University's Research Grants Management Assistant with a copy of this email as soon as possible. Internal and External funding agencies will not be informed that you have ethics approval for your project and funds will not be released until the Research Grants Management Assistant has received a copy of this email.

If you need to provide a hard copy letter of ethics approval to an external organisation as evidence that you have approval please do not hesitate to contact the Ethics Secretariat at the address below.

Please retain a copy of this email as this is your official notification of ethics approval.

Yours sincerely Dr Karolyn White Director of Research Ethics Chair, Human Research Ethics Committee (Medical Sciences)

Ethics Secretariat Research Office Level 3, Research Hub, Building C5C East Macquarie University NSW 2109 Australia T: +61 2 9850 6848 F: +61 2 9850 4465 http://www.mq.edu.au/research

Appendix 3: Methods and applications for change objectives

Determinants & Change Objectives	Methods	Applications
Knowledge & awareness (KA)		
KA1.11 Describe the benefits of physical activity (PA) *KA1.21* Describe potential risks of low PA and high sedentary behaviour (SB)	Consciousness raising	Written materials cover benefits of increasing PA and reducing sedentary behaviour in individuals with ABI.
	Persuasive communication	Messages within written materials are relevant to the ABI population and show the benefits of PA specifically for this population.
	Tailoring	Information provided is specific to benefits of PA to an ABI population.
	Modelling	Stories of individuals with ABI demonstrate individuals gaining benefits with increasing PA.
KA2.11 Understand contribution of planned and incidental activities to total PA *KA2.12* Understand FITT formula *KA2.21* Understand concept of Scaling Up *KA3.11* Describe the importance of pacing, scaling up and scaling down in managing long-term PA levels	Chunking	Detailed concepts are broken into smaller steps with keywords and schematic representations.
	Advance organizers Providing cues	Course is structured clearly around the *Active Lifestyle Model.* Model is carried through the program with each Lesson showing progress through the model schematically.

	 Modelling	Keywords are kept consistent throughout course. Keywords are designed for translation into everyday life. Stories demonstrate individuals gaining an understanding and awareness of new information gradually. Stories and examples include individuals having difficulty at times with understanding difficult concepts to maximise effect of modelling.
KA2.31 Describe types of common barriers to PA *KA3.21* Demonstrate awareness of barriers changing over time	Consciousness raising Tailoring Chunking Modelling	Written materials discuss common barriers experienced by individuals with ABI. Information about barriers is based on research into barriers in the ABI population. Common barriers broken into different groups using *Fogg Behavioral Model* as a framework. Stories include examples of individuals facing different barriers that also change over time.
KA2.41 Describe the difference between realistic expectations, positive thinking and goal setting *KA2.51* Understand the role of goal setting in returning to or maintaining different areas of life.	Consciousness raising Modelling	Written materials make direct comparisons between the concepts of expectations, positive thinking and goals. Stories show individuals gaining an awareness of the differences in these concepts, and the role of goals in building and maintaining an active lifestyle.

KA3.31 Describe how habits can assist in maintaining long term PA	Consciousness raising Modelling Implementation Intentions	Written materials provide information about the role of habits in bypassing more complex decision making and assisting in maintain PA levels. Stories demonstrate that individuals can introduce small habits easily into their life and use these to make significant changes in PA. Participants are taught the link between cues and actions in the formation of habits.
KA3.41 Understand common causes for lapses in PA.	Consciousness raising Tailoring Modelling	Written materials outline common causes for lapses in PA. Information is tailored to lapses common in the ABI population. Stories present examples of lapses experienced by individuals with ABI.

Skills & self-efficacy (SSE)		
SSE1.11 Express confidence in gaining benefits from PA	Persuasive communication Tailoring Individualization Modelling	Materials contain positive messages about the benefits of PA after ABI. Materials contain information specifically relevant to individuals with ABI. Worksheets, and communication with researchers via email and/or telephone allow for information to be individualised and benefits specific to each individual participant discussed. Stories demonstrate individuals with ABI gaining benefits from increasing participation in ABI.
SSE2.11 Identify desired planned and incidental PA for own participation	Participation Modelling Individualisation	Participants select the activities they would like to participate in. Worksheets continue to build skills around chosen activities each week. Stories show individuals with ABI participating in a variety of planned and incidental activities. Participants can discuss individual activity choices with researchers.
SSE2.12 Express confidence in application of FITT formula to planned and incidental PA	Active Learning	Worksheets encourage active participation in applying new skills.

SSE2.21 Express confidence in application of Scaling Up to planned and incidental PA *SSE3.11* Express confidence in implementing Pacing, Scaling Up and Scaling Down strategies.	Guided practice Modelling Set tasks on a gradient of difficulty Mastery	Worksheets take participants through each new skill in a guided manner. Stories show individuals with ABI applying new skills learnt, including difficulties experienced in application. Materials outline steps in gradually implementing new skills in a step by step manner to allow for progression of the difficulty of activities. Active participation in application of new skills with support allows for growing mastery of skills.
SSE2.31 Be able to confidently identify individual barriers to PA *SSE2.32* Be able to confidently use problem-solving & planning to manage barriers to PA *SSE3.21* Express confidence in identifying new barriers to PA and using problem-solving & planning to manage these	Tailoring Individualisation Active Learning Guided practice Modelling	Materials contain information regarding barriers that are common to individuals with ABI. Participants can discuss individual barriers and problem-solving strategies with researchers. Worksheets involve participants in active application of skills to identify barriers, problem-solve and plan. Worksheets take participants through each new skill in a guided manner.

	Mastery	Stories show individuals with ABI identifying their own barriers and using problem-solving and planning to manage these. Active participation in application of new skills with support allows for growing mastery of skills.
SSE2.41 Be able to confidently recognise and challenge unrealistic expectations	Individualisation	Participants can discuss individual expectations with researchers.
	Active Learning	Worksheets involve participants in active application of skills to identify and challenge unrealistic expectations.
	Guided practice	Worksheets take participants through skill of challenging unrealistic expectations in a guided manner.
	Modelling	Stories show individuals with ABI recognise and challenge expectations that are unrealistic. Stories demonstrate increasing levels of efficacy with practice.
	Mastery	Active participation in application of new skills with support allows for growing mastery of skills.
	Improving physical and emotional states	Participants are taught to interpret physiological and affective states associated with negative feelings generated from

		unrealistic expectations.
SSE2.51 Express confidence in setting short & long term goals	Participation Goal setting Modelling Individualisation	Participants select the goals that are specific to them. Skills of goal setting are covered in Lesson and Worksheet. Stories show individuals with ABI setting different short and long term goals. Participants can discuss individual goals with researchers.
SSE3.31 Express confidence in building new habits	Active Learning Guided practice Cue altering Modelling Set tasks on a gradient of difficulty Mastery	Worksheets encourage active participation in applying new skills of habit formation. Worksheets take participants through the process of building habits in a guided manner. Participants are taught the skill of selecting appropriate cues for creating preferred habits. Stories show individuals with ABI applying new skills learnt, including difficulties experienced in application. Participants are taught to start by setting small, easy to achieve habits that can be expanded over time.

		Active participation in the application of new habits with support from researchers allows for growing mastery.
SSE3.41 Express confidence in identifying lapses in PA *SSE3.42* Express confidence in developing and implementing a Relapse Prevention Plan	Tailoring Implementation intentions Planning coping responses Modelling Guided practice	Materials contain information regarding lapses in PA that are common to individuals with ABI. Participants are taught skills to identify lapses which link to a Relapse Prevention Plan. Participants are taught skills to overcome lapses in PA to avoid a relapse to a sedentary lifestyle. Stories show participants experiencing lapses in PA and how they overcame these with planned responses. Worksheet guides participants through the creation of a Relapse Prevention Plan.

Outcome expectations & beliefs (OEB)		
OEB1.11 Expect to gain benefits from being PA *OEB1.12* Believe that participation in PA is safe and beneficial *OEB1.21* Expect to reduce risks with increased PA *OEB2.11* Expect that benefits of PA can arise from both planned and incidental PA participation	Modelling Tailoring Persuasive communication Mastery	Stories demonstrate how individuals with ABI can benefit from participation in PA, that participation in ABI is safe and that both planned and incidental PA can be beneficial. Information given to participants is specific to individuals with ABI, outlining specific benefits to this population. Materials contain persuasive messages about the benefits of PA to individuals with ABI. Individuals can experience benefits from increasing participation in PA.
OEB2.12 Expect that understanding the FITT formula is helpful in the development of a PA program *OEB2.21* Expect that Scaling Up can be useful in achieving desired PA levels *OEB3.11* Expect that the application of pacing will assist in managing pain and fatigue. *OEB3.12* Expect that scaling up and scaling down can result in greater control of PA over the long-term	Modelling Persuasive communication Mastery	Stories demonstrate how individuals with ABI can benefit from using the skills of Scaling Up and Pacing, particularly to manage pain & fatigue. Stories also demonstrate increasing levels of control over PA, and reduced feelings of helplessness. Materials contain persuasive messages about the benefits of Pacing and Scaling Up to individuals with ABI. Individuals experience benefits from increasing participation in PA through the

		implementation of these strategies.
OEB2.31 Expect that barriers to PA can be identified and managed with problem-solving and planning skills	Modelling	Stories demonstrate how individuals with ABI identify and manage barriers.
OEB3.21 Expect that new barriers to PA can be identified and managed with problem-solving and planning skills	Mastery	Individuals experience benefits from increasing participation in PA through the implementation of these strategies.
OEB2.41 Believe that realistic expectations will enhance physical and emotional well-being	Belief selection	Participants are taught to link realistic expectations with enhanced emotional and physical well-being.
	Modelling	Stories demonstrate how individuals with ABI benefit from enhanced physical and emotional well-being as a result of challenging unrealistic expectations.
	Mastery	Individuals experience increased feelings of well-being from holding more realistic expectations about themselves.
OEB 2.51 Expect that goals can be achieved	Modelling	Stories demonstrate how individuals with ABI achieve their goals. Individuals demonstrate different levels of difficulty in achieving goals to ensure they are realistic.
	Mastery	Individuals gain heightened belief in goal achievement from experiencing it directly.
OEB3.31 Expect that habits can enhance PA	Modelling	Stories demonstrate how individuals with ABI enhance their PA through the implementation of healthy habits.

	Mastery	Individuals gain heightened belief in goal achievement from experiencing it directly.
OEB3.41 Expect that lapses in PA are normal *OEB3.42* Expect that lapses in PA do not have to lead to a relapse to a sedentary lifestyle. *OEB3.43* Expect that a Relapse Prevention Plan can manage a PA lapse and guide a return to desired PA levels	Modelling Belief selection Mastery	Stories demonstrate how individuals with ABI experience lapses in PA, but are able to manage them with a Relapse Prevention Plan. Participants are taught that a lapse in PA doesn't have to lead to relapse to a sedentary lifestyle. Individuals gain heightened belief in goal achievement from experiencing it directly.

Habits (H)		
H2.31 Develop routines that assist in managing barriers to PA *H2.51* Develop habits that enhance success of PA goals	Implementation intentions	Participants are taught to develop of habit formulas, which outline the link between a cue and an action.
H3.11 Develop habits that maintain PA levels despite fluctuations in motivation	Cue altering	Participants are taught to alter cues to behaviours to enhance PA.
H3.21 Develop routines that assist in identifying new barriers and in managing these	Stimulus control	Participants are encouraged to remove cues to unhealthy behaviours and add cues that promote PA.
H3.31 Develop habits that enhance PA despite fluctuations in motivation *H3.41* Develop habits that mediate the effects of PA lapses.	Early commitment	Participants are encouraged to choose rewards that will be used to celebrate actions that are triggered in a habit formula.
	Modelling	Stories demonstrate how individuals with ABI successfully develop and implement habit formulas.

Appendix 4: Examples of myMoves program materials

Excerpt from a Lesson

myMoves

Helping to Manage Physical Activity

Lesson 2: Managing Activity Levels

MACQUARIE University

MyMoves was written by Ms Taryn Jones, Dr Blake Dear, Prof Catherine Dean, A/Prof Julia Hush and Prof Nick Titov

MACQUARIE UNIVERSITY CENTRE FOR PHYSICAL HEALTH

eCentreClinic

Lesson 2: Managing Activity Levels

1. Welcome to Lesson 2 of myMoves

Welcome to Lesson 2 of myMoves. We do hope you found Lesson 1 useful in introducing you to this course. We also hope you found the DIY task and the Stories helpful in identifying some ways the Active Lifestyle Model may be applied to your life. Don't worry if you found this difficult, as we will be spending time on each of these elements over the next four Lessons.

In Lesson 2 we will be focusing on the first element of the Active Lifestyle Model – Managing Activity Levels.

By the end of this Lesson you will have a better understanding of physical activity and will be able to start to put together a physical activity program that is right for you. We will examine the elements of a really helpful formula, the FITT Formula, so you can structure your program to be at the right level for you. We will also discuss how physical activity levels can be managed using Scaling Up and Pacing to assist in managing pain, fatigue and as well as loss of strength and fitness.

Lesson 2 is the longest Lesson in the course. However, all of the information covered this week is really important. Because of this you may find it helpful to spread this Lesson out over the week and read a section at a time. Importantly, as with all of the Lessons, most people will have to read through the lessons multiple times in order to understand, absorb and remember the information.

Once again, should you have any questions please feel free to contact the myMoves Team (email: taryn.jones@mq.edu.au). We will also be in contact with you over the week to see how you are going.

Good luck!

The myMoves Team

2. The challenge of physical activity

Physical activity can be challenging for anyone - whether you are new to physical activity, trying to build up your physical activity or trying to work out how you can make your physical activity last for the long term. We understand how all of these things can become even more challenging once you have experienced an ABI.

We discussed in Lesson 1 how most people with an ABI struggle to get enough physical activity for optimal health. It is common after an ABI to have spent some time in hospital and to have lost a lot of physical fitness and strength. Your mobility may be affected by your ABI, and it is common for people to feel very anxious and fearful about physical activity. It is also common for people to find physical activity painful or uncomfortable, tiring or overwhelming. Very common questions that people with ABI have asked us are:

- "How do I even start a physical activity program?"
- "What is safe for me to do with my mobility problems?"
- "How can I be active when I get pain from exercise?"
- "How can I be active when I am so tired?"

Sometimes people may be able to start a program but then find that it isn't right and they are unsure how to change it to make it better for them. It may be they are worried about progressing an activity to make it a bit more challenging, or maybe they have progressed an activity too quickly and found they get pain so they stop altogether. Even if you have been an active person in the past, there may be new challenges that you are facing now. You may find that your old exercise regime no longer works for you and you are not sure what to do instead. Or maybe you are not sure how to adjust to your old program so that it is better suited to you now.

After an ABI most people who are struggling with managing their physical activity tend to use one or two unhelpful approaches:

- **Under-Doing physical activity**
- **Over-Doing physical activity.**

Let's have a look at these unhelpful approaches in more detail.

3. Under-Doing & Over-Doing

Under-Doing and Over-Doing physical activity are very common methods that people use to manage their physical activity. They are very common in the general population, but are especially common in people with health conditions, such as those who have had an ABI. However, these two approaches are usually not helpful ways to manage physical activity. Let's look at what Under-Doing and Over-Doing activity means:

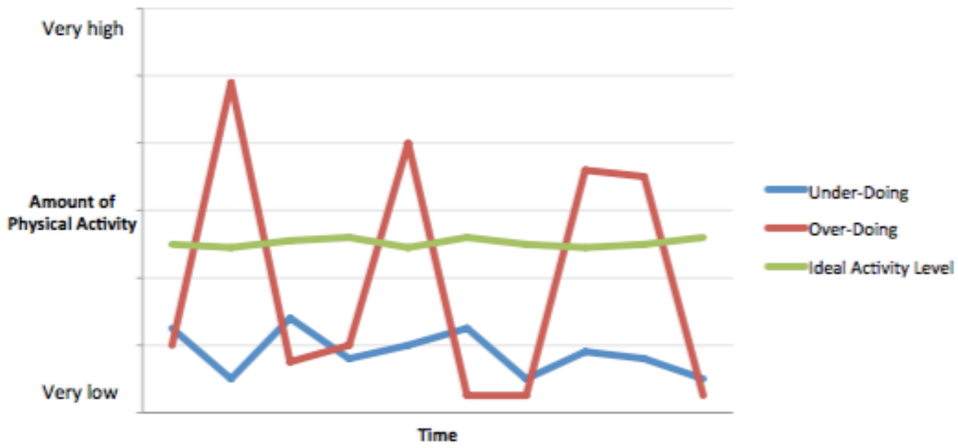
Under-Doing

Typically people who Under-Do their physical activity avoid physical activity altogether or only do very small amounts of activity that does not allow them to optimise their health and well-being.

Over-Doing

Typically people who Over-Do their physical activity often try and perform as much physical activity as they can when they are feeling motivated or feeling good, only to find that this is not sustainable. Often Over-Doing, tends to result in a period of Under-Doing that follows it.

Figure 1: Common activity behaviours



On the next page you will see a table that outlines common challenges associated with Under-Doing and Over-Doing physical activity. Check any that apply to you. You may find that you have check boxes pertaining mainly to one type of behaviour, or that you experience both at different times.

Challenges leading to Under-Doing

- ☐ Fear of causing further injury or falling
- ☐ Anxiety around further damage to the brain or body
- ☐ Lack of knowledge of how to build a physical activity program
- ☐ Lack of time
- ☐ Feelings of tiredness and fatigue – physical and/or mental
- ☐ Difficulties with mobility
- ☐ Physical activity causes pain or discomfort
- ☐ Avoiding activity as much as possible
- ☐ Spend lots of time spent sitting or lying down
- ☐ Feeling of being frozen or overwhelmed by barriers to activity
- ☐ Feeling activity is just too difficult
- ☐ Don't know how to progress current program to make it more effective
- ☐ Have been told not to do too much by a health professional or family member
- ☐ Feel embarrassed or self-conscious doing physical activity
- ☐ Just can't get motivated to be active
- ☐ No access to good facilities or locations
- ☐ Other: ______________________________ ______________________________
- ☐ Other: ______________________________ ______________________________
- ☐ Other: ______________________________ ______________________________

Challenges leading to Over-Doing

- ☐ Pain causing activity levels to fluctuate
- ☐ Find activity difficult so tend to rely on high levels of motivation and will-power
- ☐ Lack of time on a consistent basis
- ☐ Difficulty planning to fit activity in on a consistent basis
- ☐ Need someone to help with transport or exercise
- ☐ Do activity only in bursts
- ☐ Tend to push self very hard for small periods of time
- ☐ Feelings of failure when can't sustain activity over the long term
- ☐ Feelings that you should be doing exercise but don't enjoy it
- ☐ Only have small periods of time to fit activity in
- ☐ Belief that exercise is only worthwhile if you get enough done
- ☐ Activity causes fatigue
- ☐ Work around the schedule of others to fit activity in
- ☐ Need to feel motivated to be able to be really active
- ☐ Other: ______________________________ ______________________________
- ☐ Other: ______________________________ ______________________________
- ☐ Other: ______________________________ ______________________________

The effects of Under-Doing and Over-Doing physical activity

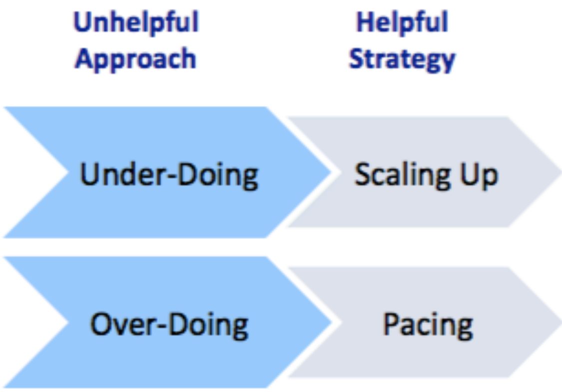
The overall problem with these two approaches is that neither is optimal for overall health and well-being.

Under-Doing activity often stops us from achieving the levels of physical activity that is needed for good health and well-being. There are also often additional problems stemming from high levels of sedentary behaviour (that is, lots of sitting and lying down). This leads to further loss of fitness and strength, that in turn makes physical activity even more difficult. Mobility can worsen, as can pain and fatigue.

Over-Doing activity often leads to fluctuations of periods of high levels of activity and periods of very little. The times of heightened activity are usually not sustained for very long, leading to feelings of failure, guilt and frustration. This can lead to low mood and worry, which are often common after ABI. Often pain is worsened during these times and activity generally becomes a negative, unpleasant experience. The alternate periods of lower activity result in a loss of fitness and strength, making it even less likely that the next heightened activity time will last.

Correcting Under-Doing and Over-Doing

There are some simple strategies that can be employed to address the problems of Under-Doing and Over-Doing.



You will also learn additional skills learnt in future Lessons on Managing Barriers, Managing Expectations and Managing Habits, which will help to build on these strategies and assist you to develop a physical activity program that will last for the long term, for you.

Before we look at the details of Scaling Up and Pacing, let's first examine FITT Formula. This provides the foundation upon which we will apply the skills of Scaling Up and Pacing, and build a program that is right for you.

Pat (64, Melbourne, Vic)

Hello. I am Pat and I am a stroke survivor from Melbourne. I am now 64, but had my stroke at 61. It really turned my world upside down I can tell you. I had considered myself pretty healthy as I wasn't overweight and I didn't smoke. But – I look back now and I wasn't really taking good care of myself. I was still working long hours as a Senior Architect for a large firm in the city. With times tough in our game after the recent financial crisis I was really working harder than ever. I loved my job, but it meant long hours at my desk. I would get out on site at times, but more often this would still involve long hours driving to different sites around the city and suburbs. I would then come home, have dinner and spend more time in my home office before going to bed. I was really pretty inactive most days.

Janice (42, Central Coast, NSW)

Hello. My name is Janice. I am 42 and live on the Central Coast of NSW. I had a car accident when I was 36 that resulted in a brain injury. At the time my two boys were only young – Blake was 4 & Josh only 2. It was a really hard time for us all, not that I remember the early days!

My accident happened not far from home. I was on my way to collect the boys from pre-school and apparently a truck lost control coming round the corner. I was airlifted to John Hunter Hospital in Newcastle and was in ICU for a week, and the acute ward for another 2 weeks or so. It was then a long hard slog of rehab for 3 months to get back my mobility. I couldn't walk initially, but now I can. It took a long time though! I can now walk for about 1km but then my right leg starts getting tired and I have to watch I don't trip over my own foot. If I am going to be out all day I still need to take a stick with me as it just gets too much after a while. I also had quite a lot of fractures from the accident – my left upper arm bone was smashed, and I had a lot of broken ribs. I had surgery to repair my arm and have some pins and plates in there to hold it together. I also get quite a bit of back pain – probably from the way I walk as I have a bit of a limp. It really bothers me when I am trying to get the housework done. I end up with pain for ages, especially after vacuuming or cleaning the bathroom. Even just picking up stuff around the house, or doing the washing can be hard.

Bridie (24, Sydney, NSW)

Hi. My name is Bridie. I am 24. I live in Sydney. I had a stroke when I was 21. I didn't even know young people had strokes!! I couldn't believe it. How could this have happened to me? It still doesn't seem fair.

My stroke was probably less severe than other people's strokes, but it made me really uncoordinated and slow to do things. I can't think very fast now and I find busy, noisy environments really stressful as I just can't focus on what people are saying. It is awful. People wonder what is wrong with you as on the outside you seem okay. I used to be a really outgoing person, but now I tend to stay in a lot. It is just easier. I have a few friends who I spend some time with but I avoid going out to pubs or restaurants with them. My friends don't really understand and they are all moving on in their lives. I still live with my mum and I had to drop out of Uni.

Huan (37, Adelaide, SA)

Hello. My name is Huan. I live in Adelaide. I would like to tell you about my experience in having a stroke. I am 37. I had my stroke 1 year ago. It gave my wife, Meiying, and I a big scare. My father had died of a stroke and so I knew a bit about them but this young? It was all a lot to take in. I thought I was going to die too. My father had been only 52 when he died. I had thought this was young for a stroke…but mine was even younger! My wife is worried that I will have another one, this time more fatal. She says that I need to become healthier and fitter so I don't have another stroke. She is right...but some days it just all seems so hard.

Sue (66, Brigadoon, WA)

Hello. My name is Sue. I am 66 and live with my husband on a small farm in Brigadoon, WA.

I had a stroke 2 years ago. It was only a mild one but it really shook my confidence. I had always been a capable person, and very active in our local community. I was involved in the local Horticulture Association as I enjoyed gardening very much. I also love horses and would volunteer each week for the Riding Develops Abilities group we run here in Brigadoon. I really loved it.

Since my stroke I have not been back to these activities. I have some trouble walking and need to use a walking stick outside. I am really scared of falling and hurting myself by walking on uneven ground. To be near the horses makes me even more worried.

Greg (22, Brisbane, QLD)

Hey. I am Greg. I am 22 and am currently studying part-time at Uni in Brisbane. I had a TBI after a fall from a ladder 4 years ago. I had been helping my dad clean out the gutters at home when I lost my balance. Next thing I knew it was 2 and half weeks later and I was skinny and weak. I needed help to do everything! I was in hospital for 10 weeks and then still had physio and OT once I got home.

I had been really fit before my accident. I was playing football at a high level but that stopped when I had my fall. My mum was too worried I would get hit in the head, and to be honest I couldn't play anyway. Although the doctors and physios had said I had made good progress, I had lost too much strength, coordination and fitness to play football. It seems like a different life - like a dream that I had once been able to play so well. I miss it heaps and it doesn't feel like good progress to me at times. I get spasms in my legs when I'm tired, especially my left one. My left arm also doesn't work as well, and when I try to run it tends to spasm up. I hate that. It makes me look a bit weird.

Excerpt from a chapter of the Stories

myMoves

Helping to Manage Physical Activity

The Stories: Chapter 3

MACQUARIE University

MyMoves was written by
Ms Taryn Jones, Dr Blake Dear,
Prof Catherine Dean, Dr Julia Hush
and Prof Nick Titov

MACQUARIE UNIVERSITY | CENTRE FOR PHYSICAL HEALTH

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Helping to Manage Physical Activity

1. Welcome to Chapter 3

Welcome to the Chapter 3 of our Stories.

In this chapter of The Stories we will see how our friends have started using the strategies of Problem solving and Planning to help manage their barriers.

Each of our friends face different barriers to the activities they want to do. Some face barriers that are mainly affecting their ability levels, whilst others struggle more with motivational issues. However, by going through the process of identifying their barriers, problem solving for solutions and implementing and reviewing a plan of action physical activity levels can be improved.

Once again, we hope you find these Stories helpful in assisting you to build the skills that will help you to manage the barriers in your life.

Kind regards,

The myMoves Team.

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5. Huan (37, Adelaide, SA)

Hello.

I started working through my barrier solutions to tennis this week. It felt strange being back on a tennis court again after so long but it has been fun. We have only played twice but the way I have worked out my position on the court and having regular rest breaks seems to be working quite well.

I have also been practicing my Scaling Up with my walking to the station each day. It is going really smoothly with no real hiccups so far. Meiying and I have gradually worked out two progressions for my drop off and it has worked well each time.

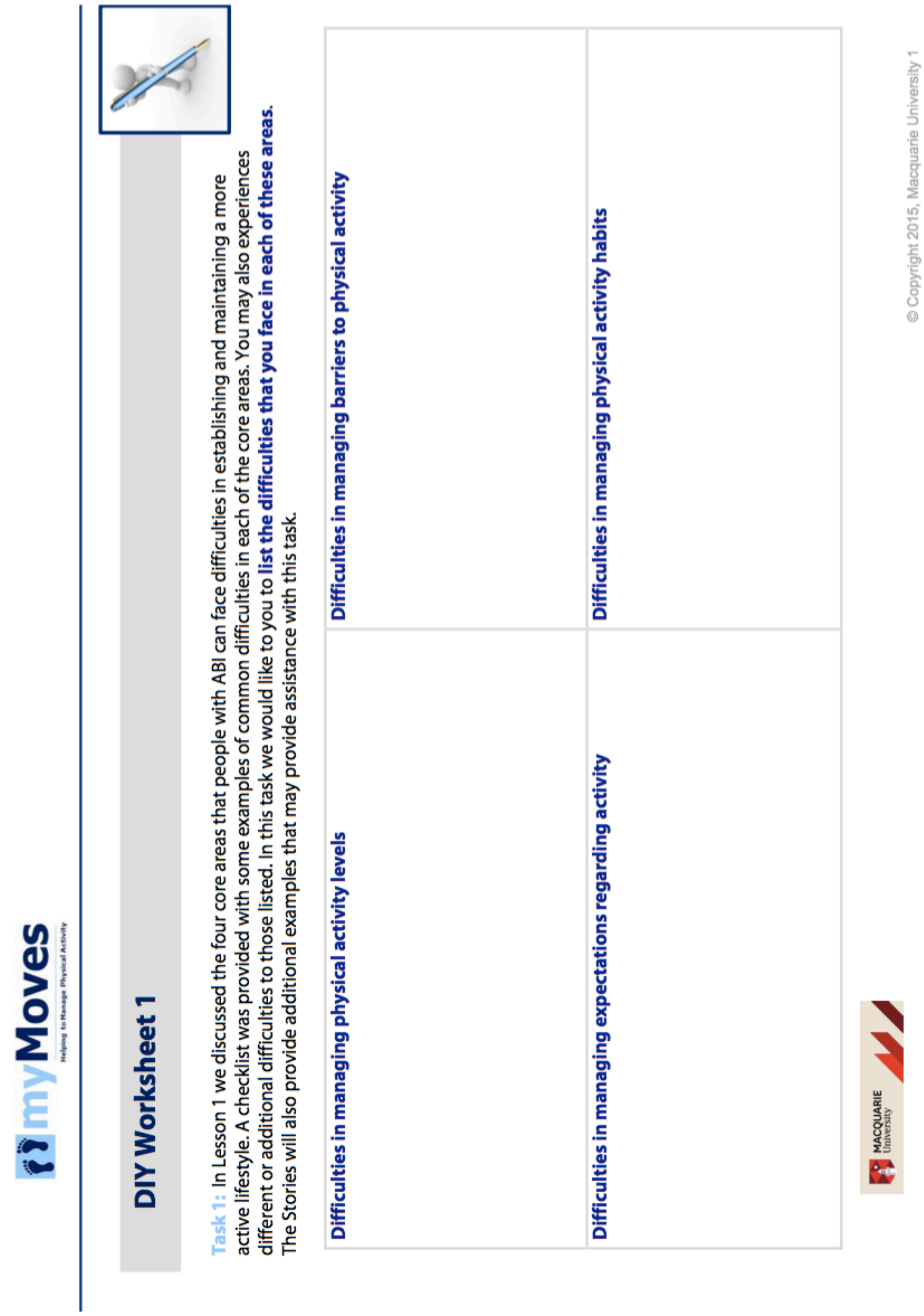
However, I can foresee a challenge coming up shortly. Closer to home there is a really big hill that I will need to walk up on my way to work and down on my way home. To be honest, it is this hill that was the main reason I hadn't walked to the station initially. Going up the hill is quite physically hard but down is also a worry because I don't feel as strong on my left leg and worry about my knee giving way.

However, I am going to try and problem solve around these barriers, rather than just avoiding them. I will start with the uphill, as this is probably the easiest barrier to think of solutions for. Meiying had suggested dropping me part of the way up the hill so I didn't have to walk the whole way. This is a good idea, although I did wonder whether starting to walk on the flat to get my leg going first might be better. So what I will do is do a few leg exercises that I had from physio at home before I leave - just 5 minutes worth, but it will get me moving. Then Meiying can drop me part the way up the hill and we can gradually extend this so I walk the entire hill over time.

For the downhill - I have had to wrack my brain a bit more for ideas. My knee has never given way but it just doesn't feel stable on a big hill like this. So, I bought one of those fold up walking sticks that I can fit in my bag. I used to use a walking stick for a period of time after my stroke so I know how to use one. I will just get it out for the steep down hill section of my walk, just to give me that extra bit of stability and confidence.

I will let you know how it goes!
Huan.

Example of a Worksheet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DIY Worksheet 1

Task 1: In Lesson 1 we discussed the four core areas that people with ABI can face difficulties in establishing and maintaining a more active lifestyle. A checklist was provided with some examples of common difficulties in each of the core areas. You may also experiences different or additional difficulties to those listed. In this task we would like to you to **list the difficulties that you face in each of these areas.** The Stories will also provide additional examples that may provide assistance with this task.

Difficulties in managing physical activity levels	**Difficulties in managing barriers to physical activity**
Difficulties in managing expectations regarding activity	**Difficulties in managing physical activity habits**

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Task 2: In Lesson 1 we discussed two main types of physical activity – planned physical activity and incidental physical activity. Over the myMoves course we are going to build the skills that can help you to increase both your planned and your incidental physical activity levels. However, the type of activities you choose to work on is entirely up to you. In this next task your job is to record **1 planned activity** and **2 incidental activities** that you would like to work on over the coming weeks. If you are stuck for ideas refer back to the list of common examples of each type of activity on page 10 of Lesson 1. Try to pick activities that you are likely to enjoy doing, feel comfortable doing and are realistically able to achieve at this stage.

Record your activities here. We will refer to these activities in Lesson 2 next week.

Activity	**Why did you pick this activity?**
Planned physical activity:	
Incidental physical activity 1:	
Incidental physical activity 2:	

Appendix 5: myMoves program website home page

Appendix 6: Activity Monitor Guide

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Helping to Manage Physical Activity

Physical Activity Monitor Guide

MACQUARIE University

MyMoves was written by
Ms Taryn Jones, Dr Blake Dear,
Prof Catherine Dean, Dr Julia Hush
and Prof Nick Titov

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1. Introduction

Welcome to the Physical Activity Monitor Guide. Here you will find all you need to know about the physical activity monitors we have sent you. We have information on how to wear them correctly, and what you need to know about how to look after the monitors over the observation week. Read the information through thoroughly, and then keep this guide handy as a reference.

You will find two activity monitors in the package we have sent you. The two devices are different. In this guide there is information specific to each of the monitors. There are also instructions on how to return the monitors to us at the end of the week.

It is important that you wear the activity monitors on the side of your body, which has been determined based on the information you have provided us. This side is specified in the sections of this guide specific to each monitor.

During the observation weeks we would like you to continue with your usual activities. You do not need to do anything different.

We appreciate your assistance in wearing these monitors. At the end of the study we will be able to provide you with a summary of your physical activity data taken from these monitors over each of the observation weeks.

We will be in contact regularly during the observation week. However, should you have any concerns or questions regarding the physical activity monitors please contact me at any time on taryn.jones@mq.edu.au

Kind regards,

Taryn Jones

2. What is in my parcel?

Your parcel contains several important items. These are:

1. A red **Actigraph** activity monitor attached to an **elastic belt**
2. An **ActivPAL** activity monitor covered in plastic wrapping
3. Five 8 x 10cm sheets of **Opsite Flexifix dressing** – you will use one to secure the activPAL on your thigh and keep the others as spares.
4. This **Activity Monitor Guide**
5. An **Activity Monitor Log Sheet**
6. A **smaller Express Post parcel bag** addressed to Taryn Jones
7. Spare **bubble wrap** to be used to wrap the activity monitors before returning them to us.

Actigraph

ActivPAL

3. When do I start wearing the activity monitors?

Both of the devices should be put on **before 11.59pm on the night of Saturday 7th February** as they are programmed to commence collecting information at midnight.

For most people, this will mean putting the monitors on before going to bed on Saturday 7th February. We will send you a text or email reminder on this date to remind you to put the devices on.

The devices can be removed on the **morning of Sunday 15th February**.

There is no "on/off" switch on either of the monitors. The monitors operate on battery and are programmed to work continuously during the observation week without you needing to do anything to them.

The following sections have information specific to each of the devices, including how to put them on correctly.

4. Actigraph

This small activity monitor **records general movement** and allows us to get a better idea of your overall activity level. It will come to you already on an elastic belt. It is important to our study that the monitor is worn correctly. The belt may feel slightly awkward at first, however most people report that after the first few hours they get used to it and don't really notice the monitor or the belt at all.

How to put on the Actigraph

- Wear this monitor on the belt **around your waist just above your ______________ hipbone** (see photo below).
- You can wear the monitor **either underneath or on top of your clothing**. However, if you have a very bulky jacket or jumper on it is best to wear the monitor underneath these.
- Adjust the belt so that the monitor sits **firmly but comfortably against your body**. It should be snug enough that it doesn't move about when you are moving. You can tighten the belt by pulling the end of the strap, or loosen it by pushing more of the belt through the loop.
- It does not matter where the **buckle** sits so position this wherever you feel is comfortable. You may need to slide the actigraph along the belt to maintain the correct position above your hipbone. You may need to secure the loose ends of the elastic by looping them through the belt.

This photo depicts correct position of the actigraph above the **left** hipbone. The position is similar for the right side. **Ensure you wear the device on the correct side** as specified by the myMoves Team.

Wearing the Actigraph

- **Do not submerge the monitor in water**. Take the monitor off for showers, baths or swimming. If you are moving through heavy rain, please try and cover the monitor.
- Try to **wear the monitor at all other times during the day**. If the monitor does not interfere with your sleep then **we encourage you to wear the monitor to bed** as well.
- Should you need to remove the monitor for any length of time, please **record this on the Monitor Log**, which should be returned with the devices at the end of the observation week.
- Should you need to remove the monitor for any reason, please **remember to put it back on again** afterwards.
- **Do not let anyone else wear the monitor** at any time. This will interfere with the data accuracy.
- Please **do not try to open** the Actigraph at any time.

5. ActivPAL

This small activity monitor records body position and movement. It allows us to understand more about your overall activity levels. This monitor will come to you already wrapped in several layers of plastic covering so it is waterproof. There will also be further plastic sheets in your package for you to attach the monitor to the front of your thigh. It is important that the monitor is attached correctly.

How to put on the ActivPAL

- The activPAL is best put on in a seated position. You may also find it easier to have someone assist you to put on the activPAL.
- Ensure the skin on the front of your _______________ thigh is **clean and dry**.
- It is very important that the activPAL is positioned the correct way up. Ensure that the sticker with the word "TOP" is placed towards the top of your thigh.
- Follow these steps for the correct way to put on the activPAL:
  1. Position the activPAL on the **front of your** _______________ **thigh about one-third of the way down from your hip to your knee**.
  2. Make sure **you can see the sticker with "TOP" on it, and that this is positioned closest to your hip**.

These photos depict correct positioning for the **right** thigh. The process is the same for the left thigh. **Ensure you apply the device to the correct side** as specified by the myMoves Team.

3. Take a piece of Opsite dressing and **peel off the white backing paper**.

4. **Pulling the Opsite firmly** to keep it as flat as you can **place the Opsite over the top of the activPAL**.

5. **Smooth the sides of the Opsite down onto your skin.** Ensure **all the edges are secure** before moving to step 6, otherwise the Opsite is likely to curl and stick to itself.

6. **Carefully peel off the plastic gridding cover** from the Opsite.

7. **Smooth the Opsite around the activPAL** to ensure there is good contact with the skin with **minimal air bubbles visible**.

Wearing the ActivPAL

- Wear the activPAL monitor **at all times during the day and night**.
- The activPAL has been wrapped for waterproofing. **It can be worn for showering, bathing and swimming**. You do not need to remove this monitor for these activities.
- The Opsite dressing used to wrap and secure the activPAL is a medical grade dressing. However, you should **monitor the skin visible under the Opsite dressing daily**. Should the skin become **red, irritated or you feel any discomfort** please remove the activPAL and position slightly lower on the front of the thigh, following the instructions above. Should the irritation continue, please remove the monitor and contact Taryn Jones on taryn.jones@mq.edu.au to discuss further.
- If the **Opsite dressing becomes loose at any time**, please remove, clean and dry the skin thoroughly, and replace the activPAL using a fresh sheet of Opsite dressing.
- Should you need to remove the monitor for any length of time, please **record this on the Monitor Log**, which should be returned with the devices at the end of the observation week.

6. Returning the activity monitors

Following the completion of the observation week, the activity monitoring devices need to be returned to Macquarie University. It is really important that they are returned as promptly as possible.

When returning the devices please wrap the monitors in the bubble wrap provided before placing them in the return Express Post bag. You will then need to post them in a yellow Express Post post-box.

The following items should be returned to us:

- The **Actigraph monitor** and elastic **belt**
- The **activPAL monitor**
- Any **unused sheets of Opsite** dressing that are in good condition
- Your **Monitor Log sheet**.

Please send your Monitor Log sheet back to us even if you did not need to record anything on it. You may need to fold this sheet in order for it to fit in the bag provided for postage.

The activPAL can be returned to us with either the waterproof dressing still in place, or without this if it has come loose with removal. The Actigraph can be removed from the belt if this is easier for packaging, just please ensure the belt is returned to us as well as the device if you have removed it.

You do not need to return this Activity Monitor Guide.

Once again, we thank you for your assistance with this research study. Should you have any concerns or questions at any stage please don't hesitate to send an email, and we can give you a call at a time that suits you and discuss this with you.

Kind regards,

The myMoves Team

Appendix 7: Ethical approval for Study IV

MACQUARIE UNIVERSITY

Office of the Deputy Vice-Chancellor (Research)
Research Office
C5C Research HUB East, Level 3, Room 324
MACQUARIE UNIVERSITY NSW 2109 AUSTRALIA
Phone **+61 (0)2 9850 4194**
Fax +61 (0)2 9850 4465
Email ethics.secretariat@mq.edu.au

28 October 2014

Associate Professor Catherine Dean
Department of Health Professions
Faculty of Human Sciences
Macquarie University NSW 2122

Dear Associate Professor Dean

Reference No: 5201400830

Title: *my move for ABI: Feasibility and acceptability of an internet delivered self-management course to increase physical activity after Acquired Brain Injury*

Thank you for submitting the above application for ethical and scientific review. Your application was considered by the Macquarie University Human Research Ethics Committee (HREC (Medical Sciences)) at its meeting on 28 August 2014 at which further information was requested to be reviewed by the Ethics Secretariat.

The requested information was received with correspondence on 21 October 2014.

I am pleased to advise that ethical and scientific approval has been granted for this project to be conducted at:

- Macquarie University

This research meets the requirements set out in the *National Statement on Ethical Conduct in Human Research* (2007 – Updated March 2014) (the *National Statement*).

Details of this approval are as follows:

Approval Date: 22 October 2014

This approval includes the following amendments:

1. An increase of the sample size from n=20 to n=40.

2. The removal of one of the FitBit zip™ and its replacement with the Actigraph GT3XE™.

These changes have been noted in the research protocol.

The following documentation has been reviewed and approved by the HREC (Medical Sciences):

Documents reviewed	Version no.	Date
National Ethics Application Form	2.2	2014
Correspondence from Associate Professor Dean responding to the issues raised by the HREC (Medical Sciences)		21/10/2014

1

MQ Research Protocol	2.0	13/10/2014
MQ Participant Information Statement (Qualtrics)		03/09/2014
Letter of Notification to Treating Medical Practitioner		
Advertisements (including A, B and C)	1	14.08.2014
Telephone Interview Schedule	1	11/08/2014
Timeline for administration of measures and Questionnaires		
Questionnaires (Initial)		14/08/2014
Questionnaires (Post Course)		14/08/2014
Questionnaires (3 month follow up)		14/08/2014
Lesson Satisfaction Questionnaire (LSQ)		14/08/2014
Course Satisfaction Questionnaire		14/08/2014

Standard Conditions of Approval:

1. Continuing compliance with the requirements of the *National Statement*, which is available at the following website:

http://www.nhmrc.gov.au/book/national-statement-ethical-conduct-human-research

2. This approval is valid for five (5) years, subject to the submission of annual reports. Please submit your reports on the anniversary of the approval for this protocol.

3. All adverse events, including events which might affect the continued ethical and scientific acceptability of the project, must be reported to the HREC within 72 hours.

4. Proposed changes to the protocol must be submitted to the Committee for approval before implementation.

It is the responsibility of the Chief investigator to retain a copy of all documentation related to this project and to forward a copy of this approval letter to all personnel listed on the project.

Should you have any queries regarding your project, please contact the Ethics Secretariat on 9850 4194 or by email ethics.secretariat@mq.edu.au

The HREC (Medical Sciences) Terms of Reference and Standard Operating Procedures are available from the Research Office website at:

http://www.research.mq.edu.au/for/researchers/how_to_obtain_ethics_approval/human_research_ethics

The HREC (Medical Sciences) wishes you every success in your research.

Yours sincerely

Professor Tony Eyers
Chair, Macquarie University Human Research Ethics Committee (Medical Sciences)

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research* (2007) and the *CPMP/ICH Note for Guidance on Good Clinical Practice.*

Appendix 8: Example of a myMoves Program Guide

myMoves

Helping to Manage Physical Activity

Program Guide: Feb 2015

MACQUARIE University

MyMoves was written by
Ms Taryn Jones, Dr Blake Dear,
Prof Catherine Dean, Dr Julia Hush
and Prof Nick Titov

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1. Welcome to myMoves

Welcome to myMoves! My name is Taryn Jones. You will recognise my name from our recent telephone call. It will also be me who will guide you through the myMoves course in the coming months. I am an experienced physiotherapist who has spent over a decade working with people with ABI - from trauma, from stroke and from other causes. I currently teach physiotherapy students at Macquarie University whilst also undertaking research designed to improve physical activity levels after ABI. I am passionate about helping people of all abilities enjoy a healthy and active life.

As part of the myMoves Team I work with a highly experienced group of clinicians and researchers, namely physiotherapists Prof Catherine Dean and Dr Julia Hush; and psychologists Dr Blake Dear and Prof Nick Titov. We are really excited to have the opportunity to work with you.

We have spent a lengthy period of time building a course that we think will offer real benefits to people who want to improve their physical activity after an ABI. Of course, this is a new and innovative type of program for people with ABI. Therefore, we are also looking forward to gaining input from you on how you find the course - what you like, and the things you feel need further improvement. Between us we can continue to improve the myMoves course for the future.

Over the next couple of pages you will find an outline of the program with important dates to note. This should allow you to plan ahead in order to maximise the benefits to be offered by the myMoves program.

I will remain in contact as we approach the myMoves commencement date. However, please feel free to contact me at any time on taryn.jones@mq.edu.au

So, welcome once again. I hope you enjoy the myMoves program!

Taryn Jones

2. Program Guide

The table below as all the important dates and basic information you will need to know for the myMoves program.

Week	Dates	What to expect
Preparation weeks	26 Jan -6 Feb	Preparation for course commencement.
	26 Jan	Demographic questionnaires emailed.
	2 Feb	Physical activity monitors to be posted from Macquarie University in Sydney.
	3-6 Feb	Physical activity monitors to arrive to you
Pre-course observation week	8 – 14 Feb	Pre-course observations and measures to occur this week.
	7 Feb	Apply activity monitors before going to bed.
	8 Feb	Pre-course questionnaires will be emailed to you for you to complete at any time over this week.
	10-15 Feb	Two phone calls will be made to complete interviews regarding your physical activity. Each call will take approx. 20-30 mins and will focus on the 2 days before the call.
	15 Feb	Complete wearing of physical activity monitors once you wake up. Remove and post back to us.
Week 1	16 Feb	Module 1 materials will be emailed to you including: **Lesson 1: An Introduction** The Stories: Chapter 1 DIY Worksheet Lesson 1 will discuss physical activity after ABI and common difficulties that people face, as well as introducing the Active Lifestyle Model.

Week 2	23 Feb	Module 2 materials will be emailed to you including: **Lesson 2: Managing Activity Levels** The Stories: Chapter 2 DIY Worksheet Lesson 2 will discuss the important components of frequency, intensity and time, and will teach you how to make programs more challenging as you improve, and also how to make things easier at different times. Getting these things right can help with managing pain, fatigue and deconditioning.
Week 3	2 March	Module 3 materials will be emailed to you including: **Lesson 3: Managing Barriers** The Stories: Chapter 3 DIY Worksheet Lesson 3 will focus on identifying, problem solving and planning to manage obstacles to physical activity.
Week 4	9 March	Module 4 materials will be emailed to you including: **Lesson 4: Managing Expectations** The Stories: Chapter 4 DIY Worksheet Lesson 4 will discuss the common problem of setting ourselves up for failure by having unrealistic expectations of what we should be doing. Learning how to be flexible in our approach to physical activity and how to adjust to changing abilities and circumstances is a key focus of this Lesson.
Week 5	16 March	Module 5 materials will be emailed to you including: **Lesson 5: Managing Habits** The Stories: Chapter 5 DIY Worksheet Habits are more reliable than motivation leading to an active lifestyle that endures. We will show you some simple skills that will embed your physical activity program into your life and make it become a habit that does not require the constant pressure to keep motivated.
Week 6	23 March	**Consolidation week**

Week 7	30 March	Module 6 materials will be emailed to you including: **Lesson 6: Keeping It Going** The Stories: Chapter 6 DIY Worksheet We will discuss some key strategies to prevent relapse in difficult circumstances and to maintain an enjoyable active lifestyle that endures.
Week 8	6 April	**Consolidation week**
	7 April	Physical activity monitors to be posted from Macquarie University in Sydney.
	8-10 April	Physical activity monitors to arrive to you
Post-course observation week	12 -18 April	Post-course observations and measures to occur this week.
	11 April	Apply activity monitors before going to bed.
	12 April	Post-course questionnaires will be emailed to you for you to complete at any time over this week.
	14-19 April	Two phone calls will be made to complete interviews regarding your physical activity. Each call will take approx. 20-30 mins and will focus on the 2 days before the call.
	19 April	Complete wearing of physical activity monitors once you wake up. Remove and post back to us.
3-month observation preparation	6 July	Physical activity monitors to be posted from Macquarie University in Sydney.
	7-10 July	Physical activity monitors to arrive to you
3-month observation week	12-18 July	Pre-course observations and measures to occur this week.
	11 July	Apply activity monitors before going to bed.
	12 July	Post-course questionnaires will be emailed to you for you to complete at any time over this week.
	14-19 July	Two phone calls will be made to complete interviews regarding your physical activity. Each call will take approx. 20-30 mins and will focus on the 2 days before the call.
	19 July	Complete wearing of physical activity monitors once you wake up. Remove and post back to us.

What do I do now?

We hope you are looking forward to starting as much as we are. Should you have any concerns or questions in the next few weeks please don't hesitate to send an email, and we can give you a call at a time that suits you and discuss this with you.

Otherwise, we will be in touch over the next few weeks with any further information you may need to know, or just to say hello!

Until then…

The myMoves Team

Appendix 9: Example of a participant physical activity report

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Activity Summary: John

Here is a summary of the activity data you recorded from the observation weeks we conducted before and immediately after you did the myMoves program.

These tables show you the following information:

Time spent sitting or lying: This is the number of hours spent sitting or lying. Please note that this does include nightly sleeping time.

Time spent standing: This is the number of hours you spent in a standing position where you were not stepping.

Time spent stepping: This is the number of hours you spent stepping.

Step count: This is the number of steps you took in total.

Sit to Stand transitions: This is the number of times you moved between a sitting and a standing position.

The data for each of these parameters has been provided for each day across the monitoring period. You will also see a weekly total for each parameter, and a daily average for the week.

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Pre-course observations					
Date	Time spent sitting/lying (hours)	Time spent standing (hours)	Time spent stepping (hours)	Step count	Sit to Stand Transitions
8 March 2015	22.93	0.8	0.27	956	16
9 March 2015	18.47	4.43	1.1	4192	34
10 March 2015	20.06	3	0.95	3656	32
11 March 2015	21.84	1.56	0.6	2322	24
12 March 2015	18.72	3.85	1.44	6064	54
13 March 2015	22.02	1.48	0.5	1962	26
14 March 2015	14.68	6.33	2.99	12838	46
Weekly Total	138.72	21.45	7.85	31990	232
Average/day across the week	19.82	3.06	1.12	4570.00	33.14

Post-course observations					
Date	Time spent sitting/lying (hours)	Time spent standing (hours)	Time spent stepping (hours)	Step count	Sit to Stand Transitions
10 May 2015	x	x	x	x	x
11 May 2015	19	3.7	1.3	5050	33
12 May 2015	19.71	3.52	0.77	2524	45
13 May 2015	22.11	1.24	0.65	2360	26
14 May 2015	19.1	3.56	1.33	5260	27
15 May 2015	18.97	4.02	1.01	3944	35
16 May 2015	16.16	6.04	1.8	6754	61
Weekly Total (6 days)	115.05	22.08	6.86	25892	227
Average/day across the week (6 days)	19.18	3.68	1.14	4315.33	37.83

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3-month observations					
Date	**Time spent sitting/lying (hours)**	**Time spent standing (hours)**	**Time spent stepping (hours)**	**Step count**	**Sit to Stand Transitions**
9 August 2015	19.54	3.13	1.33	4510	41
10 August 2015	18.15	4.1	1.76	7022	67
11 August 2015	16.45	5.95	1.6	5974	60
12 August 2015	19.24	3.51	1.25	4872	50
13 August 2015	19.46	3.73	0.81	2998	44
14 August 2015	16.04	6.53	1.43	5180	56
15 August 2015	18.14	3.98	1.89	8078	46
Weekly Total	127.02	30.93	10.07	38634	364
Average/day across the week	18.15	4.42	1.44	5519.14	52.00

Summary of changes

Since the time of the pre-program observation week:

- Your time spent in sitting or lying decreased an average of 1 hour and 40 minutes per day, which is an **8% improvement**.
- Your time spent standing increased an average of 1 hour and 22 minutes per day, which is a **44% improvement**.
- Your time spent stepping increased an average of 19 minutes per day, which is a **29% improvement.**
- Your step count increased by an average of 949 steps per day. This is a **21% improvement**.
- You moved between sitting and standing an average of 19 times more per day which is is a **57% increase**.

These are amazing results!!!! Congratulations!!!

