



# **An exploration of adherence to intensive exercise in stroke survivors**

by

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B AppSc (Physiotherapy) G Dip (Neurology)

*Thesis  
Submitted to Flinders  
University for the  
degree of*

**Doctor of Philosophy**

College of Medicine and  
Public Health

5 May 2021

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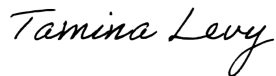
# DECLARATION

Except where reference is made in the text of the thesis, this thesis contains no material published elsewhere or extracted in whole or in part from a thesis accepted for the award of any other degree or diploma. No other person's work has been used without due acknowledgement in the main text of the thesis. This thesis has not been submitted for the award of any degree or diploma in any other tertiary institution.

Tamina Levy is the sole author of Chapter 1 (Introduction) and Chapter 8 (Discussion). The remaining chapters are multi-author chapters on which Tamina Levy was the primary author and completed the majority of the work. The development and management of the studies, data collection and analysis, publication writing, and revisions were led by Tamina Levy. Co-authors provided assistance with study development and analysis, as well as publication preparation, as outlined in subsequent chapters.

All research procedures reported in this thesis were approved by relevant Ethics Committees prior to the commencement of each study. Copies of ethics approvals are provided in Appendices 1-4.

Signed Tamina Levy

A handwritten signature in black ink that reads "Tamina Levy". The signature is written in a cursive style with a large initial 'T' and a long, sweeping underline.

Date: 5/5/2021

## ACKNOWLEDGMENTS

I would like to acknowledge all of those who have contributed their time and expertise to this thesis. Above all, I wish to acknowledge the stroke survivors and their family members who generously shared their time and stories for the studies included in this thesis. I feel privileged to have been able to learn from your experiences. I am very grateful for the support of the health professionals at Flinders Medical Centre, Rehabilitation and Palliative Services for their support and assistance with participant recruitment and their ongoing encouragement and enthusiasm regarding my research.

It was an honour and privilege to work with my primary supervisor, Professor Maria Crotty. Thank you for your guidance and the faith you have shown in me. I also thank my co-supervisors, Associate Professor Kate Laver, Dr Maggie Killington, and Professor Natasha Lannin for your support, wisdom, and advice. As my supervisors, you encouraged and challenged me to develop my research knowledge and skills and I am lucky to have had the opportunity to learn from you.

Lastly, a heartfelt thanks to my family and friends. Thank you for sharing your enthusiasm for my research, for listening, and for supporting me. I am grateful to have had so many caring and encouraging people around me.

# TABLE OF CONTENTS

<b>DECLARATION</b>	<b>ii</b>
<b>ACKNOWLEDGMENTS</b>	<b>iii</b>
<b>LIST OF TABLES</b>	<b>viii</b>
<b>LIST OF FIGURES</b>	<b>ix</b>
<b>LIST OF PUBLICATIONS AND CONFERENCE ABSTRACTS ARISING FROM THIS THESIS</b>	<b>x</b>
Publications	x
Manuscripts under review	x
Conference presentations and posters	x
Evidence of impact	xii
Grants received	xii
<b>ABBREVIATIONS</b>	<b>xiii</b>
<b>SUMMARY</b>	<b>14</b>
<b>CHAPTER 1 BACKGROUND AND LITERATURE REVIEW</b>	<b>16</b>
1.1 Stroke	16
1.1.1 Stroke Pathophysiology	16
1.1.2 Stroke Epidemiology	17
1.1.3 Upper limb deficits following stroke	18
1.1.4 Neuroplasticity	19
1.2 Rehabilitation	21
1.3 Rehabilitation following stroke	22
1.3.1 High-intensity practice	23
1.3.2 Task-specific training	25
1.3.3 The multidisciplinary team	27
1.3.4 Goal Setting	27
1.4 Exercise adherence	28
1.4.1 Exercise adherence in stroke survivors	31
1.4.2 Barriers to exercise adherence in stroke survivors	32
1.4.3 Measurements of exercise adherence	34

1.4.4 Measuring and enhancing adherence with technology	35
1.5 Behaviour change theories relevant to exercise adherence	38
1.5.1 Overview of theories	38
1.5.2 Transtheoretical Model of Behaviour Change	41
1.5.3 Theoretical Domains Framework	42
1.5.4 Behaviour Change Wheel and Capability, Opportunity, Motivation-Behaviour model	43
1.5.5 Behaviour change interventions and adherence	46
1.6 The current state of knowledge	47
1.7 Rationale for the thesis	48
1.7.1 Aims	48
1.7.2 Original contribution to the thesis	48
1.7.3 Thesis structure	48
<b>CHAPTER 2 METHODS OF MEASUREMENT OF ADHERENCE TO EXERCISE IN STROKE SURVIVORS: A SYSTEMATIC REVIEW</b>	<b>51</b>
2.1 Introduction	51
2.2 Methods	52
2.3 Results	54
2.4 Discussion	64
2.5 Strengths and limitations	67
2.6 Implications for future practice and research	67
<b>CHAPTER 3 EXPLORING THE USE OF A TABLET COMPUTER AS A METHOD OF ADHERENCE MONITORING: A FEASIBILITY STUDY</b>	<b>69</b>
3.1 Introduction	69
3.2 Methods	71
3.3 Results	76
3.4 Discussion	81
3.5 Strengths and limitations	85
3.6 Implications for future practice and research	85
<b>CHAPTER 4 EXPLORING THE USE OF A TABLET COMPUTER AS A METHOD OF</b>	

<b>ENHANCING ADHERENCE: A SINGLE-CASE SERIES</b>	<b>87</b>
4.1 Introduction	87
4.2 Methods	88
4.3 Results	91
4.4 Discussion	94
4.5 Strengths and limitations	96
4.6 Implications for future practice and research	96
<b>CHAPTER 5 WHAT ARE THE FACTORS INFLUENCING ADHERENCE TO INTENSIVE EXERCISE PROGRAMS IN STROKE SURVIVORS?: A QUALITATIVE STUDY</b>	<b>98</b>
5.1 Introduction	98
5.2 Methods	100
5.3 Results	102
5.4 Discussion	114
5.5 Strengths and limitations	118
5.6 Implications for future practice and research	118
<b>CHAPTER 6 ENGAGING CARERS DURING THE INPATIENT REHABILITATION OF STROKE SURVIVORS: A PILOT IMPLEMENTATION STUDY</b>	<b>120</b>
6.1 Introduction	120
6.2 Methods	123
6.3 Results	131
6.4 Discussion	134
6.5 Strengths and limitations	137
6.6 Implications for future practice and research	139
<b>CHAPTER 7 USING A BEHAVIOUR CHANGE MODEL TO DEVELOP A GUIDE FOR HEALTH PROFESSIONALS TO USE WHEN PRESCRIBING EXERCISES FOR STROKE SURVIVORS</b>	<b>142</b>
7.1 Background and Purpose	140
7.2 Position and Rationale	141
7.3 Discussion	152

7.4 Strengths and limitations	153
7.5 Implications for future practice and research	153
<b>CHAPTER 8 DISCUSSION</b>	<b>156</b>
8.1 Summary of findings and how research aims have been addressed	156
8.2 Original contribution to the research	158
8.3 Comparison to previous research	159
8.4 Implications for practice	167
8.5 Implications for research	171
8.6 Strengths	173
8.7 Limitations	174
8.8 Conclusion	176
<b>REFERENCES</b>	<b>179</b>
<b>APPENDICES</b>	<b>217</b>
Appendix 1 Feasibility study; Ethics approval	215
Appendix 2 Single-case series; Ethics approval	217
Appendix 3 Qualitative study; Ethics approval	219
Appendix 4 Carers Count study; Ethics approval	220
Appendix 5 Systematic review; Phase 1 search strategy	223
Appendix 6 Systematic review; Phase 2 search strategy	224
Appendix 7 Feasibility study; video analysis sheet	225
Appendix 8 Single-case series; Technology questionnaire	226
Appendix 9 Qualitative study; Interview guide	227
Appendix 10 Carers Count study; search strategy	228
Appendix 11 Systematic review; published paper	232
Appendix 12 Feasibility study; published paper	243
Appendix 13 Single-case series; published paper	244

## LIST OF TABLES

Table 1-1 Behavioural strategies used to enhance adherence to exercise .....	29
Table 1-2 Theories used to explore health-related behaviour and exercise adherence, and their applicability to this thesis.....	39
Table 2-1 Types of adherence measurement methods and type of study in which the method was used.....	58
Table 2-2 Characteristics of studies which measure adherence to physical activity or exercise recommendations .....	59
Table 3-1 Feasibility study intervention compared to the InTENSE trial movement training intervention .....	73
Table 3-2 Participant demographics at baseline.....	76
Table 3-3 Participant characteristics, mean values for exercise sessions and outcome measures (at review).....	78
Table 3-4 Average practice variables, participants 1-10.....	80
Table 4-1 Participant demographics at baseline.....	91
Table 5-1 Profile characteristics of participants (n=20).....	102
Table 5-2 Barriers and enablers to participation in an intensive upper limb exercise program mapped to Theoretical Domains Framework domains and Capability, Opportunity, Motivation-Behaviour model.....	105
Table 6-1 Content of the Carers Count intervention .....	124
Table 6-2 Implementation strategies and method of adoption .....	125
Table 6-3 Study evaluation outcomes and methodology .....	128
Table 6-4 Stages of Carers Count, activities, timelines and personnel .....	128
Table 6-5 Survey responses, stroke survivors and carers (n=60), expressed as n (%) .....	132
Table 6-6 Themes and quotes from participant and carer interviews.....	134
Table 7-1 Barriers and enablers to participation in an intensive upper limb exercise program, mapped to the Capability, Opportunity, Motivation-Behaviour model.....	143
Table 7-2 Relevant behaviour change functions and definitions.....	146
Table 7-3 Barriers to participation in exercise, mapped to the Capability, Opportunity, Motivation-Behaviour model, relevant behaviour change functions, and intervention strategies .....	148
Table 8-1 Applying the Capability, Opportunity, Motivation-Behaviour model to thesis findings....	170



# LIST OF FIGURES

Figure 1-1 The International Classification of Functioning, Disability and Health, related to the upper limb following stroke (ICF) (World Health Organisation, 2002) .....	18
Figure 1-2 Hypothetical pattern of recovery with timing of intervention strategies .....	20
Figure 1-3 Rehabilitation: who benefits, what structures are needed, what processes occur, and what is the outcome? .....	22
Figure 1-4 Illustration of the Stages of Behavioural Change.....	41
Figure 1-5 Theoretical Domains Framework constructs and Capability, Opportunity, Motivation-Behaviour model components.....	43
Figure 1-6 Behaviour change intervention design process, The Behaviour Change Wheel: a guide to designing interventions .....	44
Figure 1-7 Behaviour Change Wheel and the Capability, Opportunity, Motivation-Behaviour model components .....	45
Figure 1-8 Thesis outline.....	50
Figure 2-1 Flowchart of the selection process for Phase 1 and Phase 2 .....	57
Figure 3-1 Screenshot of video recording during home exercises, Participant 2 .....	72
Figure 3-2 Study flow chart .....	75
Figure 4-1 Phases of ABA study design in single-case experiment.....	89
Figure 4-2 Data points: baseline, intervention, and follow-up (Participants 1,5,7,10).....	93
Figure 4-3 Data points: baseline, intervention, and follow-up for Participant 9.....	94
Figure 5-1 Experiences of participants, identified from the interviews .....	104
Figure 6-1 Carers Count study; representation of stages of the study based on the Proctor framework.....	122
Figure 6-2 Participant flow through the study .....	133
Figure 7-1 Three main stages when using the Behaviour Change Wheel .....	142
Figure 7-2 Health professional guide, based on the Behaviour Change Wheel, Capability, Opportunity, Motivation-Behaviour model and synthesis of qualitative study.....	151
Figure 8-1 Structure of the thesis with research questions, thesis aims, and chapters .....	155

# LIST OF PUBLICATIONS AND CONFERENCE ABSTRACTS ARISING FROM THIS THESIS

## Publications

**Levy, T.,** Laver, K., Killington, M., Lannin, N. & Crotty, M. (2018). *A systematic review of measures of adherence to physical exercise recommendations in people with stroke*. Clinical Rehabilitation DOI: 10.1177/0269215518811903.

**Levy, T.,** Killington, M., Lannin, N. & Crotty, M. (2019). *Viability of using a computer tablet to monitor an upper limb home exercise program in stroke*. Physiotherapy Theory and Practice DOI: 10.1080/09593985.2019.1625092.

**Levy, T.,** Laver, K., Lannin, N., Crotty, M. & Killington, M. (2020). *Does the addition of concurrent visual feedback increase adherence to a home exercise program in people with stroke: a single-case series?* BMC Research Notes DOI: doi.org/10.1186/s13104-020-05202-2.

**Levy, T.,** Christie, L., Laver, K., Killington, M., Lannin, N. & Crotty, M. (2021). *Just that four-letter word hope: stroke survivors' perspectives of participation in an intensive upper limb exercise program; a qualitative exploration*. Physiotherapy Theory and Practice, in print.

## Manuscripts under review

**Levy, T.,** Laver, K., Killington, M., Lannin, N. & Crotty, M. (2020). *Development and facilitation of an exercise-based group for stroke survivors and their carers: The Carers Count group*. Disability and Rehabilitation (submitted 31/7/2020).

## Conference presentations and posters

*\*Denotes presenting author*

**Levy, T\*,** Christie, L., Laver, K., Killington, M., Lannin, N. & Crotty, M. (2021). *Just that four-letter word hope: stroke survivors' perspectives of participation in an intensive upper limb exercise program; a qualitative exploration*: Oral presentation accepted at the World Physiotherapy Conference (April 2021).

**Levy, T.,** Christie, L\*, Laver, K., Killington, M., Lannin, N. & Crotty, M. (2021). *Just that four-letter word hope: stroke survivors' perspectives of participation in an intensive upper limb exercise*

*program; a qualitative exploration*: Oral presentation accepted at the National Occupational Therapy Conference (June 2021).

**Levy, T\***. Christie, L., Laver, K., Killington, M., Lannin, N. & Crotty, M. (accepted, postponed 2020). *Just that four-letter word hope: stroke survivors' perspectives of participation in an intensive upper limb exercise program; a qualitative exploration*: Poster presentation at the SA Health Research Symposium.

**Levy, T\***, Christie, L., Laver, K., Killington, M., Lannin, N. & Crotty, M. (October 2020). *Just that four-letter word hope: stroke survivors' perspectives of participation in an intensive upper limb exercise program; a qualitative exploration*: Oral presentation at the SA Annual Stroke Forum.

**Levy, T\***, Laver, K., Killington, M., Lannin, N. & Crotty, M. (October 2019). *A systematic review of measures of adherence to physical exercise recommendations in people with stroke*: Oral presentation at the Emerging Leaders Showcase, Flinders University.

**Levy, T\***, Laver, K., Killington, M., Lannin, N. & Crotty, M. (September 2019). *A systematic review of measures of adherence to physical exercise recommendations in people with stroke*: Poster presentation at the Australian Physiotherapy Association Conference.

**Levy, T\***, Laver, K., Lannin, N., Crotty, M. & Killington, M. (September 2019). *Does the addition of concurrent visual feedback increase adherence to a home exercise program in people with stroke: a single-case series*: Oral presentation at the Australian Physiotherapy Association Conference.

**Levy, T\***, Killington, M., Lannin, N. & Crotty, M. (September 2018). *Viability of using a computer tablet to monitor an upper limb home exercise program in stroke*: Oral presentation at the Australian Physiotherapy Association Conference.

**Levy, T\***, Killington, M., Lannin, N. & Crotty, M. (August 2018). *Viability of using a computer tablet to monitor an upper limb home exercise program in stroke*: Oral presentation at the SALHN Research Symposium.

**Levy, T\***, Laver, K., Killington, M., Lannin, N. & Crotty, M. (August 2018). *A systematic review of measures of adherence to physical exercise recommendations in people with stroke*: Oral presentation at the SALHN Research Symposium.

**Levy, T\***, Killington, M., Lannin, N. & Crotty, M. (December 2018). *Viability of using a computer tablet to monitor an upper limb home exercise program in stroke*: Oral presentation at the Advancing Technology and Innovation in Rehabilitation Conference.

**Levy, T.**, Killington, M., Lannin, N. & Crotty, M. (August 2018). *Viability of using a computer tablet to monitor an upper limb home exercise program in stroke*: Poster presentation at the International Neurorehabilitation Symposium, London.

## **Evidence of impact**

**Levy, T.**, Laver, K., Killington, M., Lannin, N. & Crotty, M. (September 2020). *Maximising adherence to home exercise programs for people with stroke: a guide to applying a behaviour change model*: Infographic featured on the Australian Physiotherapy Association Twitter and Facebook pages during Stroke Week 2020.

(**Twitter metrics**; 898 impressions, 47 engagements, 35 likes, 13 retweets)

(**Facebook metrics**; 33 likes, 3 comments, 7 shares)

## **Grants received**

Southern Adelaide Local Health Network, Allied Health grant for the Carers Count study (2019).

# ABBREVIATIONS

<b>App</b>	Applications
<b>BC</b>	Behaviour change
<b>TDF</b>	Theoretical Domains Framework
<b>BCW</b>	Behaviour change wheel
<b>CIMT</b>	Constraint-Induced Movement Therapy
<b>COSMIN</b>	Consensus-based standards for the selection of health status measurement instruments
<b>COM-B</b>	Capability, Opportunity, Motivation-Behaviour
<b>DALY</b>	Disability-adjusted life years
<b>GRASP</b>	Graded repetitive arm supplementary program
<b>InTENSE</b>	Intensive therapy efficacy after neurological spasticity treatment
<b>MMSE</b>	Mini-mental state examination
<b>PRISMA</b>	Preferred reporting items for systematic reviews and meta-analysis
<b>PASIPD</b>	Physical activity scale for individuals with physical disabilities
<b>SUS</b>	System usability scale
<b>VR</b>	Virtual reality
<b>WHO</b>	World Health Organisation

## SUMMARY

Stroke is the third most common cause of death in Australia and a leading cause of disability worldwide. One of the most common deficits following stroke is hemiparesis, and consequently, a key goal of stroke rehabilitation is to restore movement impairments and associated functions. Loss of movement in the upper limb, and subsequent reduced functional use, can severely impact quality of life after stroke.

Stroke guidelines recommend large amounts of practice to potentiate motor recovery, however, in practice, providing higher doses of therapy is challenging and evidence has shown there may be low adherence to participation in higher intensity therapies. As formal rehabilitation delivered by a hospital team is typically finished within the first six months following stroke, stroke survivors must be provided with ongoing exercise programs and recommendations to continue with after discharge from rehabilitation. To complete the necessary amount of practice to maximise recovery, adherence to these programs needs to be high.

Understanding factors that influence adherence to intensive exercise programs in stroke survivors could assist health professionals to develop tailored programs that promote large amounts of practice. Factors known to influence exercise adherence in stroke survivors include the level of social support, self-efficacy, knowledge about the benefits of exercise, and support of health professionals. Health professionals have some knowledge about potential barriers to adherence to the home exercise programs they prescribe. However, there is a lack of depth in this understanding when applied to *intensive* programs, as well as a lack of research exploring strategies that can be implemented to minimise the impact of specific barriers.

Measurement of adherence to exercise programs can take various forms and there is no acknowledged gold standard. It is important to use a method of measurement that is valid in the specific population; that is, the tool measures what it is supposed to measure. Measurement of adherence can be challenging as there are many parameters to consider including dose, timing, and quality. Methods of measurement specific to stroke have included logbooks and other methods of self-report, wearable sensors, and questionnaires. However, to date, there remains uncertainty amongst health professionals as to which method of monitoring adherence is optimal.

This thesis explores exercise adherence in stroke survivors, including methods of measuring exercise adherence after stroke, and barriers and enablers to adherence to intensive programs. The thesis begins with a literature review and the aims of the thesis are detailed. The first study, described in Chapter 2, is a systematic review of methods of measurement of adherence in stroke survivors. The purpose is to identify approaches to measurement that may be utilised throughout other chapters and to provide recommendations for health professionals and researchers

regarding methods of measurement. Next, Chapter 3 details a feasibility study that explores the use of technology (a tablet computer) as a method of monitoring exercise adherence in a group of stroke survivors who had participated in an intensive home-based exercise program. This study evaluated how much exercise participants did and what factors influenced the amount of practice. Chapter 4 describes a single-case series which extended the exploration of technology use to determine if the addition of a tablet computer increased adherence to an intensive home exercise program in ten stroke survivors. Chapter 5 describes a qualitative descriptive study that explored the experiences of, and barriers and enablers to, adherence to intensive exercise programs following stroke. In Chapter 6, an implementation-effectiveness study is described where the candidate developed, implemented, and evaluated an exercise-based group for stroke survivors and their carers on an inpatient ward. The group aimed to engage carers in rehabilitation and to increase adherence to exercise of the stroke survivor, including when they were discharged from inpatient care. Chapter 7 outlines how a behaviour change model can be used to analyse barriers to adherence and develop strategies to address these. Practical implications of the research are presented in the form of a guide developed by the candidate from a synthesis of this analysis, which aims to provide health professionals with an evidence-based approach to the prescription of home exercise programs for stroke survivors. The thesis concludes with Chapter 8; a reiteration of the research aims and work completed. Strengths, limitations, and key outcomes are discussed.

# CHAPTER 1 BACKGROUND AND LITERATURE REVIEW

This introductory chapter presents background information and a rationale for focusing on exercise adherence in stroke survivors. It begins by providing an overview of the epidemiology and pathophysiology of stroke (section 1.1) and a description of the upper limb deficits that may occur following stroke, and the basic principles of neuroplasticity following stroke are presented. In Section 1.2 the concept of rehabilitation is introduced, and the specific principles of stroke rehabilitation are described in Section 1.3. Section 1.4 discusses exercise adherence, including general evidence regarding exercise adherence, exercise adherence after stroke, barriers and enablers to adherence, and measurement of adherence. An overview of behaviour change theories is presented in Section 1.5, and specific theories are then presented in detail. Section 1.6 presents the current gap in the literature. Chapter 1 then concludes by presenting the rationale for the program of research, an outline of the thesis structure, and the candidate's original contribution to the research.

## 1.1 Stroke

### 1.1.1 Stroke Pathophysiology

The World Health Organisation definition of stroke is “rapidly developing clinical signs of focal (or global) disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than that of vascular origin” (p. 114) (Aho et al., 1980). More recent advances have suggested this definition is obsolete as modern brain imaging has provided evidence of permanent injury occurring within the 24-hour window (Sacco et al., 2013). Stroke is classified as a neurological deficit caused by an acute focal vascular injury, including cerebral infarction, intracerebral haemorrhage, and subarachnoid haemorrhage (Sacco et al., 2013).

Ischemic stroke, which is the cause of 87% of stroke events (Corey et al., 2020), occurs when the blood supply to the brain is interrupted by a blood clot, leading to a cascade of events including excitotoxicity, immune responses causing neuronal cell death and ultimately, clinical symptoms (Knowland et al., 2014; George & Steinberg, 2015). The two main subtypes of ischemia are thrombosis, caused by atherosclerosis and resulting in arterial obstruction, and embolism, which occurs when particles of debris originating elsewhere block arterial access to a particular brain region (Caplan & Hacke, 2003). The timing of these events, and the subsequent immune response, is variable and can have positive and negative sequelae (Anrather & Iadecola, 2016). The site and size of the initial stroke lesion can determine the long-term effect of stroke (Langhorne, Bernhardt & Kwakkel, 2011). The middle cerebral artery, which supplies areas including the lateral cerebral cortex, basal ganglia, and internal capsule, is the most commonly



involved blood vessel in ischemic stroke (Knight-Greenfield, Nario & Gupta, 2019; Hui, Tadi & Patti, 2020). Involvement of the middle cerebral artery leads to contralateral hemiparesis, facial paralysis, and sensory loss, predominantly in the upper limb and face. Other blood vessels commonly involved in ischemic stroke are the anterior cerebral artery, posterior cerebral artery, and vertebrobasilar artery (Hui, Tadi & Patti, 2020).

Whilst the incidence of haemorrhagic stroke is less prevalent (5 to 21% of acute strokes) (Knight-Greenfield, Nario & Gupta, 2019), there is a higher mortality rate (Go et al., 2013; Truelsen et al., 2015) and evidence of better functional recovery when compared to ischemic stroke (Paolucci et al., 2003). Haemorrhagic stroke is caused by rupture of cerebral blood vessels which leads to blood accumulating in the brain tissue (Luo, Reis & Chen, 2019). Common causes of haemorrhage include hypertension and trauma (Kase, 2015). Following a haemorrhagic stroke, cell death is likely to occur after exposure to metabolites or subsequently damaged cells (Luo, Reis & Chen, 2019). Haemorrhagic strokes are commonly the sequelae of hypertension, typically in locations including the basal ganglia, thalamus, pons, and cerebellum (Knight-Greenfield, Nario & Gupta, 2019).

### **1.1.2 Stroke Epidemiology**

It is reported that in Australia a stroke occurs every nine minutes (Stroke Foundation, 2017a), and in 2017 there were 31,952 acute stroke admissions across 120 hospitals (Stroke Foundation, 2017b). The estimated total number of people living with the effects of stroke in Australia is predicted to be 1 million by 2050 (Stroke Foundation, 2017a), and the impact of stroke on the community is significant due to the burden of chronic disability. In terms of disability-adjusted life years (DALYS), a combined measure of mortality and morbidity considered to be a good indicator of social and economic disease burden (Mendis, 2013), stroke is the third leading cause of disability worldwide (World Health Organisation, 2018). Furthermore, the economic impact of stroke is substantial; in Australia, the total average lifetime cost per case (ischemic stroke) was estimated to be over \$60,000, accounting for hospital care, outpatient and community services, ambulance transfers, out-of-pocket costs, and caregiver time (Cadilhac, Carter, Thrift & Dewey, 2009).

The Global Burden of Diseases, Injuries, and Risk Factors Study, the largest and most comprehensive record of disease epidemiology levels and trends worldwide (Feigin & Vos, 2019), reported that stroke accounted for 10% of all deaths globally, and in 2016 there were approximately 13.7 million new strokes worldwide. The peak age for stroke occurrence was between the ages of 60 and 70, with between three and four million strokes reported annually (Feigin & Vos, 2019). This figure indicates that the demographics of stroke are changing, with almost 60% of strokes occurring in people under 70 years old (Feigin, 2019). Furthermore, the

incidence of stroke is declining in many higher-income countries, due to improved secondary prevention health strategies such as smoking cessation and control of hypertension (Mackay, Mensah & World Health Organisation, 2004). If current world health trends continue it is estimated that there will be 23 million first-ever strokes and nearly eight million stroke deaths in 2030 (Mathers & Loncar, 2006).

### 1.1.3 Upper limb deficits following stroke

The most common consequence of stroke is hemiparesis, or a loss or limitation of muscle strength of one side of the body, reported to occur in approximately 80% of people (Brewer, Horgan, Hickey & Williams, 2013). Furthermore, 50% of people with hemiparesis following stroke have a chronic loss of arm function (Stroke Working Group, 2016). A review reported that whilst 70-85% of stroke survivors regained their ability to walk, of those with early upper limb impairment, 50% still had a non-functional upper limb four years post-stroke (Broeks, Lankhorst, Rumping & Prevo, 1999). When considered in terms of the World Health Organisation, International Classification of Functioning, Disability and Health (see Figure 1-1) (Bunuales, Diego & Moreno, 2002), the impairment, a loss of arm strength following stroke (body function and structure), can lead to difficulties with tasks such as showering, dressing and feeding oneself (activities) and a reduced ability to participate in tasks related to life roles such as cooking, driving, and working (participation). A loss of upper limb function is a major contributor to reduced quality of life amongst stroke survivors (Nichols-Larsen et al., 2005; Franceschini, La, Agosti & Massucci, 2010; Morris, Van Wijck, Joice & Donaghy, 2013) and, in a recent qualitative study, has been identified as a high research priority by stroke survivors and their carers (Rudberg et al., 2020). Restoration of impaired upper limb movement and its associated functions is therefore a key focus in stroke rehabilitation (Kinoshita et al., 2020).

**Figure 1-1 The International Classification of Functioning, Disability and Health, related to the upper limb following stroke (ICF) (World Health Organisation, 2002)**

***This image has been removed due to copyright restriction, available from: World Health Organisation. (2002). Towards a common language for functioning. Disability and Health: International Classification for Functioning, Disability and Health. Geneva: World Health Organisation.***

Research has consistently shown that upper limb activity in stroke survivors is restricted (Rand & Eng, 2012; Kwakkel & Kollen, 2013). Upper limb rehabilitation, a process of active motor retraining that should start within the first few days after stroke, is a complex process that requires the person to relearn to activate muscles, coordinate strength and control movements (Langhorne, Coupar & Pollock, 2009; Carr & Shepherd, 1987).

At one year following a stroke, upper limb impairment was found to be associated with feelings of increased anxiety (Morris, Van Wijck, Joice & Donaghy, 2013) and a lower perception of health-

related quality of life (Franceschini, La, Agosti & Massucci, 2010). In Australia, more than 80% of stroke survivors have motor impairments (Geyh et al., 2004) which may not only decrease control of movements but may limit participation in meaningful activities (AIHW, 2013). In a longitudinal study, Ada and colleagues observed forty stroke survivors (Ada, Preston, Langhammer & Canning, 2020) and a key observation was that stroke survivors with a very weak, disabled upper limb showed very little increase in upper limb activity within the first 12 weeks. This was consistent with previous studies exploring prognostics and patterns of recovery (Nijland, van Wegen, Harmeling-van der Wel & Kwakkel, 2010; Coupar et al., 2012b; Stinear et al., 2012). Aiming to determine whether there is a window of greatest improvement in the upper limb following stroke, a recent multicentre observational study found that significant improvements were observed in motor capacity and quality of movement up to 18 months post-stroke (Borschmann & Hayward, 2020). Whilst the greatest rate of improvement was observed to occur early post-stroke, the authors reported that some individuals continued to show gains at the 24-month time point.

#### **1.1.4 Neuroplasticity**

Recovery from stroke is thought to include restitution and relearning of lost functions, as well as adaptation and compensation of spared functions (Nudo & McNeal, 2013). Neuroplasticity, a process of brain plasticity which occurs following neurological damage (Gerloff et al., 2006; Nudo, 2007), is defined as the ability of the nervous system to respond to intrinsic or extrinsic stimuli by organising its structure, function, and connections (Cramer et al., 2011).

Stroke triggers a series of molecular and cellular events that stimulate neural protection and spontaneous recovery (Overman & Carmichael, 2014). Changes observed in experimental stroke studies include growth of synapses and dendrites (Jones, Kleim & Greenough, 1996; Zhang, Zhang & Chopp, 2008), axonal remodelling and angiogenesis (Ding et al., 2008; Teng et al., 2008), and enhanced brain excitability mediated by changes in gamma-aminobutyric acid (GABA) receptors (Redecker, Wang, Fritschy & Witte, 2002). In addition to brain changes occurring within the lesioned region, stroke-induced changes are observed in adjoining areas of the ipsilateral hemisphere (Dancause et al., 2005) and the contralateral hemisphere (Jones, Kleim & Greenough, 1996). These brain changes occur during three distinct time phases which have important clinical implications (Cassidy & Cramer, 2017). The initial phase occurs within the first hours after stroke onset and represents an opportunity to salvage tissues under threat. The second phase, during the next days to weeks, corresponds to initial brain repair and spontaneous recovery. Following this, phase three represents a more chronic repair phase where modifications in brain structure are still possible (Cassidy & Cramer, 2017). Figure 1-2 illustrates a 'hypothetical pattern of recovery' following stroke (Langhorne, Bernhardt & Kwakkel, 2011).

**Figure 1-2 Hypothetical pattern of recovery after stroke with the timing of intervention strategies (Langhorne, Bernhardt & Kwakkel, 2011)**

***This image has been removed due to copyright restriction, available from: Langhorne, P., Bernhardt, J. & Kwakkel, G. (2011). Stroke rehabilitation. The Lancet, 377(9778): 1693-1702.***

Through cortical reorganisation in animal models (Nudo & Milliken, 1996; Alia et al., 2016), neuroplasticity has been seen to be influenced by experience (Li & Carmichael, 2006; Holtmaat & Svoboda, 2009) and driven by meaningful behaviour (Nudo, 2007). For example, primate studies showed that, in the absence of rehabilitative training, there is a significant reduction of the hand representation area in the primary motor cortex (Nudo, 2007) which does not occur if the primate undergoes 'training'. Similar patterns of neural plasticity have been observed in the human brain. In stroke survivors, remapping of motor cortical areas has been observed via imaging studies (Traversa et al., 1997; Liepert et al., 1998; Rossini et al., 2001), and after several weeks of rehabilitation, motor representation areas in the injured hemisphere have been seen to be enlarged compared to the initial post-stroke imaging (Carey et al., 2002). The establishment of these neural pathways is therefore enhanced by the repetitive practice of a task (Langhorne, Coupar & Pollock, 2009; Birkenmeier, Prager & Lang, 2010; Nilsson, Pekny & Pekna, 2012). This concept, (i.e. that the more a movement is repeated, the more defined the neural network becomes) (Selzer et al., 2014; Winstein et al., 2014), is the basis for rehabilitation following stroke.

Neuroplasticity following stroke is influenced by the extent and location of the stroke (Lindenberg et al., 2010; Cramer et al., 2011), the time since stroke (Cassidy & Cramer, 2017), and the specifics of the environment (Cramer et al., 2011). For example, one study from the Extremity Constraint-Induced Therapy Evaluation (EXCITE) trial (Wolf et al., 2010), a prospective, single-blind, multicentre trial exploring Constraint-Induced Movement Therapy (CIMT), found that when the two-week CIMT program was delivered early (3-9 months post-stroke), there was a significantly greater improvement in outcome measures than when it was delayed (15-21 months) (Dromerick et al., 2009). This study demonstrated that the timing of rehabilitation can influence recovery following stroke.

Most neurological reorganisation is believed to occur in the first three months following stroke, however slower changes will continue for several months, or even years to follow (Cramer et al., 2011; Cassidy & Cramer, 2017). Hence, there is potential for neuroplasticity to be shaped and positively influenced by the rehabilitation experience (Nudo, 2003; Carey, 2007; Carey, 2012). Experience and learning-based plasticity are essential for restorative change following stroke (Carey, Polatajko, Connor & Baum, 2012; Pekna, Pekny & Nilsson, 2012), hence therapeutic interventions aim to facilitate cortical reorganisation through functional demand and practice

(Buma, Kwakkel & Ramsey, 2013).

## 1.2 Rehabilitation

Rehabilitation has been described as a set of interventions that assist individuals with impairments and/or limitations from a range of health conditions to achieve and maintain optimum function to participate in everyday activities (World Health Organisation, 2011; Gimigliano & Negrini, 2017). The goal of rehabilitation should be to equip consumers to live their lives, fulfil their maximum potential, and optimise their contribution to family, community, and society (National Health Service, 2016). Rehabilitation is beneficial to the consumer and their families/carers and also for society (Gimigliano & Negrini, 2017), as it has been shown to improve a person's independence and capacity to return to work or other roles and reduce the costs related to ongoing care (Turner-Stokes et al., 2016).

The need for rehabilitation is increasing, predominantly attributed to an aging population and higher prevalence of chronic conditions (Gimigliano & Negrini, 2017). Furthermore, as access to health care has improved, more people survive serious injury and illness and require rehabilitation services (Gimigliano & Negrini, 2017). An objective of the World Health Organisation action plan on disability is to "strengthen and extend rehabilitation, habilitation, assistive technology, assistance and support services, and community-based rehabilitation" (p. 3) (World Health Organisation, 2015). However, the capacity to provide rehabilitation is still limited in some countries, especially low- and middle-income countries (World Health Organisation, 2006; World Health Organisation, 2015). In Australia, admissions for neurological rehabilitation and inpatient aged care increased on average by 4.4% yearly in public hospitals, and by 12.8% yearly in private hospitals between 2014 and 2015 (Australian Institute of Health and Welfare, 2019). Hence, demand is increasing and health services must adapt and develop to meet this growing need.

A recent editorial, presented by a highly credentialed researcher, identified features of 'effective' rehabilitation (Wade, 2020). The important features of rehabilitation summarised in this extensive review are as follows: rehabilitation should be based on the biopsychosocial model of illness; there should be an expert multidisciplinary team providing a consistent and comprehensive approach; a comprehensive and holistic initial assessment should be undertaken to achieve a full understanding of the patient's situation; interventions should be tailored to the particular patient; and changes should be monitored, evaluated against goals and checked for potential harms (Wade, 2020). The author outlined the processes of rehabilitation, presented in Figure 1-3.

Figure 1-3 Rehabilitation: who benefits, what structures are needed, what processes occur, and what is the outcome? (Wade, 2020)

*This image has been removed due to copyright restriction, available from: Wade, D. T. (2020). What is rehabilitation? An empirical investigation leading to an evidence-based description. SAGE Publications Sage UK: London, England.*

### 1.3 Rehabilitation following stroke

Stroke rehabilitation aims to reduce overall stroke-related disability (Brewer, Horgan, Hickey & Williams, 2013) and provide stroke survivors with the opportunity to restore their motor skills and regain or manage their functional difficulties (Lo, Stephenson & Lockwood, 2017). Based on compelling evidence, research findings have been synthesised into multiple clinical guidelines that provide health professionals with evidence-based recommendations for rehabilitation after stroke (Hebert et al., 2016; Stroke Foundation, 2017c). According to the guidelines, there is strong evidence for the effectiveness of a multi-disciplinary team delivering stroke rehabilitation (Langhorne, Bernhardt & Kwakkel, 2011; Fearon, Langhorne & Early Supported Discharge Trialists, 2012; Stroke Unit Trialists Collaboration, 2013; Hebert et al., 2016; Stroke Foundation, 2017c). Delivering rehabilitation in a dedicated stroke-specific environment, or stroke unit, is important and has been shown to improve outcomes by minimising preventable complications and enhancing independence (Langhorne & Pollock, 2002; Saposnik et al., 2009; Stroke Foundation, 2017c). Additionally, involvement of the patient and carer in the goal-setting process is recommended and is reported to improve motivation, engagement, and outcomes of therapy (Langhorne, Bernhardt & Kwakkel, 2011; Sugavanam et al., 2013; Stroke Foundation, 2017c). It is also strongly recommended that people with mild to moderate stroke should be discharged early, with supports if they are available (Fearon, Langhorne & Early Supported Discharge Trialists, 2012; Stroke Foundation, 2017c).

There is strong evidence that high doses of therapy can lead to improved stroke outcomes. Verbeek and colleagues (2014) found that extra rehabilitation improved walking ability (SMD 0.32, 95% CI 0.11 to 0.52) and Schneider, Lannin, Ada & Schmidt (2016) reported that when a large increase in rehabilitation was provided there was improved activity (SMD 0.39, 95% CI 0.07 to 0.71). Hence, clinical guidelines recommend stroke survivors should receive as much scheduled therapy as possible (Hebert et al., 2016; Stroke Foundation, 2017c). The content of therapy is important, and there is strong evidence that task-oriented and context-oriented training can enhance stroke recovery (Kwakkel, Kollen & Lindeman, 2004; Murphy & Corbett, 2009; Hebert et al., 2016).

In a landmark review of the evidence underlying stroke rehabilitation, Langhorne and colleagues (Langhorne, Bernhardt & Kwakkel, 2011) identified the four key principles of rehabilitation as **high-**

*intensity practice, task-specific training, multidisciplinary team care, and goal setting.*

### **1.3.1 High-intensity practice**

To drive recovery after stroke, a high dose of therapy is recommended (Kwakkel et al., 2004; Hayward, Barker, Carson & Brauer, 2014; Lohse, Lang & Boyd, 2014; Veerbeek et al., 2014; French et al., 2016; Stroke Foundation, 2017c). 'Dose' of therapy can refer to the intensity (effort), amount (of repetitions), or frequency and duration (time) of an intervention (Cooke et al., 2010; Lang, Lohse & Birkenmeier, 2015). Several systematic reviews investigating the effect of extra practice on motor outcomes have found favourable results: Kwakkel and colleagues (2004) found that extra rehabilitation improves activities of daily living (SMD 0.13, 95% CI 0.03 to 0.23) Lohse and colleagues (2014) reported that extra rehabilitation improved therapy outcomes across a range of different impairments and functions (SMD 0.35, 95% CI 0.26 to 0.45) and Verbeek and colleagues (2011) found that improved walking ability and speed resulted from extra lower limb rehabilitation (SMD 0.32, 95% CI 0.11 to 0.52)). In a recent systematic review with meta-analysis, the effects of extra rehabilitation with the same content as usual rehabilitation were investigated (Schneider, Lannin, Ada & Schmidt, 2016). The authors reported that the amount of extra rehabilitation that is needed to produce a beneficial effect is large, at least 240%, or almost three times the amount of usual rehabilitation.

Despite clinical guidelines recommending programs that deliver large amounts of practice to maximise stroke outcomes (Hebert et al. 2016; Stoke Foundation, 2017c), many reviews have indicated that the dose of rehabilitative therapy is limited (Foley et al., 2012; Kaur, English & Hillier, 2012). For example, stroke survivors participating in the A Very Early Rehabilitation Trial (AVERT), were found to engage in moderate or high levels of activity for less than 13% of their day within the initial two weeks post-stroke (Bernhardt, Dewey, Thrift & Donnan, 2004; Bernhardt et al., 2006). Furthermore, the intensity of therapy following stroke usually decreases over time and has often ceased between three- and six-months following stroke (Schaechter, 2004). This timeline coincides with a reported recovery plateau that occurs (Kwakkel, Kollen & Lindeman, 2004; Zeiler & Krakauer, 2013), however clinical studies of stroke recovery suggest this 'plateau' may be caused, in part, by this reduction in rehabilitation input (Page, Gater & Bach-y-Rita, 2004; Demain, Wiles, Roberts & McPherson, 2006). This reported plateau and subsequent reduction in therapy provided have been brought into question with an increasing understanding of experience-based neuroplasticity (Nudo, Plautz & Frost, 2001).

There are significant barriers to delivering high doses of therapy in environments where resources are scarce (Kwakkel, 2006; Kaur, English & Hillier, 2012), and health professionals may need to consider alternative methods of service delivery to augment the amount of practice undertaken by stroke survivors. Many studies have explored ways to deliver additional one-on-one therapy sessions outside of usual rehabilitation (Rodgers et al., 2003; Donaldson et al., 2009; Burgar et al.,

2011; Han, Wang, Meng & Qi, 2013). More recently, Schneider and colleagues explored whether it was feasible for inpatient stroke survivors to undertake an extra hour of upper limb practice, six days per week for four weeks (Schneider, Ada & Lannin, 2019). This study provided evidence that it was feasible to undertake this extra practice, however, due to other therapy commitments and use of therapy areas, practice was often undertaken after usual rehabilitation times and in a common space within the ward. This study demonstrates that health professionals need to be creative and innovative when considering ways to increase the dose of therapy and practice.

### ***1.3.1.1 High-intensity upper limb practice following stroke***

The amount of therapy provided is important for recovery and a Cochrane review found moderate quality evidence that upper limb function could be improved by providing at least 20 additional hours of repetitive task training (Pollock et al., 2014). However, despite this evidence for increasing dose of upper limb therapy, many studies have shown that the amount of upper limb therapy delivered in rehabilitation environments is suboptimal (Ada et al., 1994; Kuys, Brauer & Ada, 2006). An early study showed that for people within 14 days of stroke, activity of the affected upper limb accounted for only 6% of the time spent in therapy, for a total of 4-11 minutes of training time (Bernhardt, Chan, Nicola & Collier, 2007). In addition, Lang and colleagues demonstrated during an observational study of 312 inpatient therapy sessions, that practice of functional upper limb movements occurred in only 51% of sessions (Lang et al., 2009). More recently, in an exploration of the quantity and content of upper limb therapy provided to people with severe impairment following stroke, Hayward and colleagues reported a mean of 46 minutes of individual upper limb therapy and 11 minutes in group sessions, per day (Hayward, Barker, Wiseman & Brauer, 2013). Additionally, a recent survey-based study of 154 physiotherapists and occupational therapists reported that stroke survivors received a median of three upper limb based therapy sessions each week (Stockley, Peel, Jarvis & Connell, 2019). Stroke survivors have described that their time spent doing upper limb therapy is insufficient (Barker & Brauer, 2005). This may reflect a limitation in available resources, as it has been described that the amount of upper limb therapy provided is often based on what can comfortably be delivered within the health service, rather than the best evidence available (Hayward et al., 2019).

In an intervention delivering 90 hours of upper limb rehabilitation, Ward and colleagues (Ward, Brander & Kelly, 2019) demonstrated that chronic stroke survivors could make clinically important changes which were maintained at six months. The authors report that high-dose, high-intensity rehabilitation is represented by services that can “deliver higher doses than conventionally seen” (p. 1) (Ward, Brander & Kelly, 2019). When considering what is ‘conventionally seen’, Hayward and colleagues reference recent high-profile upper limb rehabilitation clinical trials that report relatively low amounts of therapy, approximately 30 minutes per day (Hayward et al., 2019). This aligns with the description provided by Langhorne and colleagues of ‘high-intensity practice’ as ‘increased therapy or intervention’ (Langhorne, Bernhardt & Kwakkel, 2011). Based on these



definitions, the interventions being explored in Chapters 3-5 of this thesis, which are comprised of 60 minutes of exercise, 6-7 days per week for 4-10 weeks, would be considered to be high-intensity.

### **1.3.2 Task-specific training**

#### ***1.3.2.1 Summary of upper limb therapy approaches***

There are many different rehabilitation interventions identified for addressing the upper limb following stroke (Pollock et al., 2014). There are several approaches to upper limb therapy, such as Constraint-Induced Movement Therapy (CIMT) (Sirtori, Corbetta, Moja & Gatti, 2009; Nijland, Kwakkel, Bakers & van Wegen, 2011; Peurala et al., 2012; Wattchow, McDonnell & Hillier, 2018), that have been extensively researched and implemented into clinical practice, based on sound evidence (Stroke Foundation, 2017c). Newer modalities such as robotic therapy (Mehrholz et al., 2012; Veerbeek et al., 2017) and virtual reality therapy (Laver et al., 2015; Gill & Dudoniené, 2019) have emerging evidence and are now included in clinical guidelines as interventions that may be used to improve upper limb function (Stroke Foundation, 2017c). Health professionals tend to use a range of therapy techniques and approaches, as highlighted in a recent survey-based study of 154 health professionals (Stockley, Peel, Jarvis & Connell, 2019). In this study, treatments identified as being used for stroke survivors with mild upper limb deficits were functional training, the Graded Repetitive Arm Supplementary Program (GRASP), active and weighted exercises, CIMT, and task-specific training. The following section of the thesis will discuss the main therapy approaches incorporated into the studies that follow in this thesis: task-specific training and the GRASP. These therapy approaches have been chosen because they are supported by strong evidence (Harris, Eng, Miller & Dawson, 2009) and are included in clinical stroke guidelines (Stroke Foundation, 2017c).

#### ***1.3.2.2 Task-specific training***

Greater benefit is known to arise from upper limb programs where the stroke survivor practices tasks directly (Rodgers, 2003; World Health Organisation, 2011). Task-specific training involves the practice of a task, or part of a task, intending to improve the ability to carry out activities (Pollock et al., 2014; Turton et al., 2017). Task-specific training focuses on goal-oriented practice and task repetition, and tasks should be meaningful to the individual (Valkenborghs et al., 2019). These principles are based on animal studies that have shown cortical reorganisation is optimal when the task is meaningful to the individual (Bayona, Bitensky, Salter & Teasell, 2005).

In Australia, audits report that task-specific training is used with 83% of stroke survivors who present with upper limb impairment, although this may be in smaller doses than recommended (Stroke Foundation, 2016). The use of task-specific training in stroke rehabilitation has been firmly embedded, and its effectiveness has been supported by extensive evidence (French et al., 2010; Pollock et al., 2014; French et al., 2016). Globally, task-specific training is recommended in most

clinical stroke guidelines (Hebert et al. 2016; Stroke Foundation, 2017c).

Importantly, task-specific training has been shown to be beneficial irrespective of time since stroke (French et al., 2016). Increasing therapy dose in the more chronic phase of stroke recovery may be a crucial factor for achieving a positive outcome (Perez-Marcos et al., 2017). Perez-Marcos and colleagues (Perez-Marcos et al., 2017) demonstrated that it was feasible to provide intensive motor rehabilitation in chronic stroke patients, using virtual reality-based functional training. Furthermore, the authors reported that the functional skills of chronic stroke survivors could be improved with intense training. Whilst these findings support ongoing intensive task-specific therapy in a chronic stroke population, barriers to participation including a lack of underlying movement need to be considered when selecting therapy approaches (Barker & Brauer, 2005; Hayward, Barker, Wiseman & Brauer, 2013).

#### 1.3.2.2.1 The Graded Repetitive Arm Supplementary Program (GRASP)

The GRASP, a self-administered intervention for the weak upper limb which is based on the principles of intensive, repetitive, and task-specific practice (Harris, Eng, Miller & Dawson, 2009; Simpson, Eng & Chan, 2017), is taught by a therapist but independently performed by the stroke survivor. The GRASP protocol was developed and evaluated in a randomised controlled trial with inpatient stroke survivors (Harris, Eng, Miller & Dawson, 2009) where participants demonstrated significant improvements in their upper limb function after four weeks of completing 60 minutes of the GRASP per day. Exercises were presented in manuals and a 'GRASP kit' of inexpensive equipment was required. Exercises included strengthening of the arm and hand (small weights, putty, hand gripper), range of movement (stretches), and gross and fine motor skills (e.g. blocks, pegs, cups). In addition, task-specific activities were incorporated, such as folding a towel and doing up buttons (Harris, Eng, Miller & Dawson, 2009).

The GRASP has been incorporated into some international stroke guidelines (Lindsay et al., 2011). The self-administered aspect of the GRASP allows stroke survivors to continue upper limb therapy beyond the traditional rehabilitation services and without direct therapist contact (Simpson, Eng & Chan, 2017). The GRASP has been used extensively to provide a structured home-based exercise program (Simpson, Eng & Chan, 2017). Simpson and colleagues (Simpson, Eng & Chan, 2017) developed a program, H-GRASP, which incorporated exercises adapted from the GRASP, behavioural strategies to promote upper limb use functionally, and support via phone monitoring. Almost all participants who completed this study achieved the target of 60 minutes of exercise daily, as reported via self-report of adherence. Whilst the program was feasible for the participation of stroke survivors living at home, limitations included a lack of control group and lack of objectivity in the measurement of adherence (i.e. self-report only).

The GRASP has been used worldwide, often in modified formats (Connell et al., 2014a; Connell,

McMahon, Watkins & Eng, 2014). In a survey-based study of occupational therapists in the United Kingdom, 63% of respondents were aware of the GRASP, 22.3% of respondents had experience of using the GRASP, and therapists' opinions suggested that the GRASP was an acceptable and feasible intervention (Connell, McMahon, Watkins & Eng, 2014). Patient perspectives of using the GRASP have also been evaluated (Harris, Eng, Miller & Dawson, 2009; Murdolo et al., 2017). Seventy-five percent of participants in a small mixed-methods evaluation of participating in the GRASP in a hospital setting identified the GRASP as the main facilitating factor in the recovery of their upper limb (Murdolo et al., 2017).

In summary, studies have shown that many stroke survivors have long-term upper limb hemiparesis that can impact their level of activity and quality of life. We know that higher doses of upper limb therapy, based on task-specific training, are required for improved outcomes following stroke. Despite this compelling evidence, it is apparent that the intensity of upper limb therapy currently being delivered following stroke is sub-optimal (Kuys, Brauer & Ada, 2006; Bernhardt, Chan, Nicola & Collier, 2007; Stockley, Peel, Jarvis & Connell, 2019).

### **1.3.3 The multidisciplinary team**

Clinical stroke guidelines recommend that stroke patients should be admitted to hospital and treated in a dedicated stroke unit and within a multidisciplinary team (Stroke Foundation, 2017c). Stroke unit care has been described as focused care delivered by a multi-disciplinary team who specialise in stroke rehabilitation (Stroke Unit Trialists Collaboration, 1997). Core components of a multi-disciplinary team include the staffing, that is, medical, nursing, and therapy staff, and coordinated team care through regular meetings (Stroke Unit Trialists Collaboration, 1997). A recent Cochrane review reported moderate quality evidence that stroke patients treated within an organised stroke unit were more likely to be alive, independent, and living at home one year following stroke (Langhorne, Ramachandra & Stroke Unit Trialists Collaboration, 2020). Positive outcomes, including earlier discharge home and less likelihood of patients requiring institutional care, have been associated with established stroke units employing skilled multidisciplinary professionals who collaborate through regular meetings and have clearly defined care pathways (Clarke, 2013).

### **1.3.4 Goal Setting**

Goal setting, defined as “a directive activity, incorporating the following steps: goal selection, task analysis, assessment, decision, action initiation and evaluation” (p. 226) (McGrath & Davis, 1992), is widely accepted as an integral component of rehabilitation (Wade, 2009). During the rehabilitation of the stroke patient, it is recommended that health professionals set goals in collaboration with the stroke survivor and their family/carer, provided they are willing to participate (Stroke Foundation, 2017c). Strategies to enhance the patient-centred aspect of goal setting include setting goals at the patients' bedside and providing education and training to the patient

and health professionals about the process (Rosewilliam, Roskell & Pandyan, 2011). Goal setting can be used to enhance motivation and adherence (Sugavanam et al., 2013), to ensure the team works towards the same goals, to ensure important actions are not overlooked, and to allow monitoring of change to interventions (Wade, 2009). Goals should be patient-stated, well defined, specific, and challenging (Stroke Foundation, 2017c).

## **1.4 Exercise adherence**

Exercise adherence has had multiple definitions in the literature, with some authors providing their own definition, commonly based on the parameters being measured, including frequency, duration, intensity, and accuracy (Bailey et al., 2020). The World Health Organisation defines adherence as “the extent to which a person’s behaviour – taking medication, following a diet and/or executing lifestyle changes, corresponds with agreed recommendations from a healthcare provider” (p. 18) (World Health Organisation, 2003). Adherence is a multidimensional construct (Kolt et al., 2007) where the individual, who considers the influences of the advised intervention on their behaviour and motivation, is an active decision-maker in the process (Bailey et al., 2020). When describing adherence to prescribed exercise programs, adherence can be described in terms of whether people undertake the prescribed number of exercises, the intensity of exercise within a session, or the time (duration) taken to perform the exercises (Jack, McLean, Moffett & Gardiner, 2010). Quantification of the amount of practice is challenging (Lang, Lohse & Birkenmeier, 2015) and there is a lack of consistency when reporting parameters across studies.

Poor adherence to the treatment of chronic diseases, such as stroke, leads to poor health outcomes and increased health care costs (Rivera-Torres, Fahey & Rivera, 2019). Exercise adherence is reported to be high in the initial stages of participation but tends to reduce over time (Campbell et al., 2001; Lonsdale et al., 2017). Adherence to treatment, including exercise, is proposed to be critical for an intervention to achieve a positive outcome (Vermeire, Hearnshaw, Van Royen & Denekens, 2001; Pisters et al., 2010; Beinart et al., 2013). Subsequently, there has been extensive research exploring interventions to enhance adherence across a range of health domains, most notably medication adherence (Nieuwlaat et al., 2014) and physiotherapy prescribed self-management strategies (Peek, Sanson-Fisher, Mackenzie & Carey, 2016). A systematic review of interventions for enhancing medication adherence found that several interventions, such as providing written instructions and follow-up phone calls, improved medication adherence (Nieuwlaat et al., 2014). Peek and colleagues (Peek, Sanson-Fisher, Mackenzie & Carey, 2016) identified 12 different interventions to aid patient adherence to exercises, including goal setting and an activity monitor and feedback system, however, there was insufficient evidence to provide clinical recommendations. Additionally, a recent systematic review explored the effectiveness of using behaviour change techniques to enhance adherence to activity recommendations in a musculoskeletal population (Eisele et al., 2019). The authors reported that

there was moderate quality evidence for the effectiveness of common behaviour change techniques including goal setting, self-monitoring, and feedback, on enhancing adherence to physical activity. Systematic review evidence has also identified self-motivation, self-efficacy, previous adherence behaviour, and social support as predictive of adherence to home-based physical therapy programs (Essery, Geraghty, Kirby & Yardley, 2017). Further behavioural strategies used to enhance adherence are presented in Table 1-1.

**Table 1-1 Behavioural strategies used to enhance adherence to exercise**

<b>Behavioural strategy to enhance adherence</b>	<b>Some key components of the behavioural strategy</b>	<b>Example study</b>
<b>Coaching</b>	<p>Health education and health promotion. Engages the patient as a partner.</p> <p>Focuses on self-management. Incorporates agenda-setting, decision making, and behaviour change planning (Ervin, Jeffery &amp; Koschel, 2012).</p>	<p><b>Author: Askim et al., 2018</b></p> <p>Design: Multi-site randomised controlled trial, control group = usual care, intervention group = monthly coaching on physical activity (PA). Participants: n=380, community-dwelling stroke survivors, 10-16 weeks post-stroke.</p> <p>Results/conclusion: No significant difference in motor function. Stroke survivors receiving coaching were more active than the control group. The intervention should be regarded as safe.</p>
<b>Individual counselling</b>	<p>1:1 consultation. Focus primarily on enhancement of an individual's behaviour.</p> <p>Some protocols may be specific to the individuals' stage of change (precontemplation/contemplation/action).</p> <p>A plan is made to improve behaviour (Proper et al., 2003).</p>	<p><b>Author: Morris, MacGillivray &amp; Mcfarlane, 2014</b></p> <p>Design: Systematic review of RCTs and meta-analyses examining interventions to increase long-term participation in PA. Participants: 11 included studies involving 1704 participants.</p> <p>Results: Some evidence that tailored counselling alone or with supervised exercise improves long-term PA in stroke survivors better than supervised exercise and general advice.</p>
<b>Self-management strategies</b>	<p>Thoughts, goals, plans, and acts that support behaviour. Can mediate an association between self-efficacy and behaviour.</p> <p>Includes self-monitoring and positive self-talk. Encourage patients to take an active part in their health care (Dishman et al., 2005).</p>	<p><b>Author: Jones, 2006</b></p> <p>Design: Extensive literature review, focused on self-management related to chronic disease.</p> <p>Results: Strong evidence to support the use of self-management programs and their effect on health outcomes.</p>

<p><b>Self-efficacy strategies</b></p>	<p>Strategies address goal setting, how much effort is invested in achieving the goals, and resilience when faced with difficulties.</p> <p>Four main sources of self-efficacy: mastery experiences (break the task into smaller components); vicarious experience (compare and model to others); verbal persuasion (using a significant other to increase self-belief); and, physiological feedback (interpret feelings as positive i.e. a mindset) (Jones &amp; Riazi, 2011).</p>	<p><b>Author: Picha &amp; Howell, 2018</b></p> <p>Design: Model development to improve patient adherence to home exercise programs by addressing self-efficacy through individualised treatment. Participants: Two case examples.</p> <p>Results: Self-efficacy is a common barrier to adherence and should be individually addressed with each patient before the implementation of home exercise programs.</p> <p><b>Author: Sniehotta, Scholz &amp; Schwarzer, 2005</b></p> <p>Design: Longitudinal study, exploring the intention-behaviour gap. Participants: n=437, in patients with coronary heart disease.</p> <p>Results: Self-efficacy and outcome expectancies were the strongest predictors of intentions to exercise.</p>
<p><b>Goal setting</b></p>	<p>Directs attention, effort, and action towards goal-relevant actions. Motivates the patient to use existing skills and knowledge or search for new knowledge. Feedback is key to tracking progress.</p> <p>Patients need a commitment to the goal, which is enhanced by self-efficacy. Goals can be set by others, set jointly, or be set by the patient (Locke, Frederick, Lee &amp; Bobko, 1984).</p>	<p><b>Author: Evans &amp; Hardy, 2002</b></p> <p>Design: A goal setting intervention study with three groups: goal setting intervention group, social support control group, and control group. Participants: 77 participants with sports injuries.</p> <p>Results/conclusion: The goal setting group adhered significantly more to the rehabilitation program than the other two groups. Goal setting resulted in improved self-efficacy.</p>
<p><b>Motivational strategies</b></p>	<p>Central to behaviour change, introducing external strategies to engage patients to participate in a behaviour.</p> <p>Can include setting goals, establishing rewards, using positive thinking, and using positive imagery. Sharing and exchanging with others can be significant (Golay, Lager &amp; Giordan, 2007).</p>	<p><b>Author: Oyake et al., 2020</b></p> <p>Design: Three round Delphi survey to provide a comprehensive list of effective motivational strategies. Participants: 198 rehabilitation experts, rated the effectiveness of motivational strategies.</p> <p>Results: Seven strategies were considered very effective in increasing patient motivation; control of task difficulty, goal setting, providing feedback regarding results of practice, goal-oriented practice, praise, providing a suitable rehabilitation environment, and practice related to the patient's experience.</p>
<p><b>Individualisation of program</b></p>	<p>Development of an exercise program considering specific, individual goals.</p> <p>Can account for specific patient impairments and barriers (Moorcroft,</p>	<p><b>Author: Donoso Brown et al., 2020</b></p> <p>Design: Scoping review of home program practices for supporting adherence. Participants: 70 studies included in</p>

	Dodd, Morris & Webb, 2004).	<p>qualitative synthesis.</p> <p>Results: Half of the included studies reported individualising programs, reflecting an increased emphasis on client-centred practice.</p>
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### 1.4.1 Exercise adherence in stroke survivors

Rates of adherence to physical activity and exercise in stroke survivors have been explored in many studies. In a survey-based study, Miller and colleagues found that only 65.3% of stroke survivors who completed a six-month rehabilitation program, and received a home exercise program, reported ongoing adherence with some of the exercises (Miller et al., 2017). Despite ongoing supervision of an exercise program, Tiedemann and colleagues reported that, one year after follow-up, participants were completing only 44% of the recommended level of exercise per day (Tiedemann et al., 2012).

In a longitudinal study of adherence patterns in stroke survivors, Yao and colleagues identified three distinct ‘phases’ of adherence behaviours (Yao et al., 2017). Firstly, they reported a ‘rapid increase phase’, occurring between the first and sixth weeks, whereby stroke survivors had a strong will to recover, encouraged by the enhanced recovery that occurs early after stroke. Between weeks six and 21, when most stroke survivors had returned home, the authors observed a ‘slow decrease phase’, where many stroke survivors received less support and guidance, and subsequently adherence levels reduced. From weeks 21 to 24, the authors noted a ‘slow phase’, where the effects of rehabilitation were reduced, and stroke survivors tended to settle into their new functional level. The authors stated that “without intervention, their adherence may continue to remain at this level and new health problems may occur” (p. 1438) (Yao et al., 2017).

Many studies have explored the link between adherence to exercise or physical activity guidelines and outcomes after stroke (Duncan et al., 2002; Micieli, Cavallini & Quaglini, 2002; Veerbeek et al., 2011; Foley et al., 2012; Wang et al., 2013). Duncan and colleagues reported that improved adherence to post-stroke guidelines enhanced functional gains at six months post-stroke (Duncan et al., 2002). More recently, Gunnes and colleagues (Gunnes et al., 2019a) assessed the associations between participants’ degree of adherence to exercise and functional outcomes 18 months after participation in their study, and found a statistically significant relationship existed. This study cohort was community-dwelling, older stroke survivors who had received monthly coaching to encourage adherence.

Strategies to enhance adherence to exercise in stroke survivors have been explored. High rates of

adherence to exercise are regarded as indicative of high motivation (Maclean, Pound, Wolfe & Rudd, 2002). Interventions based on motivational strategies, via individualised tailored counselling, were effective in increasing activity in a mixed population (Van der Ploeg et al., 2006), and the use of motivational strategies in stroke rehabilitation has been shown to enhance adherence to programs and improve outcomes (Cheng et al., 2015; McGrane, Galvin, Cusack & Stokes, 2015). A recent scoping review exploring what strategies were used to support adherence to home-based exercise following stroke reported the most frequently used strategies were the integration of technology, individualisation of programs, written directions, phone or in-person check-ins, and caregiver support (Donoso Brown et al., 2020). Self-efficacy, or a persons' belief about their capabilities, has been seen to be a strong predictor of adherence (Bandura, 1977; Dixon, Thornton & Young, 2007; Essery, Geraghty, Kirby & Yardley, 2017; Picha & Howell, 2018), and patients with low self-efficacy may avoid activities they see as threats, lessen efforts towards difficult tasks, dwell on failures, or lack the commitment to goals (Bandura 1990). Hence, programs that incorporate strategies to enhance self-efficacy and encourage problem-solving and decision-making have been recommended (Caetano et al., 2020).

As formal rehabilitation is typically finished within the first six months following stroke (Miller et al., 2017), stroke survivors should be provided with ongoing exercise programs and recommendations to continue with following discharge (Miller et al., 2017). Home-based therapy potentially enables a greater dose of motor training to occur beyond inpatient rehabilitation (Coupar et al., 2012a; Brown et al., 2015), hence stroke survivors are often prescribed home exercise programs (Jones, 2006). There has been an increased focus on home exercise programs in stroke rehabilitation with the move to shorter inpatient programs and prolonged and distant monitoring of outpatient programs (Donoso Brown et al., 2020). Adherence to home-based programs is important for positive outcomes (Duncan et al., 2002), however, it has been reported that 50-70% of patients are either non-adherent or partially adherent to home-based physiotherapy programs (Bassett, 2003; Beinart et al., 2013). This highlights the need for strategies to enhance adherence to home programs (Grau-Pellicer, Lanza, Jovell-Fernández & Capdevila, 2020), as patients' adherence to self-managed home-based therapy is essential for long-term benefits (Hayden, Van Tulder & Tomlinson, 2005).

#### **1.4.2 Barriers to exercise adherence in stroke survivors**

Evidence has shown that many stroke survivors experience physical and psychological barriers (Langhorne, Bernhardt & Kwakkel, 2011) which may limit their engagement in physical activities over time (Simpson et al., 2011; Morris, 2016). A report on adherence to long-term therapies states that "the ability of patients to follow treatment plans in an optimal manner is frequently compromised by more than one barrier, usually related to different aspects of the problem" (p. XIV) (World Health Organisation, 2003). Adherence is promoted by the belief that participation in the



intervention will be effective (i.e. outcome expectancy), and the ability of the individual to participate in the intervention (i.e. efficacy expectation) (Flegal et al., 2007). Long-term, a complex combination of factors seems to influence adherence to exercise in stroke survivors, some of which are modifiable (Morris, 2016). Factors identified as influencing adherence to home-based, self-managed physical therapies include the following: intention to engage, self-motivation, self-efficacy, previous adherence behaviours, social support, poor knowledge about stroke and exercise, slow recovery, dependence on others, and attitude of the society (Chen, Neufeld, Feely & Skinner, 1999; Essery, Geraghty, Kirby & Yardley, 2017; Nicolson et al., 2017; Débora Pacheco et al., 2019; Mahmood et al., 2019; Meade, Bearne & Godfrey, 2019; Lin et al., 2020; Moore, Holden, Foster & Jinks, 2020).

It has been noted that barriers to self-managed physical therapy may be different from clinic-based therapy, and specific factors should therefore be considered when planning home-based programs (Alexandre, Nordin, Hiebert & Campello, 2002). Self-managed home-based programs are characterised by features, such as the lack of supervision and uncertainty about the therapy, which may further reduce rates of adherence (Carter, Taylor & Levenson, 2003; Kirby, Donovan-Hall & Yardley, 2014). For example, in a study exploring adherence to a prescribed home exercise program in older adults with impaired balance, Forkan and colleagues (Forkan et al., 2006) reported that 90% of participants had received a program, but 37% were no longer performing it.

In a qualitative exploration of factors influencing adherence to prescribed home-based exercises, having a supportive family member was considered the most important determinant of adherence, and a barrier expressed by many participants was a lack of professional supervision or contact with health professionals (Mahmood et al., 2019). Additional barriers to participation in home exercise programs identified include: the mode of exercise delivery (Lambert et al., 2017); the persons' attitude towards stroke (Lin et al., 2020); environmental issues (Rimmer, Wang & Donald, 2008; Nicholson et al., 2014); pain (Sluijs & Knibbe, 1991; Hammel, Jones, Gossett & Morgan, 2006; Nicholson et al., 2014; Moore, Holden, Foster & Jinks, 2020); and a lack of available time (Sluijs & Knibbe, 1991; Jurkiewicz, Marzolini & Oh, 2011). The role of the health professional, especially via goal setting and monitoring of progress, has also been identified as an important factor determining adherence to home-based exercise programs (Meade, Bearne & Godfrey, 2019; Moore, Holden, Foster & Jinks, 2020).

#### ***1.4.2.1 Barriers to adherence to upper limb rehabilitation programs in stroke survivors***

Further research exploring barriers specific to participation in upper limb rehabilitation has identified a lack of motivation, a lack of physical movement, and fatigue as key factors (Barker, Gill & Brauer, 2007; Poltawski et al., 2015). Research has explored barriers to upper limb rehabilitation and recovery, from a stroke survivor and health professional perspective. For example, in a recent

study Meadmore and colleagues (Meadmore, Hallewell, Freeman & Hughes, 2019) identified that, due to resource pressure and a lack of communication and education, positive upper limb behaviours such as engagement were not established early following stroke. In addition, psychosocial factors, including cognitive and psychological barriers limited sustained engagement in upper limb therapy. Other key barriers identified by health professionals include a lack of time (Bayley et al., 2012), staff skill levels, and knowledge gaps (McCluskey, Vratisstas-Curto & Schurr, 2013; Baatiema et al., 2017; Mudge, Hart, Murugan & Kersten, 2017), difficulty selecting therapies (Bayley et al., 2012), and access to resources (Bayley et al., 2012; Baatiema et al., 2017; Mudge, Hart, Murugan & Kersten, 2017). From the stroke survivors' perspective, a survey-based exploration of factors contributing to upper limb recovery reported the greatest perceived barrier to recovery was 'not enough movement to work with' (Barker, Gill & Brauer, 2007). This was consistent with the findings of Damusch and colleagues (Damush et al., 2007) who used stroke survivor focus groups and found the most significant barrier was the physical impairments experienced after stroke.

Whilst there has been evidence exploring barriers to exercise programs in stroke survivors, there is a paucity of research exploring barriers to *intensive* exercise programs in stroke survivors. One qualitative study by Signal and colleagues (Signal et al., 2016) explored factors that influenced a 12-week high-intensity (three sessions per week) group-based strength and walking program. The authors reported that key factors determining adherence included making progress, self-motivation, the effect of fatigue, and the sense of frustration experienced when the exercises were more challenging. To date, no studies have explored factors influencing adherence to *intensive upper limb* exercise programs in stroke survivors.

### **1.4.3 Measurements of exercise adherence**

Parameters used for measuring exercise adherence can include frequency, session attendance, a behavioural component, time, the number of sessions completed, exertion (subjective), exercise replication, and intensity (objective) (Bailey et al., 2020). Researchers must make decisions about what parameters to measure when reporting adherence. Ward and colleagues describe intensity as "dose per session" (p. 498) (Ward, Brander & Kelly, 2019), and time spent in therapy sessions or duration of time spent exercising has been used in many large clinical trials (Winstein et al., 2016; Gunnes et al., 2019b). Time continues to be the dominant measure reported in research (Kwakkel et al., 2004; Kaur, English & Hillier, 2012) and international clinical guidelines (Stroke Working Group, 2012; Stroke Foundation, 2017c). Whilst some issues with reporting time as a measure have been described (Connell et al., 2014b), in the absence of new evidence or recommendations, time spent exercising is still a favoured measure of reporting and will be the parameter used to represent exercise adherence throughout this thesis.

The World Health Organisation states that "measurement of adherence provides useful information

that outcome-monitoring alone cannot provide, but it remains only an estimate of a patient's actual behaviour" (p. 20) (World Health Organisation, 2003). In clinical practice, accurately monitoring a patient's exercise adherence is important and helps guide treatment progressions. Furthermore, within research trials, it is essential to accurately measure and document adherence to the intervention to enable accurate analysis of the intervention effect. Several systematic reviews have been undertaken, exploring various aspects of measurement of adherence. These have included measures of adherence to nonpharmacologic self-management in musculoskeletal conditions (Hall et al., 2015) and measures of exercise adherence in musculoskeletal conditions (McLean et al., 2017). Due to methodological and quality issues, these reviews have concluded that no clear recommendations could be made, and future research is required to ensure measurement of exercise adherence is evidence-based. Another systematic review investigated what adherence measures were used in trials of home-based interventions (Frost et al., 2017). The authors found that diaries, reporting frequency of exercise, were most often used. Self-developed questionnaires were also commonly used, however overall evidence for most measures was limited. Due to this lack of robust development and inadequate psychometric properties, there is no one measure for exercise adherence that is recommended.

Self-report using a logbook or diary was the most common form of adherence measure identified in recently published work by Donoso Brown and colleagues (Donoso Brown et al., 2020). Whilst this research synthesised 70 studies to draw this conclusion, it is important to acknowledge that the reliability of self-report has been challenged, with evidence showing there is a tendency to overestimate or underestimate how much is done (Prince et al., 2008; Bollen et al., 2014). Furthermore, self-report measures can be subject to many forms of bias, including recall bias and social desirability response bias (Sackett, 1979; Sharot, 2011). Bollen and colleagues (Bollen et al., 2014) conducted a systematic review, aiming to identify and evaluate self-report measures being used for home-based rehabilitation programs. Whilst 58 studies and 61 measures were included, the authors only identified two measures that scored positively for content validity, and there were many poorly developed measures of adherence. An earlier review by Prince and colleagues (Prince et al., 2008) compared direct versus self-report measures for assessing physical activity and found low to moderate correlation existed between the two methods. Hence, the authors concluded there was a need for the development of valid, accurate, and reliable measures.

#### **1.4.4 Measuring and enhancing adherence with technology**

Technology-based methods of measurement are becoming more common in clinical and research environments (Kaplan & Stone, 2013). The use of technology ranges from the use of a pedometer to computer applications (Donoso Brown et al., 2020). Wearable sensors are used extensively in clinical and research settings to monitor post-stroke activity for both the lower limb (Powell, Parker,

St-James & Mawson, 2016) and upper limb (Wang et al., 2017). Whilst technology, such as accelerometers, has enhanced the objectivity of adherence measurement (Kaplan & Stone, 2013), devices can be expensive and inconvenient to wear, and uptake of many of these devices has been limited (Hayward et al., 2016). Wearable sensors can also be used as a means of enhancing adherence to exercise and physical activity. A recent systematic review explored the effectiveness of upper limb wearable technologies for improving activity in stroke survivors (Parker, Powell & Mawson, 2020). Due to study design issues, there was insufficient evidence to support the use of wearable technologies for improving upper limb activity in stroke survivors, however, the authors did note that technology had the potential to engage users outside of clinical sessions.

In addition to providing a measurement function, technology-based programs delivered via mobile devices, mHealth, provide novel ways to deliver home exercise programs and encourage increased adherence to prescribed programs (Nicolson et al., 2017; Ezeugwu & Manns, 2018; Bennell et al., 2019). A recent study explored the effectiveness of a mHealth application (app) in improving levels of physical activity in a group of chronic stroke survivors (Grau-Pellicer, Lalanza, Jovell-Fernández & Capdevila, 2020). At the end of the intervention phase, which consisted of supervision through the app and an eight-week rehabilitation program, significant improvements were found in community ambulation and reduction of sitting time. The authors concluded that mHealth technology provided a novel way to promote adherence to home exercise programs in stroke survivors.

Stroke survivors are generally willing to use technology to support themselves with home-based exercises (Hung, Huang, Chen & Chu, 2016; Edgar et al., 2017). With technological advances, more studies are investigating the role of web-based systems of recording and monitoring exercise practices as a means of influencing exercise adherence. Several studies have investigated the effect of technology use on increased physical activity levels and rehabilitation outcomes across a range of health conditions (Jonkman, van Schooten, Maier & Pijnappels, 2018). This includes the use of mobile phone text messaging programs which, despite being a simple intervention, are effective at increasing adherence to exercise in a range of conditions (Müller, Khoo & Morris, 2016; Chen et al., 2017), including stroke (Shaughnessy, Resnick & Macko, 2006; Micallef, Baillie & Uzor, 2016).

Mobile phone usage has grown in developing nations and Australia is one of the leading drivers of smartphone use with 88% ownership reported in 2017 (Wigginton, 2017). Smartphone applications (apps) have become an integral component of healthcare, with benefits including monitoring and treating diseases, facilitation of diagnoses (Onashoga, Sodiya, Omilani & Ajisegiri, 2011; de Barros et al., 2013), and providing health service delivery (Zhang et al., 2014). A recent systematic review (Nussbaum et al., 2019) explored the use of mHealth apps in rehabilitation. Of the 102 studies included across all areas of rehabilitation, 14 were focused on stroke rehabilitation, and apps were

used for monitoring and feedback in a range of areas including physical activity, management of home-based exercises, and functional skills training. One recent study exploring the effectiveness of a smartphone activity app in improving physical activity in stroke survivors (Grau-Pellicer, Lalanza, Jovell-Fernández & Capdevila, 2020) found that participants increased their adherence to community ambulation by 105% and reduced their sitting time by 30% in response to app use. The authors acknowledged some challenges with the use of technology in stroke participants and recommended technology tailored to stroke survivors' characteristics, especially cognitive and physical impairments. It has been reported that stroke survivors with more severe deficits may have more difficulties with using technology in rehabilitation (Lohse et al., 2014).

Mobile phones and tablet devices can also provide a platform for providing exercise instructions with video, audio, and/or reminder functions (Emmerson, Harding & Taylor, 2019). A recent study (Chung et al., 2020) found that using multimedia approaches to provide exercise instruction resulted in increased adherence compared to written or verbal instructions, and this is supported by systematic review evidence (Emmerson, Harding & Taylor, 2019). One form of technology that has been promoted as being motivating and interactive is virtual reality (VR). Systematic review evidence has shown that VR systems are feasible to use and have positive effects on mild to moderate upper limb deficits after stroke (Laver et al., 2015). A recent mixed-methods study explored the feasibility of using a low-cost, personalised stroke therapy system adapted from a commercially available VR device (Warland et al., 2019). Results of this study reported high feasibility and acceptability, including positive responses in terms of enjoyment, feedback, motivation, and adherence to out of session programs. Comparable results in terms of feasibility and acceptance were found in a recent exploration of ActivABLES, an intervention incorporating interactive games and a feedback system that aimed to motivate and promote home-based exercise in community-dwelling stroke survivors (Olafsdottir et al., 2020).

Innovative and novel technology systems continue to be developed and researched, many involving visual feedback systems (Chae, Kim, Lee & Park, 2020; Thielbar et al., 2020). Several studies have explored methods of providing stroke survivors with visual feedback on the performance of prescribed exercises. Visual feedback, one form of extrinsic feedback, has been shown to play a role in motor learning, and concurrent visual feedback can enhance the performance of a task (Sigrist, Rauter, Riener & Wolf, 2013). Visual feedback can include vision of one's own body, VR, or a score on a screen (Molier, Van Asseldonk, Hermens & Jannink, 2010). Aiming to develop a system to reduce compensatory movements in stroke survivors, Lin and colleagues (Lin et al., 2019) developed and tested a visual feedback system using real-time video or an avatar reflecting users' movements. One aim of this system was to reduce the need for therapist supervision while ensuring stroke survivors achieved ongoing levels of exercise. The effect of visual feedback has been explored in further studies: Emmerson and colleagues (Emmerson, Harding & Taylor, 2016) used a tablet device to video record stroke survivors

performing their exercises, with additional commentary from the health professional; and in a small cohort of stroke survivors, visual feedback incorporating the use of a mirror was reported to lead to improvements in the 'control structure' of the upper limb (Urra, Casals & Jané, 2015). The authors concluded that further research was needed to explore the best methods of implementing visual feedback in rehabilitation.

In summary, evidence has demonstrated that in order to achieve an adequate intensity of upper limb rehabilitation, stroke survivors need to adhere to home-based exercise programs beyond the formal rehabilitation period. However, it is apparent that even in programs that are not considered intensive, adherence to home-based exercise is sub-optimal in stroke survivors. Overall, studies have shown some barriers to exercise adherence in stroke survivors, however, there is a lack of evidence exploring adherence to upper limb programs that are implemented at a level of intensity recommended for maximising outcomes. Furthermore, in order to monitor stroke survivors' adherence to intensive upper limb home exercise programs, health professionals need to use evidence-based methods of measurement. However, the evidence to date demonstrates that there are no gold standard methods of measurement, and health professionals should be cautious using methods that rely only on patient self-report.

## **1.5 Behaviour change theories relevant to exercise adherence**

A theory is a "coherent and non-contradictory set of statements, concepts or ideas that organizes, predicts and explains phenomena, events, behaviour, etc." (p. 2) (Eccles et al., 2005). Using theory in the design of interventions allows key constructs influencing the behaviour to be identified which should lead to a change in behaviour (Hardeman et al., 2005).

### **1.5.1 Overview of theories**

Several theoretical frameworks can be applied to understand health-related behaviour and adherence to exercise. Details of how different theories were used in this thesis are presented in Table 1-2.

**Table 1-2 Theories used to explore health-related behaviour and exercise adherence and their applicability to this thesis**

Theory (Author, year)	Relevance to health-related behaviour and adherence	Main concepts	How theory is applied in this thesis
<b>Behaviour Change Wheel (BCW), incorporating Capability, Opportunity, Motivation model (COM-B model) (Michie, Van Stralen &amp; West, 2011)</b>	Identifies sources of behaviour that could be targeted with intervention. The model recognises that behaviour is part of an interacting system involving capability, opportunity, and motivation.	Proposes that for any behaviour to occur a person must have the psychological and physical capability, the physical and social opportunity, and the motivation (automatic and reflective). There are three main stages when using the BCW: understand the behaviour, identify intervention options, and identify content and implementation options.	Used the TDF and corresponding COM-B model to identify barriers and enablers to participation in intensive exercise for stroke survivors. <b>(Chapter 5)</b> Used the BCW and COM-B model to develop a guide for health professionals to use when prescribing exercises for stroke survivors. <b>(Chapter 7)</b>
<b>Theoretical Domains Framework (Michie et al., 2005)</b>	Developed to help explain implementation problems and inform implementation interventions. Consists of 14 domains that can influence behaviour change.	Includes 14 key domains, covering 84 theoretical constructs. Objectives include identifying influences (barriers and enablers) on behaviours, systematic intervention design, and guidance on identifying behaviour change techniques. Is a refined version of the COM-B model.	Used the TDF and corresponding COM-B model to identify barriers and enablers to participation in intensive exercise for stroke survivors. <b>(Chapter 5)</b>
<b>Transtheoretical Model of Behaviour Change (Prochaska, DiClemente &amp; Norcross, 1993)</b>	Used to understand the 'when and how' of behaviour change. Four keys are stages of change, decisional balance, processes of change, and self-efficacy.	Stages of change = precontemplation, contemplation, preparation, action, and maintenance. Some people will cycle through the stages – learn from relapses and mistakes. Decisional balance = weigh up the advantages and costs. Influencing perceptions of pros and cons may assist in behaviour change. To reach a stage of action, pros must outweigh cons.	To explore stroke survivors' experiences of participating in intensive exercise, the theory formed the basis of the interview guide. <b>(Chapter 5)</b> To explore staff perceptions of the Carers Count group, the theory formed the basis of the focus group guide. <b>(Chapter 6)</b>

<b>Social Cognitive Theory (Bandura, 1986)</b>	Used to describe the influence of individual experiences, actions of others, and environmental factors on individual health behaviours.	Key constructs are knowledge of risks and benefits, perceived self-efficacy, outcome expectations, health goals, facilitators and social support, barriers to change. Self-efficacy is considered a key component of behaviour change.	Analysed stroke survivors' self-efficacy for exercise as a component of exploration of factors influencing exercise. <b>(Chapter 3)</b>
<b>Theory of Planned Behaviour (Ajzen, 1991)</b>	Developed from the theory of reasoned action to apply in studies of beliefs, attitudes, and behavioural intention.	Considers how cognition (behavioural, normative and control beliefs) and broader constructs (i.e. attitude towards behaviour, subjective norm, perceived behavioural control, and intention) influence behaviour. Intention is considered the key predictor of behaviour change.	Not used in this thesis.
<b>Self-determination theory (Deci &amp; Ryan, 1985)</b>	Used to understand the degree to which a persons' behaviour is self-motivated and self-determined.	Key components are autonomy (feelings of being the origin of one's behaviour), competence (feeling effective) and relatedness (feeling understood).	Assessed extrinsic forms of motivation as factors that may enhance adherence to exercise in stroke survivors. <b>(Chapters 3 and 4)</b>



The following section of this thesis will provide more detail regarding the main theories chosen by the candidate to use within this research: the Transtheoretical Model of Behaviour Change, the Theoretical Domains Framework, the Behaviour Change Wheel, and the Capability, Opportunity, Motivation- Behaviour model. These theories were considered to be most relevant as they have been used extensively in adherence-based studies (Adams & White, 2003; Jackson, Eliasson, Barber & Weinman, 2014; McGrady, Ryan, Brown & Cushing, 2015).

### 1.5.2 Transtheoretical Model of Behaviour Change

The Transtheoretical Model of Behaviour Change (Prochaska & DiClemente, 1982; Romain, Horwath & Bernard, 2018), first described in 1982 as a mechanism to support smoking cessation (Prochaska & DiClemente, 1982), proposes that peoples' health-related behaviour reflects their readiness to change. Within the model, behaviour change is represented as a dynamic process that encompasses five discreet stages. The stages include: pre-contemplation and contemplation which occur before a person is ready to change and as they start to get ready to change; preparation, which is the stage where the person takes small steps towards change; action, where changes have been made and the person needs to continue to work hard to make more changes; and maintenance, where the person has maintained change and works towards preventing a relapse (Figure 1-4).



Figure 1-4 Illustration of the Stages of Behavioural Change (developed from Prochaska & DiClemente, 1982)

To progress through these stages the theory describes ten processes of change, which are either experiential processes involving thoughts, feelings, or perceptions related to the behaviour, or behavioural processes which include environmental cues and social support (Prochaska & DiClemente, 1982; Romain, Chevance, Caudroit & Bernard, 2016). The interaction between the experiential and behavioural processes is predictive of moderate physical activity levels (Romain, Horwath & Bernard, 2018). Another core construct of this model, or mediator of change, is 'decisional balance', the weighing up of pros and cons that occurs during the process of change. In addition, self-efficacy, based on Bandura's self-efficacy theory (Bandura, 1977), is another key mediator to change identified in the model and reflects the individuals' confidence in their ability to make changes. Numerous studies have reported a strong link between exercise self-efficacy and behaviour change (Marcus, Selby, Niaura & Rossi, 1992; Marcus, Eaton, Rossi & Harlow, 1994).

The Transtheoretical Model of Behaviour Change has been the theoretical basis for many behaviour change studies, including dietary change (Di Noia, Contento & Prochaska, 2008), drug adherence (Johnson et al., 2006), and weight management (Johnson et al., 2008). The model was able to predict exercise behaviour in a group of community-dwelling stroke survivors (Garner & Page, 2005), where a higher stage of motivational readiness was associated with a higher level of participation in exercise. A meta-analysis of the applications of the Transtheoretical Model of Behaviour Change to physical exercise reports a strength of the model is that it treats behaviour change as a dynamic process, rather than an 'all or nothing' concept (Marshall & Biddle, 2001). Another review of the Transtheoretical Model of Behaviour Change concluded that activity interventions based on the model are generally more effective than others in short term activity uptake (Adams & White, 2003).

### **1.5.3 Theoretical Domains Framework**

The Theoretical Domains Framework (TDF), which can be considered as an extension of the Capability, Opportunity, Motivation-Behaviour model (COM-B) (Michie, Atkins & West, 2014), was developed using a consensus approach and consists of 14 validated domains that are connected to components of the COM-B: skills, knowledge, emotion, behavioural regulation, environmental context and resources, social influences, professional/social role and identity, beliefs about capabilities, optimism, beliefs about consequences, intentions, goals, reinforcement, and memory, attention and decision processes (Arden et al., 2019).

A recent guide (Atkins et al., 2017) highlighted the benefits of using the TDF, including the provision of a theoretical basis for studies, identification of barriers to the diffusion of evidence into practice, and a method of progressing from research into intervention. Potential applications of the TDF include data collection using interviews or focus groups, synthesising evidence in systematic reviews, and guiding behaviour change technique selection when designing interventions (Atkins et

al., 2017). In addition, the TDF has been used to identify factors relating to treatment adherence across a range of health conditions (Bosch et al., 2014; McCullough et al., 2015; Presseau et al., 2017; Arden et al., 2019), including stroke (Nicholson et al., 2014; Stewart, Power, McCluskey & Kuys, 2019), and the validity of the TDF has been demonstrated (Cane, O'Connor & Michie, 2012). This validation study by Cane and colleagues (Cane, O'Connor & Michie, 2012) reported three key advantages to the TDF: a comprehensive description of possible influences on behaviour, clarity about each of the influences, and links to behaviour change techniques.

The links between the TDF constructs and the COM-B components are illustrated in Figure 1-5.

**Figure 1-5 TDF constructs and COM-B components, a guide to using the Theoretical Domains Framework of behaviour change to investigate implementation problems (Atkins et al., 2017)**

*This image has been removed due to copyright restriction, available from: Atkins, L., Francis, J., Islam, R., O'Connor, D., Patey, A., Ivers, N., Foy, R., Duncan, E. M., Colquhoun, H. & Grimshaw, J. (2017). A guide to using the Theoretical Domains Framework of behaviour change to investigate implementation problems. Journal of Implementation Science, 12(1): 77.*

#### **1.5.4 Behaviour Change Wheel and Capability, Opportunity, Motivation-Behaviour model**

The Behaviour Change Wheel (BCW) is a synthesis of 19 frameworks of behaviour change (Michie, Atkins & West, 2014) which provides a systematic method of characterising interventions and can be used in intervention evaluation and theory development (Michie, Atkins & West, 2014). The BCW is a practical tool that can be applied in research to move from identifying barriers and enablers to selecting relevant interventions for change (Michie, Atkins & West, 2014). Within the BCW, capability, opportunity, and motivation interact to influence the behaviour: this is the core of the BCW, the Capability, Opportunity, Motivation-Behaviour model (COM-B) (Michie, Van Stralen & West, 2011). The BCW describes that behaviour will only change if one or more of these three components change (Michie, Atkins & West, 2014). The BCW identifies nine intervention functions that can be applied to the behaviour, as well as seven policies that can be used in the delivery of the intervention options (Michie, Atkins & West, 2014). Intervention functions are linked to specific behaviour change techniques which are presented in a subsequent publication, The Behaviour Change Technique Taxonomy (Michie et al., 2013).

There are three main stages to consider when using the Behaviour Change Wheel to guide intervention design: (1) understand the behaviour; (2) identify intervention options; and (3) identify content and implementation options (Atkins & Michie, 2015). This process is illustrated in Figure 1-

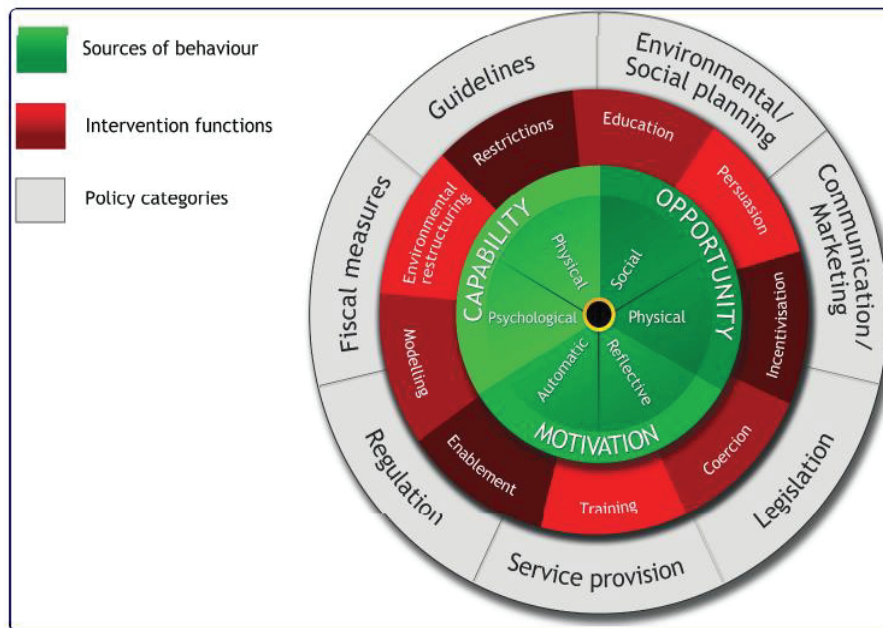
**Figure 1-6 Behaviour change intervention design process, The Behaviour Change Wheel: a guide to designing interventions (Michie, Atkins & West, 2014)**

***This image has been removed due to copyright restriction, available from: Michie, S., Atkins, L. & West, R. (2014). The behaviour change wheel: a guide to designing interventions. Silverback publishing.***

The COM-B, a model of behaviour that can also be used to guide behavioural change interventions, is intended to be a starting point for choosing interventions that are most likely to be effective (Michie, Van Stralen & West, 2011); this first step in applying the BCW aims to analyse the behaviour and identify barriers that the intervention is intended to change (Nelligan, Hinman, Atkins & Bennell, 2019). Within capability, the model distinguishes between physical capability and psychological capability, or the capacity to engage in the necessary thought processes to participate in the behaviour (Michie, Van Stralen & West, 2011). Opportunity is described as either the physical opportunity presented by the environment or the social opportunity afforded by the cultural issues that determine how we think about the behaviour (Michie, Van Stralen & West, 2011). Motivation can be either reflective, which represents the psychological processes that drive behaviour, or automatic which refers to the emotions and impulses that drive behaviour (Michie, Van Stralen & West, 2011; Govender et al., 2017).

Once the behaviour has been analysed using the COM-B, using the BCW, the next stage is to identify intervention options through the selection of intervention functions such as education or training, and consideration of policy categories such as environmental planning (Michie, Atkins & West, 2014). Figure 1-7 illustrates the COM-B components, intervention functions, and policy categories. The final aspect of the process is the identification of implementation options, through the selection of behaviour change techniques (Michie et al., 2013), which form the 'active

ingredients' of the behaviour change, and the mode of delivery.



**Figure 1-7 BCW and COM-B components, The Behaviour Change Wheel: a new method for characterising and designing behaviour change intervention (Michie, Van Stralen & West, 2011)**

The BCW has been used to define a variety of behaviour change interventions (French et al., 2013; Sinnott et al., 2015; Steinmo, Fuller, Stone & Michie, 2015). Furthermore, the COM-B model has been used extensively in the adherence literature (Alexander, Brijnath & Mazza, 2014; Jackson, Eliasson, Barber & Weinman, 2014; Flannery et al., 2018; Arden et al., 2019), and has been reported to be a more comprehensive explanation of adherence than other behaviour change models (Jackson, Eliasson, Barber & Weinman, 2014), being explicitly developed to inform behaviour change interventions. A recent study described the development and psychometric testing of a generic self-evaluation questionnaire to assess capability, opportunity, and motivation (Keyworth et al., 2020). One important finding of this study was evidence supporting the use of the COM-B for predicting health professionals' delivery of behaviour change interventions, that is, the positive predictive validity of the COM-B model. Fitzsimons and colleagues (Fitzsimons et al., 2020) reported another positive aspect of using the COM-B is its strong alignment to the International Classification of Functioning, Disability and Health (ICF) (World Health Organisation, 2002), whereby exploring factors within the COM-B such as motivation and capability will enable the development of an intervention that promotes meaningful participation (Dean, Siegert & Taylor, 2012).

### **1.5.5 Behaviour change interventions and adherence**

Evidence supports the use of theory-based interventions and exercise programs (Glanz & Bishop, 2010; Michie & Prestwich, 2010; Prestwich et al., 2014), and fully understanding the factors influencing adherence to exercise enables the subsequent design of programs to be theory-based (Craig et al., 2008). Theory allows researchers to be systematic and thorough in exploring behaviour (French et al., 2012). Despite this, it has been reported that there is a lack of interventions that are developed on a theoretical background (Chapman & Bogle, 2014).

Whilst many exercise-based trials have utilised behaviour change interventions in their programs (Salbach et al., 2004; Page, Levine & Leonard, 2005; Wolf et al., 2006), there is a lack of studies that consider strategies to sustain long-term adherence (Morris & Williams, 2009). Across a broad range of areas, researchers have used theories to explore factors influencing behaviour prior to designing interventions that specifically consider these factors. For example, Nelligan and colleagues (Nelligan, Hinman, Atkins & Bennell, 2019) used the Behaviour Change Wheel (Michie, Atkins & West, 2014) to identify barriers and enablers to exercise in people with knee arthritis, and a short messaging service program was subsequently developed to address these factors. In a study that aimed to develop an intervention to improve smoking cessation in pregnant indigenous women, Gould and colleagues (Gould et al., 2017) used the Behaviour Change Wheel (Michie, Atkins & West, 2014) and Theoretical Domains Framework (Atkins et al., 2017) to translate evidence from a qualitative analysis and guide implementation of an intervention design. A recent study (Munir et al., 2018) followed the Behaviour Change Wheel and Capability, Opportunity, Motivation-Behaviour model (Michie, Atkins & West, 2014) to conduct focus groups, and subsequently used behaviour change techniques to develop an intervention aimed at increasing standing time in the workplace.

Within the stroke population there is research exploring interventions based on behaviour change theories. For example, in a recent study, Stewart and colleagues (Stewart, Power, McCluskey & Kuys, 2019) designed a participatory tailored staff behaviour change intervention guided by the Behaviour Change Wheel and the Theoretical Domains Framework, aiming to increase active practice of stroke inpatients. The Behaviour Change Wheel formed the basis for a further study aimed at reducing sedentary behaviour in stroke survivors (Hall et al., 2020). In this study, co-production workshops were delivered, and the structured framework of the Behaviour Change Wheel enabled the authors to identify the target behaviour and design an intervention to address this. Nicholson and colleagues (Nicholson et al., 2014) used the Theoretical Domains Framework to identify barriers and enablers to physical activity perceived by stroke survivors, and reported it enabled a successful synthesis of participants' responses to meaningful theoretical domains.

## 1.6 The current state of knowledge

Formal rehabilitation services have reduced in duration and there is now a greater need for ongoing rehabilitation to be delivered through self-managed home-based exercise programs (Miller et al., 2017; Donoso Brown et al., 2020). Studies show us that to benefit from rehabilitation, stroke survivors need to adhere to intensive and repetitive practice (Lohse, Lang & Boyd, 2014; Schneider, Ada & Lannin, 2019). Furthermore, there is strong evidence that for upper limb recovery, the intensity of therapy is critical (Pollock et al., 2014). In stroke survivors, adherence to exercise programs is suboptimal, and some barriers to adherence have been identified (Langhorne, Bernhardt & Kwakkel, 2011; Simpson et al., 2011; Morris, 2016; Essery, Geraghty, Kirby & Yardley, 2017). In section 1.4.2 of this thesis, the candidate has presented literature describing key barriers and enablers to exercise in stroke survivors, however, these studies have not reported on barriers and enablers to participation in *intensive* upper limb exercise programs, as is needed according to best practice guidelines. Health professionals need to understand these factors as the delivery of, and adherence to, intensive upper limb exercise programs aligns with high-level evidence.

Section 1.4.3 of this thesis described aspects of measurement of adherence to exercise in stroke survivors. A recent scoping review exploring measurement methods post-stroke was presented, however at the time of planning the studies presented in this thesis, there was a lack of stroke-specific reviews of measurement methods. Given the important role adherence plays in determining the effectiveness of an intervention, the candidate identified that a systematic review in the stroke population was warranted. Furthermore, in Section 1.4.3 the candidate presented literature challenging the reliability of self-report as a stand-alone measure of adherence. It was considered important to explore some objective measurement methods, in the form of technology devices, that could be used by stroke survivors in their home environment. This would ensure accuracy of measurement of the stroke survivors' adherence as well as identifying inaccuracies in self-reporting.

As described in Section 1.5.5, evidence supports the development of interventions that are based on behavioural theories (Michie & Prestwich, 2010; Prestwich et al., 2014). The candidate identified that physiotherapists have an opportunity to influence adherence to exercise programs and subsequent outcomes if they assess barriers and enablers, and then develop specific and individualised behavioural interventions to address the identified barriers. To date there has been a lack of studies exploring adherence to exercise which incorporate behaviour change models and provide recommendations for health professionals, and this was considered by the candidate to be a gap in the literature.

## 1.7 Rationale for the thesis

### 1.7.1 Aims

The three aims of this thesis are outlined below and illustrated in Figure 1-8.

**Aim 1: (a)** To systematically explore methods of measurement of exercise adherence in stroke survivors

**(b)** To assess the feasibility of using technology as a method of measurement of exercise adherence in stroke survivors

**Aim 2:** To explore barriers and enablers to exercise adherence in stroke survivors participating in an intensive intervention

**Aim 3:** To identify appropriate behaviour change strategies and inform the development of an intervention/approach to improve adherence to home-based exercise programs in stroke survivors

### 1.7.2 Original contribution to the thesis

Except where reference is made in the thesis, no person's work has been included in this thesis without acknowledgment in the main text. This thesis has not been submitted for assessment at any other tertiary institution.

All research studies reported in this thesis were approved by the relevant Ethics Committees before the commencement of each study.

This introductory chapter has provided the background and rationale for the thesis. The following chapters that contain published research material include a statement about the contribution of the candidate.

### 1.7.3 Thesis structure

The thesis structure is presented in Figure 1-8.

Aim 1 will be addressed through three studies:

- Chapter 2, a systematic review of the literature on methods of measurement of adherence to exercise in stroke survivors.

Two possible approaches to measuring independent home practice will be assessed:

- Chapter 3, a feasibility study, will assess the use of a tablet computer to monitor adherence



to a home-based exercise program.

- Chapter 4, a single-case series, will assess the feasibility of the use of accelerometers to monitor adherence to a home-based exercise program.

Aim 2 will be explored through four studies:

- Chapter 3, a feasibility study that evaluates factors that may have influenced adherence to a prescribed intensive home-based exercise program.
- Chapter 4, a single-case series that explores the role of technology (a tablet computer) on adherence to a prescribed intensive home-based exercise program.
- Chapter 5, qualitative interviews which explore the experience of, and barriers and enablers to, an intensive home-based exercise program.
- Chapter 6, an implementation study that examines the role of the carer in enhancing adherence to exercises following discharge from the inpatient environment.

Aim 3 will be addressed in Chapter 7 with a synthesis of study findings and consideration of appropriate behaviour change strategies. A practical guide will be presented for health professionals to use when developing home exercise programs for stroke survivors.

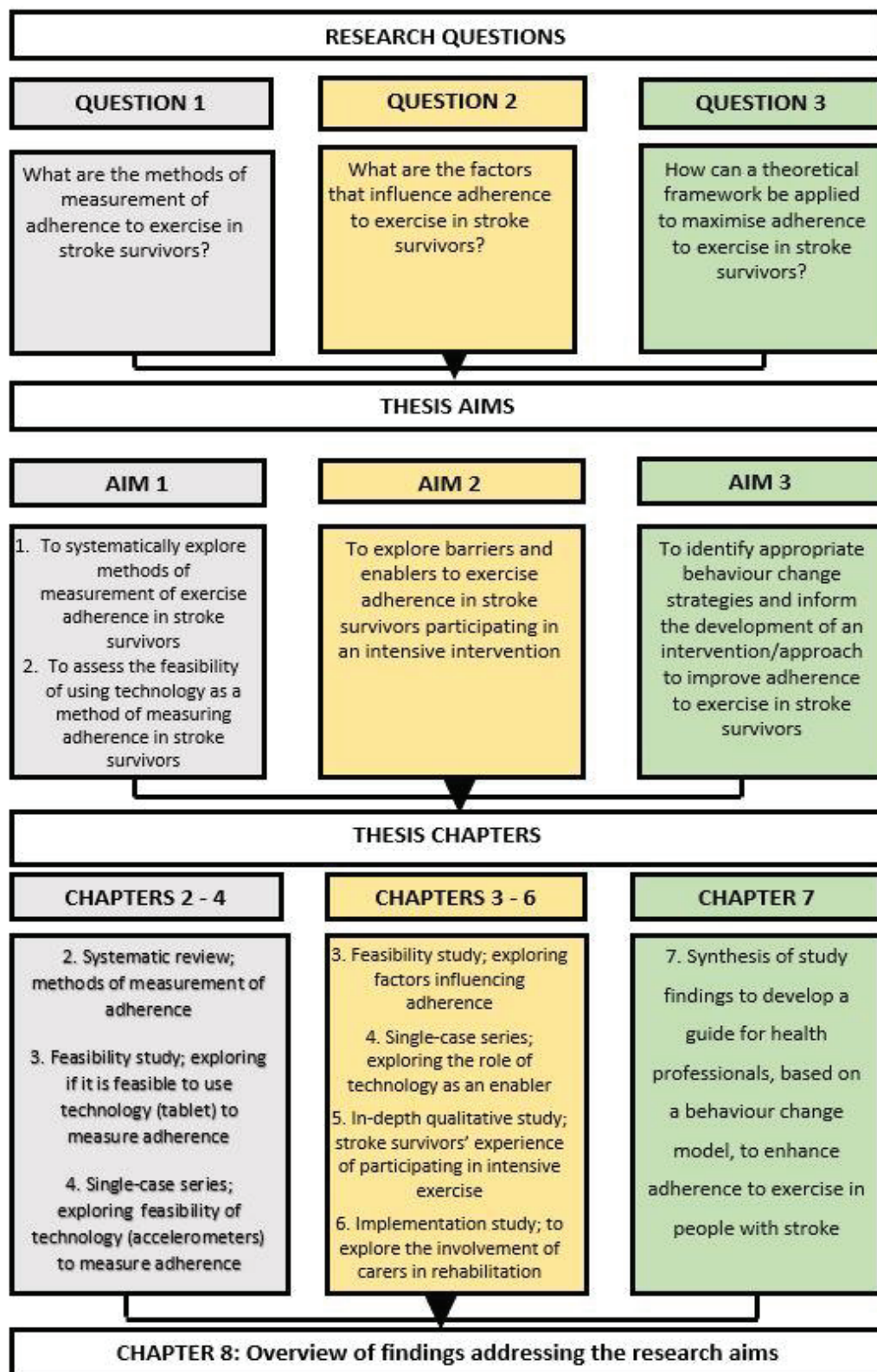


Figure 1-8 Thesis outline

## **CHAPTER 2 METHODS OF MEASUREMENT OF ADHERENCE TO EXERCISE IN STROKE SURVIVORS: A SYSTEMATIC REVIEW**

This chapter answers Aim 1(a) of the thesis: “To systematically explore methods of measurement of exercise adherence in stroke survivors”. This chapter describes a systematic review conducted and is presented with minor changes for thesis formatting from the publication, ‘A systematic review of measures of adherence to physical exercise recommendations in people with stroke’ (Levy et al., 2018), published in *Clinical Rehabilitation*.

This review was completed to determine if there were any methods of measurement to exercise adherence in stroke survivors that had established reliability and validity and could be recommended for clinical and research use. It was important to explore this before conducting the remaining studies in this thesis where adherence to exercise programs was being evaluated.

As the lead author for the publication, the candidate’s contribution was 80% of this chapter. The candidate developed the research questions with the guidance of supervisor KL. The candidate registered the study protocol with the International Prospective Register of Systematic Reviews (PROSPERO). The candidate worked with a medical librarian regarding databases, search terms and strategy, completed data collection and screening, as well as data analysis and writing results. Co-author and supervisor KL assisted in data analysis. All co-authors were involved in editing and proof-reading the manuscript. Each author has consented to the inclusion of this work in the thesis, as per the submission of thesis form.

### **2.1 Introduction**

Evidence demonstrates that higher doses of therapy are associated with better outcomes after stroke (Kwakkel et al., 2004; Veerbeek et al., 2014; Schneider, Lannin, Ada & Schmidt, 2016). However, providing high doses of therapy in practice is challenging and health professionals face several barriers including limited resources and low tolerance amongst stroke survivors to participation in high-intensity therapy (Kwakkel, 2006; Kaur, English & Hillier, 2012). Health professionals are encouraged to establish independent practice outside of supervised therapy time as a way of increasing therapy dose (Schneider, Lannin, Ada & Schmidt, 2016).

However, the benefits of increasing therapy dose by prescribing independent practice depend on adherence to the prescribed program; studies suggest that adherence reduces over time (Findorff, Wyman & Gross, 2009). Adherence to exercise programs is especially challenging after stroke (Morris & Williams, 2009), with between 30% and 50% of patients ceasing their exercise programs

within the first year (Kåringen, Dysvik & Furnes, 2011).

Measurement tools that quantify adherence to exercise programs provide information for health professionals about what the client is doing, in many cases during times of the day when health professionals are unable to observe the practice. Measurement of adherence can take various forms and there is no acknowledged gold standard (Holden et al., 2014). Previous systematic reviews have assessed adherence to home-based rehabilitation (Frost et al., 2017), self-reported measures of home-based rehabilitation (Bollen et al., 2014), patient or provider adherence questionnaires in physiotherapy (Holden et al., 2014), and measures assessing non-pharmacological self-management in musculoskeletal conditions (Hall et al., 2015). These previous reviews have concluded that trials included largely self-developed questionnaires that lacked sufficient evidence of psychometric properties (Bollen et al., 2014; Holden et al., 2014; Hall et al., 2015). However, to date, no review has summarised methods of measurement of adherence to exercise and physical activity recommendations in stroke.

It is important to use a method of measurement of adherence that is valid in the specific population; that is, the tool measures what it is supposed to measure (DeVellis, 2016). Given the important role adherence plays in determining the efficacy of an intervention, the adherence measurement methods chosen should be guided by the specific patient diagnosis group and by evidence of their measurement properties when tested within this group.

With a limited understanding of the best methods of measuring adherence validly for the stroke population, the primary aim of this study was to identify adherence measurement methods used to quantify adherence to exercise and physical activity recommendations. The secondary aim was to report on the psychometric properties of the identified methods and synthesise findings to provide recommendations for both clinical and research use.

## **2.2 Methods**

This systematic review was registered with PROSPERO International prospective register of systematic reviews (2017 CRD42017069102).

This review was conducted in two parts. An initial search was conducted to identify adherence measurement methods to exercise or physical activity in the stroke population. Following this, a second search was conducted to identify studies investigating the psychometric properties of the methods identified in phase one. This review is reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2009).

### **2.2.1 Phase 1: Identification of adherence measurement methods**

A search of eight electronic databases (MEDLINE, CINAHL, PsycINFO, Cochrane Library of Systematic Reviews, Sports Discus, PEDro, PubMed, and EMBASE) was conducted in July 2017 and updated in September 2018 to identify adherence measurement methods. The search strategy for MEDLINE is included in Appendix 5. An equivalent search strategy was individualised for all other databases and no limits were placed on publication dates.

Studies were included if they were: (1) published in English; (2) included participants diagnosed with stroke (or greater than 80% of the study population was diagnosed with stroke); (3) quantified adherence to exercise or physical activity recommendations; (4) were patient or health professional reported; (5) were defined and replicable measures, and (6) were tested in patients >18 years old. Studies were included if they were conducted in any therapeutic setting including inpatient, outpatient, and community settings. Studies using objective tools (which were not patient or health professional reported), such as accelerometers, were excluded. Conference abstracts that described eligible adherence measurement methods were included.

Once duplicates were removed, titles and abstracts of all identified studies were reviewed for inclusion by two independent reviewers, and agreement was achieved through discussion when needed. The same two reviewers screened the full-text articles for the inclusion and exclusion criteria. A third reviewer was available to resolve differences. Data extracted included the population that the tool had been used with, the setting the tool had been used in, the type of intervention it was measuring, whether it was patient or health professional administered, and study and measurement-specific information.

### **2.2.2 Phase 2: Properties of included adherence measurement methods**

To identify the psychometric properties of included adherence measurement methods, a search of eight electronic databases (MEDLINE, CINAHL, PsycINFO, Cochrane Library of Systematic Reviews, Sports Discus, PEDro, PubMed, and EMBASE) was conducted in February 2018. The search strategy for MEDLINE is included in Appendix 6. An equivalent search strategy was individualised for all other databases and no limits were placed on publication dates.

Studies were included if they: (1) were published in English; (2) included participants diagnosed with stroke (or greater than 80% of the study population was diagnosed with stroke); and (3) reported research investigating at least one psychometric property for an adherence measurement method identified in phase 1. Psychometric properties included validity and responsiveness.

Once duplicates were removed, titles and abstracts of all identified studies were reviewed for inclusion by two independent reviewers and agreement checked. The same two reviewers screened the full-text articles for the inclusion and exclusion criteria. A third reviewer was available

to resolve differences.

Papers identified in phase one were grouped according to the type of adherence measurement method used. For phase two we planned to assess measurement properties following the recommendations of the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) (Terwee et al., 2012).

## **2.3 Results**

The review process for both searches is shown in the flowchart (Figure 2-1). Phase 1 identified a total of 48 articles for inclusion in our review, which included seven different adherence measurement methods (several studies evaluated multiple tools). Phase 2 failed to identify any articles which reported the psychometric properties of included adherence measurement methods for inclusion in our review.

### **2.3.1 Phase 1: Identification of adherence measurement methods**

A total of 6130 citations were identified using the search strategy; of these, 179 articles were selected for full-text review, and 48 studies were identified as being eligible for inclusion. These 48 articles contained seven separate adherence measurement methods. Table 2-1 provides a summary of adherence measurement methods and study design. We found that researchers used different terms for their adherence measurement methods and there is no widely accepted terminology; we describe the adherence measurement methods based on the terminology used by the researcher within the study description.

Of the adherence measurement methods identified, diaries and logbooks were most frequently used. Studies seldom described the content within the diaries or logbooks. Some studies identified the parameters of exercise or activity that were recorded. The duration and frequency of exercise or physical activity were most frequently recorded in the diary or logbook. Table 2-2 presents the method and characteristics of the included adherence measurement methods.

Diaries were used in 18 of the identified studies. All home diaries were completed by the patient. Three of the identified studies utilised diaries as a component of the Constraint-Induced Movement Therapy (CIMT), where the focus was on recording the amount of activity performed with the affected upper limb (Winstein et al., 2003; Roberts et al., 2005; Taub et al., 2013). Many of the included studies used diaries to record the duration or frequency of exercise or physical activity that was performed (Gabr, Levine & Page, 2005; Roberts et al., 2005; Galvin et al., 2011; Askim et al., 2012; Batchelor et al., 2012; Treger, Landesman, Tabacaru & Kalichman, 2014; Gunnes, Indredavik & Askim, 2015; Koh et al., 2015; Walter, Hale & Smith, 2015; Dean et al., 2016; Gunnes et al., 2017; Menezes et al., 2017). The type of physical activity performed was included in the diary in seven studies (Winstein et al., 2003; Roberts et al., 2005; Askim et al., 2012; Taub et al.,

2013; Gunnes, Indredavik & Askim, 2015; Dean et al., 2016; Askim et al., 2018). The specific method of recording in the diaries was not described in six of the identified studies (Taskinen, 1999; Gabr, Levine & Page, 2005; Walter, Hale & Smith, 2015; Kumar & Sheehy, 2016; Gunnes et al., 2017; Lannin et al., 2018).

Logbooks or daily activity logs were used as adherence measurement methods in 16 of the included studies. Four of the studies used a log to record the time of functional activity and/or adherence to mitt use during CIMT (Pierce et al., 2003; Brogardh & Sjolund, 2006; McCall et al., 2011; Baldwin et al., 2018). A further study used a logbook to record the type of activity performed during a goal-directed upper limb activity program (Moore et al., 2016). The most frequently recorded exercise or activity parameter was duration (Pierce et al., 2003; Brogardh & Sjolund, 2006; Sullivan & Hedman, 2007; McCall et al., 2011; Mayo et al., 2013; Kara & Ntsiea, 2015; Emmerson, Harding & Taylor, 2017; Simpson, Eng & Chan, 2017; Baldwin et al., 2018; Bonnyaud et al., 2018). Other parameters recorded in the logbooks included weekly step activity (Danks, Roos, McCoy & Reisman, 2014), intensity (Mayo et al., 2013), and the number of sets and repetitions of exercise (Turton et al., 2013; Emmerson, Harding & Taylor, 2017; Simpson, Eng & Chan, 2017). Other studies did not provide any specific details regarding the method of recording in the logbooks (Ada et al., 2003; Linder et al., 2015).

Three of the included studies reported that subjects were asked to keep a 'record of practice' or recording sheet indicating how often they exercised (McClellan & Ada, 2004; Chan, Immink & Hillier, 2012; Malagoni et al., 2016). In the study by Malagoni and colleagues (Malagoni et al., 2016), participants were asked to fill out a daily training record indicating exercise completion and any adverse events. This record was then used by the authors to produce an adherence percentage ('retention rate') – where the number of planned sessions relative to the recorded sessions was calculated. It was not clear whether this methodology was developed by the authors or based on previous research.

Hayward and colleagues (Hayward, Neibling & Barker, 2015) utilised a journal for recording adherence in their case study. Repetitions and a quality reflection were recorded.

This review identified a survey, exploring exercise beliefs and adherence, originally developed by Miller (Miller, 2009). The written exercise survey collected data including whether participants recalled being provided with a home exercise program. For those that indicated a 'yes' response, data on adherence, non-adherence, reasons for non-adherence, perception of loss of function since discharge, and exercise attitudes were collected (Miller et al., 2017). This survey was developed after a literature review and was pilot tested and reviewed by experts in the field. The author acknowledged that a limitation of their study was a lack of validity of the survey. An additional study included in this review used a phone survey to assess adherence, however, no

details of the survey were available (Kuno, Morino & Takamatsu, 2015).



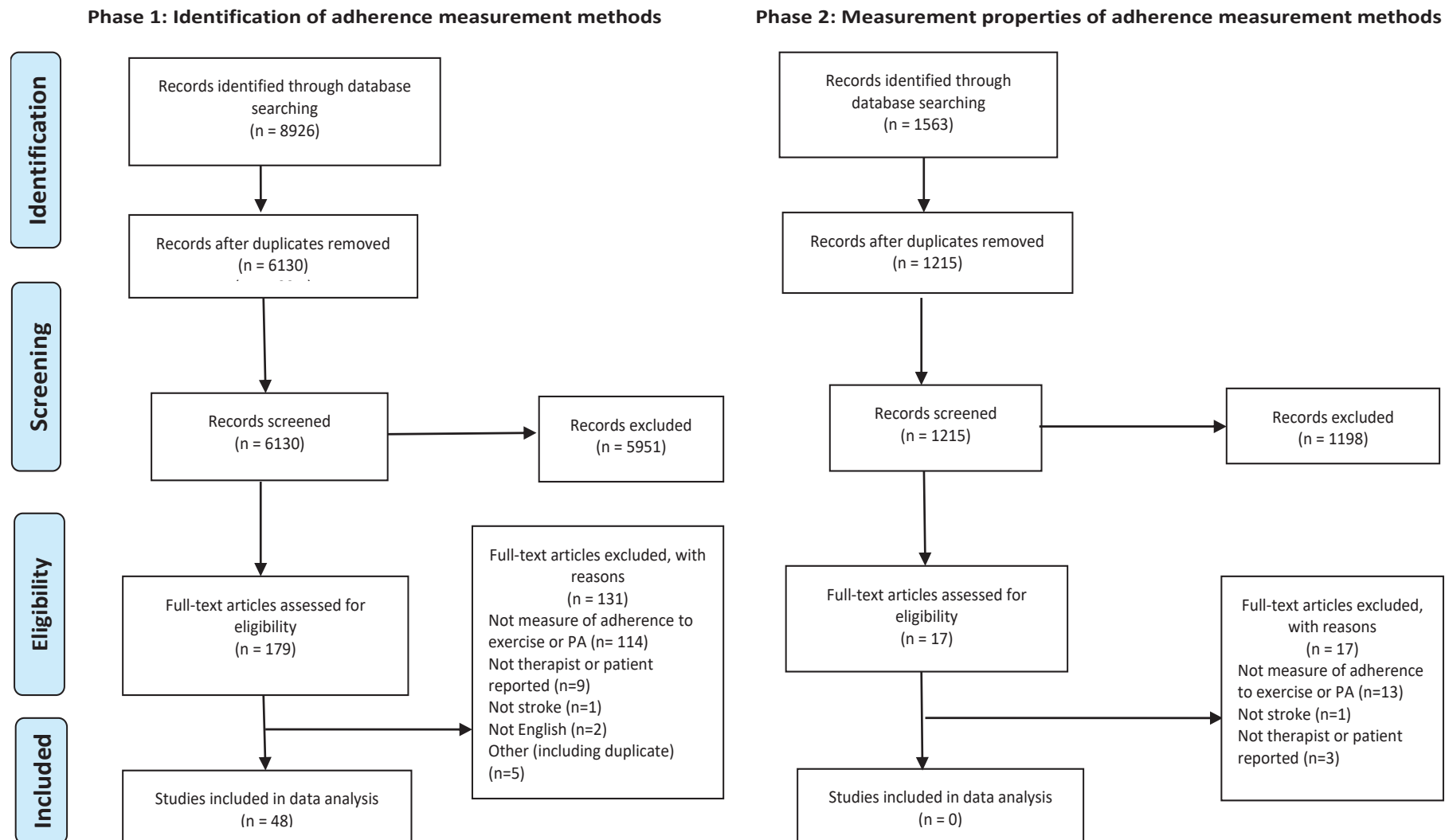


Figure 2-1 Flowchart of the selection process for Phase 1 and Phase 2

**Table 2-1 Types of adherence measurement methods and type of study in which the method was used**

<b>Type of adherence measurement method</b>	<b>Number of studies identified using the method</b>	<b>Experimental studies [study reference]</b>	<b>Descriptive studies [study reference]</b>
<b>Diary</b>	18	Winstein et al., 2003; Gabr, Levine & Page, 2005; Galvin et al., 2011; Askim et al., 2012; Batchelor et al., 2012; Treger, Landesman, Tabacaru & Kalichman, 2014; Gunnes, Indredavik & Askim, 2015; Koh et al., 2015; Walter, Hale & Smith, 2015; Dean et al., 2016; Gunnes et al., 2017; Menezes et al., 2017; Askim et al., 2018; Lannin et al., 2018	Taskinen, 1999; Roberts et al., 2005; Taub et al., 2013; Kumar & Sheehy, 2016
<b>Logbook</b>	16	Ada et al., 2003; Brogardh & Sjolund, 2006; Sullivan & Hedman, 2007; Mayo et al., 2013; Turton et al., 2013; Benvenuti et al., 2014; Danks, Roos, McCoy & Reisman, 2014; Linder et al., 2015; Moore et al., 2016; Baldwin et al., 2018; Bonnyaud et al., 2018	Pierce et al., 2003; McCall et al., 2011; Kara & Ntsiea, 2015; Emmerson, Harding & Taylor, 2017; Simpson, Eng & Chan, 2017
<b>Record of practice</b>	3	McClellan & Ada, 2004; Chan, Immink & Hillier, 2012; Malagoni et al., 2016	
<b>Journal</b>	1		Hayward, Neibling & Barker, 2015
<b>Survey</b>	2		Kuno, Morino & Takamatsu, 2015; Miller et al., 2017
<b>Questionnaire</b>	4		Touillet et al., 2010; Jurkiewicz, Marzolini & Oh, 2011; Yao et al., 2017; Mahmood, Solomon & Manikandan, 2018
<b>PASIPD</b>	4		Rand et al., 2010; Brown et al., 2014; Mansfield et al., 2017; Brauer, Kuys, Paratz & Ada, 2018

*PASIPD = The Physical Activity Scale for Individuals with Physical Disabilities*

**Table 2-2 Characteristics of studies which measure adherence to physical activity or exercise recommendations**

Author	Adherence measurement method	Setting	Sample size	Study type	Details of adherence measurement method			
					Type of exercise	Frequency	Duration	Int/Reps
<b>Askim et al., 2012 (PA)</b>	diary	community	390	RCT (p)	✓	✓	✓	✓
<b>Askim et al., 2018 (PA)</b>	diary	community	380	RCT	✓	✓	✓	✓
<b>Batchelor et al., 2012 (PA)</b>	diary	community	16	RCT	?	✓	?	?
<b>Dean et al., 2016 (PA)</b>	diary	community	48	RCT (p)	✓	✓	✓	X
<b>Gabr, Levine &amp; Page, 2005 (PA)</b>	diary	community	12	RCT	?	?	?	?
<b>Galvin et al., 2011 (PA)</b>	diary	In/Comm	40	RCT	X	✓	✓	✓
<b>Gunnes, Indredavik &amp; Askim, 2015 (PA)</b>	diary	community	41	RCT	✓	✓	✓	✓
<b>Gunnes et al., 2017 (PA)</b>	diary	community	41	RCT	✓	✓	✓	✓
<b>Koh et al., 2015 (PA)</b>	diary	community	100	RCT (p)	X	✓	✓	X
<b>Kumar &amp; Sheehy, 2016 (PA)</b>	diary	community	10	pre and	?	?	?	?

				post				
<b>Lannin et al., 2018 (PA)</b>	diary	community	37	RCT (pilot)	X	✓	✓	✓
<b>Menezes et al., 2017 (PA)</b>	diary	community	38	RCT (p)	X	✓	✓	✓
<b>Roberts et al., 2005 (PA)</b>	diary	Out/Comm	9	pre and post	✓	✓	✓	✓
<b>Taskinen, 1999 (PA)</b>	diary	Out/Comm	5	pre and post	?	?	?	?
<b>Taub et al., 2013 (PA)</b>	diary	outpatient	6	pre and post	✓	✓	X	X
<b>Treger, Landesman, Tabacaru &amp; Kalichman, 2014 (PA)</b>	diary	community	86	RCT	X	✓	✓	✓
<b>Walter, Hale &amp; Smith, 2015 (PA)</b>	diary	community	5	pre and post	?	?	?	?
<b>Winstein et al., 2003 (PA)</b>	diary	outpatient	222	RCT	✓	✓	✓	✓
<b>Ada et al., 2003 (PA)</b>	logbook	community	27	RCT	?	?	?	?
<b>Baldwin et al., 2018 (PA)</b>	logbook	community	19	RCT (pilot)	✓	?	✓	?
<b>Benvenuti et al., 2014 (PA)</b>	logbook	community	143	descriptive	X	✓	X	X
<b>Bonnyaud et al., 2018 (PA)</b>	logbook	community	220	RCT (p)	✓	✓	✓	?

<b>Broghard &amp; Sjolund, 2006 (PA)</b>	logbook	community	16	RCT	X	✓	✓	X
<b>Danks, Roos, McCoy &amp; Reisman, 2014 (PA)</b>	logbook	community	16	pre and post	X	✓	X	✓
<b>Emmerson, Harding &amp; Taylor, 2017 (PA)</b>	logbook	community	62	RCT	X	✓	✓	✓
<b>Kara &amp; Ntsei, 2015 (PA)</b>	logbook	community	36	RCT	✓	✓	✓	X
<b>Linder et al., 2015 (PA)</b>	logbook	community	85	RCT	?	?	?	?
<b>Mayo et al., 2013 (PA)</b>	logbook	community	87	RCT	X	X	✓	✓
<b>McCall et al., 2011 (PA)</b>	logbook	Out/In	4	ITS	✓	✓	✓	X
<b>Moore et al., 2016 (PA)</b>	logbook	In/Comm	60	RCT (p)	✓	✓	X	X
<b>Pierce et al., 2003 (PA)</b>	logbook	outpatient	17	pre and post	X	✓	✓	X
<b>Simpson, Eng &amp; Chan, 2017 (PA)</b>	logbook	community	8	pre and post	✓	✓	✓	✓
<b>Sullivan &amp; Hedman, 2007 (PA)</b>	logbook	community	10	single case	✓	✓	✓	X

<b>Turton et al., 2013 (PA)</b>	logbook	community	50	RCT (p)	✓	X	X	✓
<b>Chan, Immink &amp; Hillier, 2012 (PA)</b>	record of practice	community	14	RCT	?	?	?	?
<b>Malagoni et al., 2016 (PA)</b>	record of practice	community	12	RCT	X	✓	X	X
<b>McClellan &amp; Ada, 2004 (PA)</b>	record of practice	community	26	RCT	X	✓	X	X
<b>Hayward, Neibling &amp; Barker, 2015 (PA)</b>	journal	community	1	single case	✓	✓	✓	✓
<b>Miller et al., 2017 (PA)</b>	phone survey	community	55	descriptive	X	✓	✓	X
<b>Kuno, Morino &amp; Takamatsu, 2015 (HP)</b>	survey	community	46	pre and post	?	?	?	?
<b>Mahmood, Solomon &amp; Manikandan, 2018 (PA)</b>	questionnaire	community	55	descriptive	X	✓	✓	X
<b>Jurkiewicz, Marzolini &amp; Oh, 2011 (PA)</b>	questionnaire	community	14	descriptive	?	?	?	?
<b>Touillet et al., 2010 (HP)</b>	questionnaire	community	9	descriptive	✓	✓	✓	X
<b>Yao et al., 2017 (HP)</b>	questionnaire	inpatient	87	descriptive	?	?	?	?
<b>Brauer, Kuys, Paratz &amp; Ada, 2018 (PA)</b>	PASIPD	community	128	RCT (p)	X	✓	✓	X

<b>Brown et al., 2014 (PA)</b>	PASIPD	community	61	prospective	X	✓	✓	X
<b>Rand et al., 2010 (PA)</b>	PASIPD	community	40	pre and post	X	✓	✓	X
<b>Mansfield et al., 2017 (PA)</b>	PASIPD	outpatient	11	pre and post	X	✓	✓	X

Abbreviations: PASIPD = Physical Activity Scale for Individuals with Physical Disabilities; RCT = Randomised Controlled Trial; In/Comm = Inpatient / community; Out / Comm = Outpatient / Community; RCT (p) = Randomised Controlled Trial (protocol); Out / In = Outpatients / Inpatients; Int / Reps = Intensity / Repetitions  
Key: ✓ = details included; X = details not included; ? = unclear if included

**PA** = patient administered; **HP** = health professional administered

Four papers included in this review used questionnaires as adherence measurement methods. Jurkiewicz and colleagues (Jurkiewicz, Marzolini & Oh, 2011) developed a 16-item questionnaire adapted from a previous study. The questionnaire included questions about the type and amount of exercise, factors that motivated them to participate, and reasons why they missed their workout. Touillet and colleagues (Touillet et al., 2010) described a semi-structured activity questionnaire which explored the type of activity as well as duration and frequency. In a study exploring longitudinal patterns of adherence to exercises in people with stroke, Yao and colleagues (Yao et al., 2017) utilized the Questionnaire of Exercise Adherence, a 14-item questionnaire consisting of three dimensions: adherence to exercise, effective supervision, and advice seeking. An additional study included in this review developed a questionnaire that examined consistency between prescribed treatment and exercises completed (Mahmood, Solomon & Mandikan, 2018).

The Physical Activity Scale for Individuals with Physical Disabilities (PASIPD) was included in four papers identified in this review (Rand et al., 2010; Brown et al., 2014; Mansfield et al., 2017; Brauer, Kuys, Paratz & Ada, 2018). The PASIPD is a 13-item self-report questionnaire that assesses physical activity in three domains: recreation, household, and occupational activities.

### **2.3.2 Phase 2: Properties of included adherence measurement methods**

The search for the second phase of this review, aimed at synthesising the published psychometric properties of the adherence measurement methods, identified 1215 citations, and a total of 17 papers were sought in full text. Of these studies, none of the studies met all the inclusion criteria. Hence, analysis of the psychometric properties of the identified adherence measurement methods was not possible.

## **2.4 Discussion**

This review identified that while there are adherence measurement methods used to assess adherence to exercise or physical activity recommendations after stroke, there are no published psychometric studies of these tools. Seven adherence measurement methods have been described in the literature: diaries, logbooks, a record of practice, journal, surveys, questionnaires, and the PASIPD. There is no clear consensus on the optimal adherence measurement method to exercise or physical activity recommendations after stroke, since it remains plausible that existing approaches are not psychometrically sound. The findings of this review are consistent with other reviews involving other populations, demonstrating that researchers tend to use tools that are developed and administered in an ad hoc manner, and existing measures have not been tested for reliability or validity (Bollen et al., 2014; Holden et al., 2014; Hall et al., 2015; Frost et al., 2017).

Additional methods of monitoring, such as telephone monitoring and follow-up face to face meetings, were used in a number of other studies included in this review (Winstein et al., 2003;



Treger, Landesman, Tabacaru & Kalichman, 2014; Gunnes, Indredavik & Askim, 2015; Koh et al., 2015; Gunnes et al., 2017; Menezes et al., 2017; Askim et al., 2018; Bonnyaud et al., 2018). In addition, Gunnes and colleagues (Gunnes, Indredavik & Askim, 2015) combined participant-reported diaries with an adherence form completed by the physiotherapist on review of the diary. The adherence form was intended as a method of quality assurance and was completed at regular review appointments. The author combined the two measures and expressed this as a single value representing adherence. Given that the use of a diary or logbook is common, determining the validity and reliability of these approaches seems the most logical place to start.

Whilst no studies met the inclusion criteria for phase two of the review, we excluded one study involving a coded physical activity diary (Vanroy et al., 2014). This study was not included as it described patterns of physical activity rather than adherence to a prescribed program. These types of coded diaries are frequently used in stroke research activity trials; each day is divided into time intervals and codes are provided that represent specific activities. Patients are asked to choose the primary activity performed over the time interval. It is hypothesised that this sort of diary use may be easier for stroke survivors to comply with as it minimizes writing, but there is not yet research to support this suggestion. Health professionals may consider this method of diary use when aiming to measure stroke survivors' adherence to exercise programs, but further research should be conducted before assuming that a diary of exercise represents actual exercise completed.

While participants were responsible for self-reporting in most studies, some studies also incorporated caregiver involvement in the recording process. Caregivers were required to either record the amount of exercise performed in the logbook or sign-off the completed exercises (Mayo et al., 2013; Benvenuti et al., 2014; Kara & Ntsiea, 2015). Caregiver support may increase the consistent use of adherence measurement methods; however, consideration must be given to the demands and burden placed on the caregiver. Again, however, there were no published studies to determine whether caregivers are accurate in their reporting of completed exercise and the role of caregivers in physical activity and exercise studies warrants further research.

Our review did locate one tool; the PASIPD is a 13-item self-report questionnaire that captures physical activity in three domain areas (recreation, household, and occupational activities). While we could not synthesise findings from psychometric studies completed specifically in a stroke population, the PASIPD has published reliability and validity coefficients (test-retest reliability .77; criterion validity correlation .3) when used for measuring physical activity in individuals with disabilities (mixed population) (van der Ploeg et al., 2007; Rand et al., 2010). Thus, the PASIPD may be considered to be a tool for measuring physical activity in a population of people with disabilities. However, it was not designed to be a tool for measuring adherence although it was used for this purpose in one study identified in this review (Brown et al., 2014). To use the PASIPD

as an adherence measurement method, Brown and colleagues adapted the original assessment (Brown et al., 2014), however it has not had psychometric evaluation for this purpose. Thus, further research to understand the validity and reliability of the PASIPD as an adherence measurement method is still required.

This systematic review was deliberately limited to identifying adherence measurement methods through methods of client or health professionals report (and thus, we excluded approaches such as the use of accelerometers). We made this decision because there is already systematic review evidence for the role of accelerometry to monitor physical activity in stroke survivors, concluding that accelerometers yield valid and reliable data about physical activity after stroke (Gebruers et al., 2010). Despite this strong evidence, the uptake of accelerometers by health professionals to monitor activity remains limited (Hayward et al., 2016) and there is anecdotal evidence that independent use by stroke survivors is difficult. Furthermore, the use of accelerometers does not allow the health professional to monitor specific components of adherence such as counting repetitions. It is therefore important for health professionals to have inexpensive, readily available, quick, and reliable adherence measurement methods that they or their patients could administer to measure adherence. This review has identified that currently, such a method does not exist in the stroke literature.

Many studies identified in this systematic review recruited community-dwelling participants who were capable of participating in an unsupervised exercise program. Of the studies incorporating cognitive and communication function into their inclusion and exclusion criteria, participants were excluded if they had issues that would prevent them from following instructions relating to the intervention or method of assessment, including a lack of ability to follow two-step commands or mild cognitive deficits. A number of studies reported a mini-mental state examination cut-off score indicative of mild cognitive impairment (MMSE 18-23) (Winstein et al., 2003; Roberts et al., 2005; Rand et al., 2010; Galvin et al., 2011; Taub et al., 2013; Gunnes, Indredavik & Askim, 2015; Malagoni et al., 2016; Askim et al., 2018; Lannin et al., 2018). Thus, our findings also failed to identify adherence measurement methods that may be suited to a population with greater levels of cognitive disability.

As the adherence measurement methods identified in this review varied in terms of their format and detail, at this stage it is not possible to recommend which is most likely to provide the most reliable and valid information in the stroke population. The most frequently used adherence measurement method identified in this review is the patient diary. The main limitation of this method is the possibility of inaccurate reporting with a bias towards over-reporting (Visser, Brychta, Chen & Koster, 2014). Exploration of some of the more advanced implementations of diary use identified in this review, such as a coded diary and regular health professional review, warrant

further investigation and validation.

The issue of bias was addressed in a small number of the included studies and must be considered in analysis. Studies that rely on patient self-report can be subject to many forms of bias including recall bias, optimism bias, and social desirability response bias (Sackett, 1979; Van de Mortel, 2008; Pannucci & Wilkins, 2010; Sharot, 2011). Recall bias was identified as a limiting factor in survey-based studies (Miller, 2009), and self-report instruments such as diaries were reported to be vulnerable to patients' inaccuracies (Gunnes, Indredavik & Askim, 2015).

The findings of this review echo those in other fields. A systematic review of exercise adherence in the musculoskeletal field concluded that the measures identified were unacceptable for use and highlighted the importance of the development and evaluation of appropriate measures (McLean et al., 2015). The development of a validated measure of adherence to exercise or physical activity in people with stroke should be a priority to provide researchers and health professionals with a greater understanding of this important concept (Beinart et al., 2013).

## **2.5 Strengths and limitations**

This review had several strengths. Firstly, the conducted search was thorough and was assisted by a librarian with extensive experience in health-based systematic reviews. Secondly, the screening process was rigorous and conducted by two independent reviewers. Lastly, the review captured measurement methods but also considered psychometric properties of those methods identified, aiming to provide sound evidence-based recommendations to researchers and health professionals.

Limitations of this systematic review include possible bias as studies not published in English were not included. In this systematic review, studies were excluded if there was less than 80% of stroke survivors in the mixed population. It may be that some studies excluded from Phase 2 contained evidence of studies with sound measurement properties that could apply to stroke survivors. The grey literature was not searched in this systematic review which may be a further limitation. The greatest limitation, however, remains the lack of published psychometric studies testing whether the clinical tools we use to monitor adherence to physical activity and exercise programs for stroke survivors are sound.

## **2.6 Implications for future practice and research**

This review has highlighted that there is a lack of a uniform method of measurement of adherence to exercise or physical activity recommendations in the stroke population.

This study has identified diaries and logbooks as the most frequently used adherence measurement methods, however, there is a lack of standardisation when utilising these tools.

Testing the reliability and validity of existing measures and considering the development of new tools is an area that requires further research.

Health professionals need to consider the reliability of the methods of adherence monitoring they use and consider simultaneously using more than one method to increase confidence in their findings; for example, supplementing self-report measures such as diaries with objective data collection measures.

Based on the findings of this systematic review, the next chapter of this thesis will explore a novel method of monitoring exercise adherence in stroke survivors using tablet technology. This next study will also use multifaceted methods to monitor adherence (self-report and the tablet device), reflecting the lack of a single standardised recommended method identified in this review.

# **CHAPTER 3 EXPLORING THE USE OF A TABLET COMPUTER AS A METHOD OF ADHERENCE MONITORING: A FEASIBILITY STUDY**

This chapter answers Aim 1(b) of the thesis, “to assess the feasibility of using technology as a method of measurement of exercise adherence in stroke survivors” and Aim 2 of the thesis, “to explore barriers and enablers to exercise adherence in stroke survivors participating in an intensive intervention”. This chapter describes a feasibility study and is presented with minor changes for thesis formatting from the publication, ‘Viability of using a computer tablet to monitor an upper limb home exercise program in stroke’ (Levy et al., 2019), published in *Physiotherapy Theory and Practice*.

This study was conducted to assess the feasibility of using a tablet computer to collect information on the exercise practices of stroke survivors participating in a home-based exercise program. As concluded in the systematic review, Chapter 2, there is a lack of standardised measures of exercise adherence recommended for use in the stroke population. The tablet computer is an affordable and readily available form of technology and the candidate chose to explore its feasibility as a usable and accurate method of adherence monitoring for health professionals. In addition, this study sought to understand factors influencing adherence to intensive upper limb exercise programs in stroke survivors.

As the lead author for the publication, the candidate’s contribution was 80% of this chapter. The candidate developed the research questions and methodology with the guidance of supervisors MK, NL, and MC. The candidate conducted the practical assessments, reassessments, and intervention. Co-author and supervisor MK assisted in data analysis. All co-authors were involved in editing and proof-reading the manuscript. Each author has consented to the inclusion of this work in the thesis, as per the submission of thesis form.

## **3.1 Introduction**

As outlined in Chapter 1, there is a growing body of evidence that suggests a positive relationship between motor recovery after stroke and the dose of therapy provided (Kwakkel et al., 2004; Lohse, Lang & Boyd, 2014; Veerbeek et al., 2014; Schneider, Lannin, Ada & Schmidt, 2016). There are, however, significant challenges faced when delivering high-dose upper limb therapy (Kwakkel, 2006; Kaur, English & Hillier, 2012), and to overcome these health professionals may also need to encourage practice outside of therapy times (Schneider, Lannin, Ada & Schmidt, 2016). The use of home-based therapy as one component of a motor training program potentially enables an even greater dose of motor training to be provided after stroke (Coupar et al., 2012a;

Brown et al., 2015).

Technology (including gaming) has been used to increase the amount of activity during rehabilitation, partly through improved engagement in therapeutic activities (Brown et al., 2015; White, Janssen, Jordan & Pollack, 2015). As well as being used to prompt exercise and practice, technology in rehabilitation is used to accurately measure activity levels. Chapter 2 reported that objectively quantifying the amount of rehabilitation practice remains a limitation in both clinical and research fields. Having the ability to accurately measure the amount of practice enables health professionals to determine and then subsequently modify exercise dose (Connell et al., 2014b). Traditional methods to measure the amount of practice include recording time (using a stopwatch) and/or counting repetitions; whilst these methods are convenient and affordable there are limitations regarding their reliability, especially when they depend on self-report (Kwakkel et al., 2004; Kwakkel, 2006; Lang, Wagner, Edwards & Dromerick, 2007; Kaur, English & Hillier, 2012). Technological advances, such as accelerometers, provide an opportunity for a more objective recording of activity (Lang, MacDonald & Gnip, 2007; Lang, Wagner, Edwards & Dromerick, 2007); however, despite growing evidence about their accuracy, there has been limited uptake in clinical or research environments (Hayward et al., 2016). Furthermore, these devices can be costly, which can preclude their purchase for many health services.

A better understanding of the ability for off-the-shelf forms of technology (such as tablet computers or mobile phones) that could be used to accurately measure the amount of practice in rehabilitation is needed. Given that little is known about the potential for the use of tablet computers (such as iPads) as tools for measuring adherence, it was considered important to explore the implementation of this approach from the perspective of the stroke survivor and the health professional. This study focuses on the usability of the tablet computer from the stroke survivors' perspective and the utility of the tablet computer as an approach to providing the health professional with accurate information on stroke survivors' exercise practice.

Therefore, the primary aim of this study was to assess the feasibility (acceptability and implementation) of using a tablet computer to collect accurate information on stroke survivors' exercise practice.

The secondary aims were:

- a) to determine the amount and quality of health professional directed upper limb exercise that stroke survivors can do at home.
- b) to evaluate the factors that may influence adherence to the prescribed intensive upper limb exercise program.

## 3.2 Methods

### 3.2.1 Design

This feasibility study was a sub-study embedded within the InTENSE randomised controlled trial (ACTRN 12615000616572) (Lannin et al., 2020). This parent trial tested the efficacy of an intensive, protocol-based, upper limb exercise program for stroke survivors who had received botulinum toxin type-A injections. Consistent with the InTENSE trial, the inclusion criteria for the present study included a diagnosis of stroke, aged 18 years or older, time since stroke greater than 3 months, willingness to cease all non-trial related upper limb therapy for 3 months, scheduled to receive botulinum toxin type-A injections to at least one upper limb muscle that crossed the wrist, and cognitive ability to participate in therapy (as determined by a score of fewer than 5 errors on the Short Portable Mental Status Questionnaire). Participants randomised into the intervention group of the InTENSE trial were approached for this feasibility study between September 2016 and March 2017 until 10 participants had been recruited. Written, informed consent was obtained from all participants. Ethical clearance for this feasibility study was granted by the Southern Adelaide Clinical Human Research Committee (246.15).

Participants were set up with a tablet computer (Apple model A1474) on Day 1 of the 10-week motor retraining period and asked to video record each exercise session performed, using the MoviePro app, a video recording app that was downloaded onto the tablet computers for a small fee. This required participants to tap on a single app and press the Record button at the start and end of their exercise session. All video footage was downloaded weekly during the study period by the investigator.

Each participant was assigned a unique reference number and all practice days from week 1 to 10 were numbered sequentially. An external person selected the practice days for analysis using the random selection function in Microsoft Excel, and the video analysis schedule for each participant was then placed in a sealed, opaque envelope. Once a participant had completed their 10-week program, the envelope was opened and the selected sessions for video analysis were then analysed. A total of four videoed practice sessions were randomly selected per participant, so a total of 40 sessions over the whole sample were analysed for the 10 participants. In all recordings analysed the participant and the affected arm were clearly visible to the investigator.

The investigator, an experienced physiotherapist, created a video analysis sheet that recorded each participant's self-reported exercise duration as well as investigator observations from the recorded session on the tablet, including actual duration of exercise, the number of exercises performed, and the number of repetitions. The investigator also gave a subjective rating of the quality of practice. This scale was a 100mm vertical visual analogue scale (0-10) and was based on an existing scale (Pomeroy et al. 2003), with the lowest value of 'essentially no quality' and a

top value of 'essentially total quality'. When analysing the motor retraining sessions, quality of practice was rated in terms of the amount of undesirable compensatory movements; in analysing the electrical stimulation sessions, the quality was rated in terms of the success of stimulation in eliciting the goal movements (See Appendix 7 for a copy of the video analysis sheet). To demonstrate participant set-up for this intervention, a screenshot from a video recording of Participant 2 is presented as Figure 3-1.



**Figure 3-1 Screenshot of video recording during home-exercises, Participant 2, copied with participant consent**

The InTENSE intervention commenced immediately following botulinum toxin type-A injection, firstly providing two weeks of serial casting with the wrist positioned in maximum available extension (Lannin et al. 2020). Following removal of the last cast, a 10-week motor retraining program was provided, including strengthening, fine motor tasks, and repetitive functional arm movements. In addition to 12 clinic appointments, all participants were prescribed a home exercise program which included elements of strength training, task-specific motor training, and dexterity practice. Participants with active movement were prescribed a motor training program based on the Graded Repetitive Arm Supplementary Program (GRASP) (Harris, Eng, Miller & Dawson, 2009), while participants without active movement were prescribed a functional electrical stimulation exercise program (Howlett, Lannin, Ada & McKinstry, 2015). The GRASP prescribes one hour of daily upper limb exercises, and a manual of exercises is provided (Harris, Eng, Miller & Dawson, 2009). The GRASP guidelines are available at: [www.rehab.ubc.ca/jeng](http://www.rehab.ubc.ca/jeng). All participants were asked to practice their tailored home program for 60 minutes each day, seven days per week.



Participants were not requested to count or record repetitions, just to record the total minutes of practice per day. Participants who were practicing the exercises based on the GRASP were provided with a booklet and worked their way through the booklet for a total of 60 minutes. Participants practicing the electric stimulation program were instructed in the stimulation of four muscle groups for 15 minutes each, to give a total of 60 minutes. All participants were provided with a recording sheet and were asked to record the amount of time they spent exercising during each session at home with any rest periods eliminated from the reported time (minutes). Table 3-1 outlines processes in the InTENSE intervention and this feasibility study.

**Table 3-1 Feasibility study intervention compared to the InTENSE trial movement training intervention**

	Number of clinic-based sessions : number of face to face home sessions	Requested amount of independent practice	Use of ES if unable to activate muscles against gravity	Use of the GRASP (level determined by active movement)	Set-up session with iPad, including training	Instructed to record 100% independent practice on iPad	Weekly visit to home to download video recordings
<b>InTENSE Intervention</b>	12:1-2	60 minutes per day, 7 days per week	Yes	Yes	No	No	No
<b>Feasibility Intervention</b>	12:1-2	60 minutes per day, 7 days per week	Yes	Yes	Yes	Yes	Yes

### 3.2.2 Outcome measures

#### 3.2.2.1 Primary outcome: The System Usability Scale

The System Usability Scale, a 1 to 5 Likert scale that measures participants' experience with using the technology, was completed to assess participants' ease of use and satisfaction with the tablet computers (Bangor, Kortum & Miller, 2008). This was administered at follow-up after the completion of the 10-week intervention period.

#### 3.2.2.2 Secondary outcomes:

##### 3.2.2.2.1 Practice variables

- i) Practice time (tablet computer) – the duration of time spent exercising, recorded on the tablet computer
- ii) Practice time (self-report) – the duration of time spent exercising, reported by the participant
- iii) Number of exercises completed – the number of exercises completed, recorded on the tablet computer

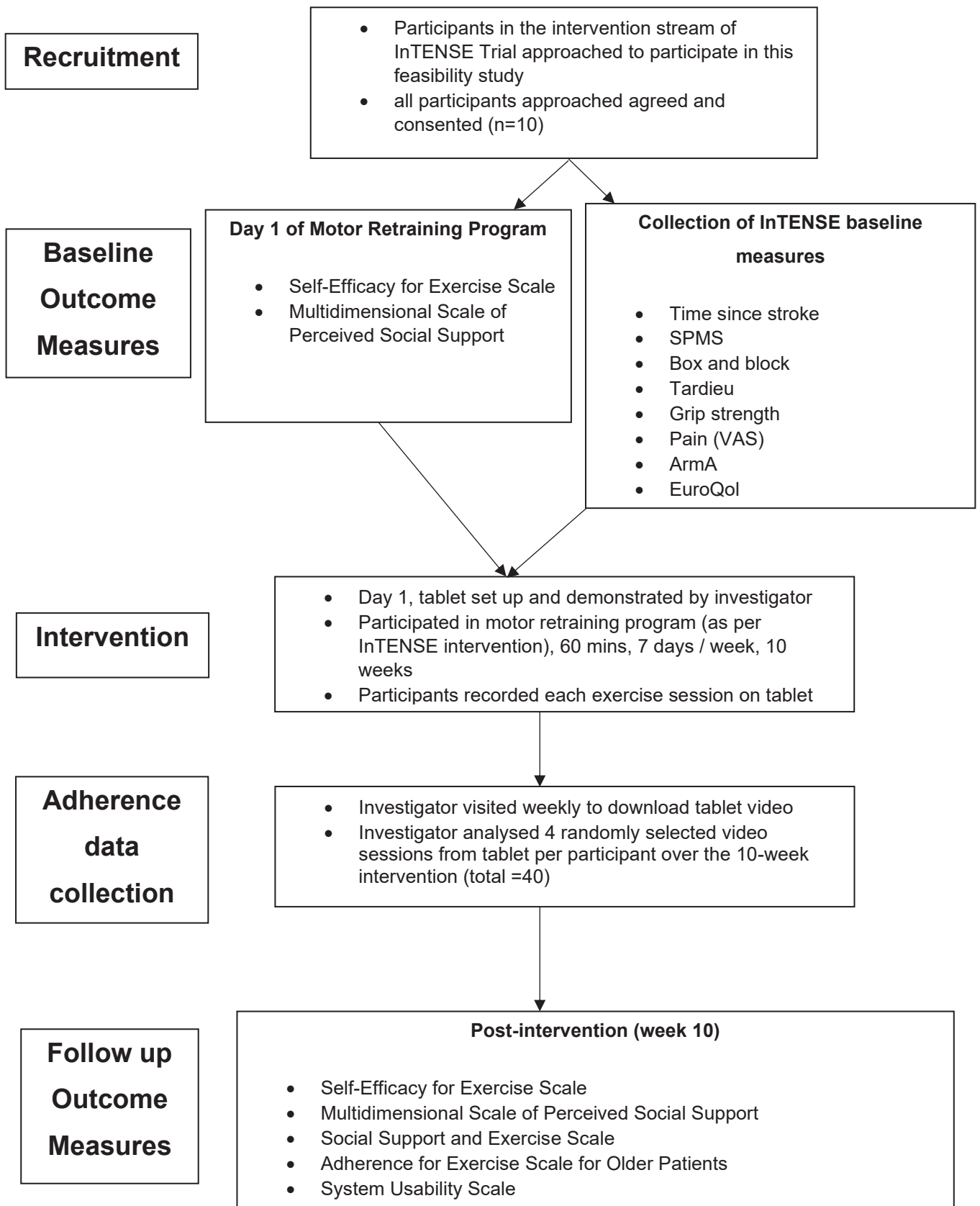
- iv) Repetitions performed- the number of repetitions performed, recorded on the tablet computer
- v) Quality rating- the quality of movement performed, rated by the investigator

#### 3.2.2.2.2 Adherence variables

- i) The Self Efficacy for Exercise Scale, scored from 0 to 10, measuring participants' confidence in their ability to perform the prescribed exercises (Resnick & Jenkins, 2000), was administered at baseline and follow-up.
- ii) The Multidimensional Scale of Perceived Social Support, measuring the participants' feelings about the support received from friends, significant others, and family (Zimet, Dahlem, Zimet & Farley, 1988), was administered at baseline and follow-up.
- iii) The Social Support and Exercise Scale, a 1 to 5 Likert scale in which participants rated how often friends and family assisted with exercises (Sallis et al., 1987), was administered at follow-up.
- iv) The Adherence for Exercise Scale for Older Patients (AESOP), a 43-question scale that assesses factors that may have influenced exercise adherence (Hardage et al., 2007), was administered at follow-up.

Demographic data were also collected to describe participants and understand additional factors that may have affected the amount of practice and adherence. The demographic data included: time since stroke (recorded in years and months); Short Portable Mental Status examination, which assesses mental status and records the number of errors (0 to 10) to 10 questions (Pfeiffer, 1975); the Box and Block test, a test of manual dexterity which counts the number of blocks successfully transported over a partition (Cromwell, 1976); the Tardieu scale, which rates spasticity (Gracies et al., 2010); grip strength (kilograms) using a Jamar dynamometer (Bertrand et al., 2015); pain severity on a visual analogue scale, where 0 is no pain and 10 is the worst pain imaginable (Downie et al., 1978); the ArmA (arm activity measure) scale, a 0 to 4 scale assessing the amount of difficulty experienced during specific self-care activities of the limb over the previous 7 days (Ashford, Turner-Stokes, Siegert & Slade, 2013); and the EuroQoL-5 dimension 3 level (EQ5D-3L) scale, a health-related quality of life scale measured on a 0 (equivalent to dead) to 10 (full health) scale (Devlin et al., 2018).

An outline of the study design is presented in Figure 3-2.



SPMS : Short Portable Mental Status; VAS : Visual Analogue Scale; ArmA : Arm activity measure; EQ5D: EuroQol 5 Dimension

Figure 3-2 Study flow chart

### 3.2.3 Data analysis

#### 3.2.3.1 Primary outcome: The System Usability Scale

Descriptive statistics were used to calculate the means and range of the System Usability Scale, and analyses were conducted using Statistical Package for the Social Sciences (SPSS) (IBM SPSS Statistics Version 22).

#### 3.2.3.2 Secondary outcomes

##### 3.2.3.2.1 Practice variables

An analysis was undertaken to investigate the experiences of the 10 individuals. Data on practice time, demographics, and quality of life for individuals were then combined. Descriptive statistics were used to describe the characteristics of the sample.

##### 3.2.3.2.2 Adherence variables

For each participant, the total scores for the Self-Efficacy for Exercise Scale and the Multidimensional Scale of Perceived Social Support were calculated at baseline and follow-up. Scores for the Social Support and Exercise Scale and the Adherence for Exercise Scale for Older Patients were calculated at follow-up.

## 3.3 Results

Participant demographics are outlined in Table 3-2. The 10 subjects recruited for this study were aged 47-79 years old with a mean age of 61.5 years. There were three females, and seven participants had suffered a right-sided stroke several years before commencing on the study (mean time since stroke was 8.5 years).

**Table 3-2 Participant demographics at baseline**

ID	age	sex	diagnosis	Time since stroke (years)	SPMS	BBT	Tardieu	Grip (kg)	Pain scale	ArmA (clean palm)	ArmA (pickup glass)	ArmA (open jar)	EQ5 D
1	69	F	L CVA	6.16	3	0	1	2	1.0	0	4	4	1.0
2	68	M	R CVA	6.64	1	17	2	3	1.6	3	0	2	.52
3	65	M	R CVA	14.61	0	0	2	3	6.8	3	4	3	.52
4	52	M	L CVA	1.67	0	0	2	4	0	0	4	4	.77
5	48	F	R CVA	1.15	2	0	2	1	0	0	4	4	.44
6	74	M	R CVA	29.41	2	0	1	0	5.5	2	4	2	.34
7	79	M	L CVA	1.13	3	0	3	2	4.4	1	4	4	.51
8	64	M	R CVA	5.94	1	31	2	16	0	0	1	0	.84
9	47	F	R CVA	15.91	1	0	2	0	.1	0	4	4	.76
10	49	M	R CVA	2.09	0	0	2	5	0	2	4	4	.18

SPMS: Short Portable Mental Status; BBT: Box and Block test; ArMA; Arm Activity Measure; EQ5D: EuroQol 5 Dimension Scale

All 10 participants were living in their own homes when they commenced the study. There were, however, varying degrees of social support and levels of motivation across these participants. A description of individual cases is presented in Table 3-3.

Baseline EQ5D scores had a mean value of .59 (range, .18-1.0), indicating a low health-related quality of life. Only two participants had a score above zero on the Box and Block test, indicating that the participant group was severely impaired at the commencement of this study.

### **3.3.1 Primary outcome**

The mean score for the System Usability Scale was 85.5 (range, 47.5-100) which suggests a high degree of perceived usability of the tablet computer. Participants were all willing to use the tablet computer and reported only minimal technical issues.

The additional cost of this intervention included the cost of the tablet device and the health professional's time for initial set-up and ongoing support of the technology, and time for analysis of video downloads (approximately 4 hours per participant). Apart from the initial set-up of the device and time spent downloading and analysing the videos, there was a small amount of time spent troubleshooting the technical issues that arose on three occasions; twice a participant was unable to record a session as he had inadvertently changed a setting on the tablet computer and on a third occasion the video did not record as the video library was at capacity.

### **3.3.2 Secondary outcomes**

#### **3.3.2.1 Practice variables**

##### **3.3.2.1.1 Single case analysis**

The amount of time spent exercising on the tablet and the accuracy of self-report is presented as mean values in Table 3-4. The mean time spent exercising, as recorded on the tablet computer, ranged from 26.4 minutes to 68.4 minutes. Four participants exercised consistently above the prescribed 60 minutes per day (participants 1, 2, 4, and 8). Of these people, three participants (participant 1, 2, and 8) all demonstrated active, functional movement in their impaired upper limb (rated as greater than Level 2 InTENSE criteria for upper limb activity, Table 3-3), and one participant (participant 4) was highly motivated plus had a very supportive partner.

**Table 3-3 Participant characteristics, mean values for exercise sessions and mean values SUS, SES and MSS (at review)**

ID	Occupation	Living situation	Social descriptors	Upper limb Activity (InTENSE criteria)	Self-reported time (min)	Tablet Recorded time (min)	Tablet time minus self-reported (min)	Exercises completed	Reps	Quality rating (0=no Quality 10=total Quality)	SUS mean	SES - review mean	MSS - review mean
1	Housewife	Lives with supportive husband	Enjoys cooking and looking after grandchildren, Independent with exercises	Level 2/3	61.2	62.8	1.6	14.3	166.3	7.3	67.5	8.6	5.8
2	Electrician, own business	Lives with supportive wife and daughter	Highly motivated, independent with set up and performance of exercises	Level 3	66.5	66.5	0.0	19.5	388.0	8.8	100.0	9.1	5.9
3	Volunteer	Lives with supportive wife who works part-time	Highly motivated, independent with set up and performance of exercises	Level 2	51.3	51.6	.40	12.8	140.0	5.8	92.5	8.7	6.0
4	Retired	Lives with supportive wife and two adult children	Highly motivated, independent in all activities and exercises	Level 2	67.5	68.4	.90	8.5	101.3	6.8	100.0	7.6	6.9

5	Unemployed	Divorced, lives with three adult children	Flat affect, relies on daughter to motivate and set up for exercise	Level 2	67.5	59.8	-7.7	12.8	175.5	5.8	100.0	8.6	5.3
6	Retired	Commenced in own home, moved to respite due to illness	Lacks initiation, only exercises when wife is present to assist him	Level 1	61.3	40.2	-21.1	3.3	128.0	1.8	47.5	9.7	4.0
7	Retired	Commenced in own home, moved to respite	Motivated but reliant on assistance to set up exercises, limited support once in respite	Level 1/2	48.0	36.2	-11.8	7.8	78.0	3.0	75.0	6.3	7.0
8	Retired	Lives with supportive wife	Motivated and independent with exercises	Level 3	62.5	62.6	.10	11.8	224.3	8.5	100.0	10.0	6.5
9	Pensioner	Lives with elderly parents and has carers	Participated more effectively when carer present	Level 2	48.8	26.4	-22.3	8.5	71.0	4.5	95.0	10.0	7.0
10	Pensioner	Lives with supportive wife	Very low mood ("ready to give up"), needed assistance with set-up	Level 2	60.0	28.9	-31.1	2.5	75.8	4.0	77.5	7.0	5.1

**INTENSE criteria:** Level 1 = Nil (Electrical stimulation program): Cannot elevate shoulder, doesn't possess Grade 1 wrist extension; Level 2 = able to elevate shoulder and has Grade 1 wrist extension; Level 3 = Able to pick up a small block (e.g., score of 1 or more from Box & Block Test)

SUS = System Usability Scale, SES = Self-efficacy for Exercise Scale, MSS = Multidimensional Scale of Perceived Social Support

**Table 3-4 Average practice variables, participants 1-10**

ID	InTENSE criteria (based on GRASP)	Self-reported time (mins)	Tablet recorded time (mins)	Exercises completed	Repetitions	Quality
1	2-3	61.15	62.77	14.3	166	7.25
2	3	66.50	66.50	19.5	388	8.75
3	2	51.25	51.60	12.8	140	5.75
4	2	67.50	68.37	8.5	101	6.75
5	2	67.50	59.80	12.8	175	5.75
6	1	61.25	40.18	3.3	128	1.75
7	1-2	48.00	36.18	7.8	78	3.00
8	3	62.50	62.60	11.8	224	8.50
9	2	48.75	26.42	8.5	71	4.50
10	2	60.00	28.90	2.5	75	4.00

There were four participants (participants 6, 7, 9, and 10) who exercised for far less than the recommended time (i.e. did 40 minutes or less practice daily). These participants were all noted to have little to no active movement in their impaired upper limb. When exploring these cases further it is noted that three of these participants (participants 6, 7, and 9) had the least amount of social support (see Table 3-3). Whilst participant 10 had good social support, he was noted by the investigator to have a very low mood and on one visit commented that he was “ready to give up”. The four participants (participants 6, 7, 9, and 10) who performed the least amount of exercise were also noted to record a greater difference between their self-reported and tablet recorded practice times. The potential influence of motor activity on the accuracy of self-report may be further supported by observing the accurate recorders - participants 1, 2, 3, 4, and 8. In the analysis of ‘total time resting’ the investigator observed that only two participants (participants 5 and 9) took breaks of longer than two minutes during the recorded sessions.

Participants completed a mean of 10.15 (range, 2.5-19.5) different exercises from the program. The mean score for the quality of movement rating scale was 5.6 and a wide range was evident (see Table 3-4).

#### 3.3.2.1.2 Group analysis

Despite all participants being asked to practice for one hour daily, descriptive statistics showed a small amount of variability in the length of each session (as reported by both the participants and recorded on the tablet computer). There was also variability in the number of repetitions observed on analysis. The mean time recorded on the tablet computer was 50.3 minutes (range, 26.4-68.4) and the mean time recorded by participants was 59.4 minutes (range, 48.0-67.5). The mean difference between self-report and actual recorded exercise time was 9.1 minutes. The mean number of repetitions observed per session was 155 (range, 71-388), with variability affected by the range of motor ability within our small study.



### **3.3.2.2 Adherence variables:**

The mean score for the Self Efficacy for Exercise Scale was 8.58 (range, 7.33-10.0) at baseline and 8.54 (range, 6.33-10.0) at review. Six of the participants showed an improved self-efficacy score and the greatest increase was demonstrated in Subject 6. The self-efficacy scores of 3 participants worsened at follow-up with Subject 10 demonstrating the greatest decrease, while the self-efficacy score of Subject 9 remained the same.

The mean score for the Multidimensional Scale of Perceived Social Support was 5.83 (range, 4.67-6.67) at baseline and 5.96 (range, 4.0-7.0) at review. The mean score for the AESOP was 4.36 (range, 3.09-4.91) and the highest degree of adherence demonstrated with this scale was in Subject 5. The means calculated for the Social Support and Exercise Scale were 1.33 (range, 1.0-3.38) for support received from friends and 2.36 (range, 1.23-3.46) for support received from family; that is, the support from family was more important than that from friends in this group of participants.

## **3.4 Discussion**

This feasibility study demonstrated that monitoring stroke survivor activity using video recordings is feasible and may prove to be more accurate than self-report. In this study, the benefit of having the ability to monitor exercise practice with the tablet computer device was greatest in participants who were more impaired, as they showed the greatest variability between recorded minutes and self-reported minutes of practice. The use of the tablet computer also enabled the investigator to assess the quality of a participant's home exercise practice. The use of the tablet computer for recording practice may therefore prove beneficial in clinical practice as an objective and readily available method of monitoring adherence.

The primary aim of this study was to assess the feasibility (acceptability and implementation) of using the tablet computer to collect accurate information on stroke survivors' exercise practice. Acceptability and implementation are two key areas of focus in feasibility studies (Bowen et al., 2009). Damschroder and colleagues (Damschroder et al., 2009) highlight the importance of monitoring barriers or facilitators during the process of implementation. A lack of carer support could be considered a barrier to implementation in this study.

All participants managed the technology by themselves, with carer support or with minimal support from the investigator, and hence the intervention was implemented as planned and proposed. Participants required varying degrees of assistance for the exercises and tablet use in this study: Subjects 2, 3, 4, 5, and 8 were all independent with the exercises and tablet use; subjects 6, 7, and 9 needed some assistance to set up and use the device; and subjects 1 and 10 needed some motivation and encouragement from carers. Whilst technology use in this study was primarily non-

problematic, it must be noted that for clinical utility technology failure may be a barrier. Mean scores on the System Usability Scale were high, indicating that participants were very accepting of using the technology to monitor in their own homes and hence acceptability of the intervention was established. Similar results were found in a large qualitative study which explored the acceptability of tablet use in a group of stroke patients (White, Janssen, Jordan & Pollack, 2015), and found that tablet use was feasible, acceptable, and of benefit even in those stroke survivors with limited computer experience.

Feasibility, and hence utility, must also be considered from a health professional's perspective. This study suggests benefits including the ability to monitor those participants who were considered less likely to adhere, for example, those with less social support or the more impaired. The video playback enabled the investigator to assess the quality of the participant's exercise practice and provide feedback on performance, as well as check the accuracy of self-report. The main negative from the health professional's perspective was the time-consuming aspect of the video analysis. To improve clinical utility a modified approach to video analysis could be taken, whereby health professionals analyse windows of activity ('snapshots') rather than full video recordings. A full analysis of each session was undertaken in this study to report on a range of outcomes such as repetitions and quality. In a clinical setting, where health professionals are often setting exercise targets of the duration of time spent exercising, it would be possible to simply look at the recorded time rather than view an entire exercise session.

The reliability of self-reporting has been extensively described in the literature. A systematic review by Prince and colleagues (Prince et al., 2008) showed a low to moderate correlation between self-report and direct measures of physical activity. In a study in older persons comparing self-reported adherence to physical activity recommendations to accelerometer recordings, the investigators found that 56.8% of the participants reported adherence to recommendations, however, based on accelerometry this percentage was only 24.6% (Visser, Brychta, Chen & Koster, 2014). Findings from our feasibility study showed a higher degree of accuracy in self-report than these previous studies, particularly in people with a greater level of motor ability. An observational study of inpatients undergoing rehabilitation identified that some patients were able to accurately count repetitions (Schrivener, Sherrington, Schurr & Treacy, 2011). Hence, health professionals should endeavour to identify rehabilitation participants who can accurately report exercise intensity.

In a report on physical activity assessment in the general population, the authors concluded that a mixed approach of assessment, combining objective and subjective techniques involving novel devices will be most effective (Ara et al., 2015). This is the approach of adherence assessment taken in the present study. Our study showed that half the participants were extremely accurate in reporting the practice time, while half over-reported how much activity was performed. In the present study, there was a difference of 9.1 minutes found between session time (tablet computer)

and self-reported time. The candidate acknowledges that this may reflect a lack of adherence to tablet computer use for recording all activity performed, and thus, we cannot be sure that it does represent over-reporting of practice. The candidate also only analysed four randomly selected sessions per participant (total of 40 observations) and it is plausible that these sessions do not represent the overall reporting behaviours of the participants across the full 10 weeks. The clinical importance of under-or over-reporting warrants further investigation. It is important to mention that another factor that may contribute to over-reporting in this and other studies is the participants' desire to please the health professional. It should be acknowledged that participants in this study may have had improved exercise adherence due to the role of the tablet computer and the investigator monitoring this, that is the health professionals 'watching over' them.

Many authors have investigated the amount of time people with stroke are active in therapy. In a systematic review exploring activity during physiotherapy sessions in people with stroke, Kaur and colleagues (Kaur, English & Hillier, 2012) found that people spent less than two-thirds of their physiotherapy sessions engaged in physical activity, which may suggest that the same is true during participation in health professional directed home exercise programs. However, in the present study, analysis of videos revealed that in most sessions observed participants took minimal rest breaks and remained active throughout. Rests were predominantly used for reading the next exercise or gathering equipment with only two participants observed to be inactive for any measurable period. This provides support for self-practice as an effective rehabilitation approach in this patient group, however, it must be remembered that some patients may not achieve the recommended dosage when participating in a self-directed program. The use of the tablet device as a fidelity check was beneficial.

The duration of sessions continues to be referred to as a proxy measure of intensity in clinical guidelines. The present study used the duration of practice and counting repetitions to describe the intensity of exercise. Chan (Chan, 2015) reports that intensity can have numerous meanings in the field of rehabilitation; it can be described in terms related to the amount of work or energy exerted by the participant, it can be reported by amount of repetitions or by the duration of tasks performed. Furthermore, Kwakkel (2006) describes the complexity of defining intensity of rehabilitation and highlights that in the literature it is described in a range of different ways, including in terms of frequency of repetitions, amount of external work, and amount of time dedicated to practice. An observational study by Connell and colleagues (Connell et al., 2014b) looked at time, repetitions, and accelerometry as measures of intensity during a structured upper limb exercise program in a group of stroke survivors. They concluded that time may not be the most accurate measure of intensity and that counting repetitions was feasible when using a structured exercise program, such as used in the InTENSE trial. In the present study, the mean exercise time was 50.3 minutes (SD 16.04) and the median number of repetitions were 134.0. In the study by Connell and colleagues (Connell et al., 2014b), the mean time was 48.5 minutes (SD 7.8 minutes) and median

purposeful repetitions were 251. The lower number of repetitions in the present study can be explained by a greater level of impairment of participants in this study population in comparison to the participants in the study by Connell and colleagues (Connell et al., 2014b), that is, severity of stroke will influence the time taken to complete tasks and the ability to self-practice.

The role the health professional plays in enhancing adherence in clinical practice is important to consider. Whilst this was not formally assessed in this study, three participants commented to the investigator that they were conscious of the fact that the investigator may have monitored their practice. This may be seen as a form of 'supervision' and there is extensive research that suggests motivation and compliance can be enhanced through supervision of exercise programs (Schutzer & Graves, 2004; Picorelli et al., 2014). Several participants in this study reported finding the tablet technology engaging and believed they benefited from being able to see themselves exercising.

Self-efficacy refers to the individual's confidence in their ability to complete a given task and is associated with higher levels of exercise adherence (Essery, Geraghty, Kirby & Yardley, 2017). A systematic review exploring the influence of self-efficacy on stroke recovery found that self-efficacy was positively associated with mobility, activities of daily living, and quality of life, and negatively associated with depression (Korpershoek, van der Bijl & Hafsteinsdóttir, 2011). In the study by Visser and colleagues (Visser, Brychta, Chen & Koster, 2014), low self-efficacy was reported as being a factor that may contribute to older persons misperceiving their adherence to physical activity recommendations. In the present study, self-efficacy was very similar at baseline and review (8.58 at baseline, 8.54 at review). This may be explained by the fact that the participants had a very high self-efficacy at baseline. The participants in the InTENSE clinical trial had agreed to a high level of participation and thus they could be considered as highly motivated.

The importance of the role of social support on health has been extensively reported in the literature (McAuley et al., 2003; DiMatteo, 2004; Brenner & Marsella, 2008). The precise means by which social support improves health outcomes is not completely understood but may include benefits such as buffering stress, influencing the ability to adjust, and supporting adherence to treatment (DiMatteo, 2004). The findings from this feasibility study, where participants who had less reliable social supports were amongst those who practiced less, are in line with other works (Essery, Geraghty, Kirby & Yardley, 2017), suggesting higher levels of social support are associated with better adherence to exercise. Visser and colleagues (Visser, Brychta, Chen & Koster, 2014) found older people with low levels of social support were also more likely to misperceive their adherence to exercise recommendations. In this feasibility study, an exploration of individual case studies revealed that the participants who had less social support were amongst those who exercised less. The support from family, as reported by the Social Support and Exercise Scale, was more important than that from friends in this group of participants. This finding suggests that future trials of upper limb home exercise program efficacy should stratify for baseline activity

and availability of support from family.

### **3.5 Strengths and limitations**

The study sample was small and comprised of community-dwelling stroke survivors who were on average 8.5 years after stroke (i.e. chronic); the findings of this study may be different in a less chronic population. The population recruited in this feasibility study were highly motivated participants, having consented to an intensive trial protocol (InTENSE) and this may have influenced consistent use and positive acceptability of the tablet. In this study, adherence was explored via two methods: through the amount of time spent exercising and via an outcome measure, the Adherence for Exercise Scale for Older Patients. Whilst this measure has been shown to have content validity (Bollen et al., 2014) in an elderly population, a limitation of this present study may be that not all of the 10 participants in this study would be considered 'elderly'. Although daily videos were recorded and stored, only four randomly selected sessions were analysed per participant, giving a total of only 40 observed sessions. Further examination of more video sessions over a longitudinal period may provide a different picture of exercise adherence over time. Whilst only analysing four sessions may be considered a limitation, the sessions were randomly selected and thus differences can be considered to occur by chance. Furthermore, having the video analysis assessor blinded to the self-report measures would have improved the rigour of the study findings.

The systematic review presented in Chapter 2 reported a lack of uniform methods of measurement of adherence to exercise or physical activity recommendations in the stroke population. A strength of the present study was it used more than one method of adherence measurement, as recommended in Chapter 2: self-report and tablet computer recordings. This ensured confidence with the reporting of the amount of practice and it enabled the candidate to identify inaccuracies in self-reporting across a small number of randomly selected observational sessions.

Except for the System Usability Scale, participant experience was not formally assessed. A mixed-methods study with in-depth qualitative interviews would have provided a greater understanding of the feasibility of this approach to adherence monitoring and exploration of factors that may have influenced adherence to this intensive upper limb exercise program. This would be an area for exploration in further studies.

### **3.6 Implications for future practice and research**

This study found that stroke survivors who participated in an intensive upper limb rehabilitation program were able to use a tablet computer to video record their upper limb home exercise sessions. A wide range in the amount of time participants spent exercising was found, and

variables including social support and level of impairment may have influenced adherence to the exercise program. Given the small sample of observations per participant, and the small number of participants overall, further research using a larger sample with a longitudinal analysis of video recordings is warranted to confirm findings from this feasibility study.

The tablet computer was found to be a feasible way to use technology to measure adherence to a home-based exercise program in a group of stroke survivors. With improved access to technology, health professionals need to consider other methods of technology use that can accurately capture stroke survivors' exercise adherence. The next study in this thesis will therefore explore the feasibility of using upper limb accelerometry as another method of measuring adherence to home-based exercise programs.

Several participants in this study described benefiting from the real-time visual feedback aspect of the tablet use, that is, they felt their performance was assisted by being able to see how they were moving. This feature of tablet use has not been explored and warrants further investigation. Based on these findings, the next study will use a single-case series to investigate the role of concurrent visual feedback (via tablet technology) on promoting adherence to home-based exercise programs in stroke survivors.

# **CHAPTER 4 EXPLORING THE USE OF A TABLET COMPUTER AS A METHOD OF ENHANCING ADHERENCE: A SINGLE-CASE SERIES**

This chapter answers Aim 1(b) of the thesis, “To assess the feasibility of using technology as a method of measurement of exercise adherence in stroke survivors” and Aim 2 of the thesis, “To explore barriers and enablers to exercise adherence in stroke survivors participating in an intensive intervention”. This chapter describes a single-case series, and is presented with minor changes for thesis formatting from the publication, ‘Does the addition of concurrent visual feedback increase adherence to a home exercise program in people with stroke: a single-case series?’, published in BMC Research Notes (Levy et al., 2020).

As presented in Chapter 3, the tablet computer is an affordable and readily available form of technology, and the candidate demonstrated in Chapter 3 that it was a feasible method of technology use for measurement of exercise adherence in the stroke population. Several participants in the feasibility study described benefits from the real-time visual feedback aspect of tablet use and it was concluded that this feature warranted further investigation. Hence, the candidate chose to explore this through a single-case series, addressing Aim 2 by exploring whether the concurrent visual feedback could function as an enabler to exercise adherence. In addressing Aim 1(b) of the thesis, the candidate chose to further explore the potential role of technology, in the form of wrist-worn accelerometry, as a method of measuring adherence to a home-based exercise program.

As the lead author for the publication, the candidate’s contribution was 80% of this chapter. The candidate developed the research questions and methodology with the guidance of supervisor MK. The candidate conducted practical assessments, reassessments, and intervention. Co-author and supervisor MK assisted in data analysis. All co-authors were involved in editing and proof-reading the manuscript. Each author has consented to the inclusion of this work in the thesis, as per the submission of thesis form.

## **4.1 Introduction**

The use of mobile tablet devices to increase engagement in rehabilitation is increasing as services, staff, and clients have greater access to technology (White, Janssen, Jordan & Pollack, 2015). Tablet computers, such as iPads®, are portable, inexpensive, intuitive to use, and many individuals own these devices (Kizony et al., 2016). In terms of recovery from stroke, there is increasing evidence supporting the use of technology in rehabilitation (Saposnik et al., 2010; White, Janssen, Jordan & Pollack, 2015).

Whilst there is an increasing number of mobile applications installed on tablet computers to increase participation in therapy, there is a lack of research around the use of tablet computers as a means of video recording participation in therapy and providing real-time feedback. In a review of tablet use in stroke rehabilitation, Ameer and Ali described the benefits of using a device with a camera within and outside of therapy; including allowing the health professional to record sessions and keep a record of patients' performance, as well as providing real-time feedback (Ameer & Ali, 2017). This finding is consistent with an exploratory study using video feedback of functional tasks after stroke, which found that participants who were provided with visual feedback during a task expressed more satisfaction with their performance (Gilmore & Spaulding, 2007). Currently, there is a lack of studies investigating the role real-time feedback, via tablet use, may play in exercise adherence following stroke, and the potential use of these devices as a method to promote exercise adherence should be explored.

Technology devices can also be utilised as a method to monitor adherence. Researchers and health professionals require accurate methods to measure adherence. However, measuring adherence to rehabilitation programs is challenging, and consensus regarding the gold standard is lacking (Holden et al., 2014; Levy et al., 2018). Accelerometers are relatively new wearable sensors, designed to measure movement in activity counts (Hayward et al., 2016). The advantage of accelerometer use is that an objective measure of performance can be gained. There is evidence that accelerometers produce reliable and valid metrics of upper limb use (Uswatte et al., 2000; Gebruers, Truijen, Engelborghs & De Deyn, 2014) and the feasibility of using these devices to monitor exercise adherence in stroke survivors should be explored.

The primary aim of this study was to determine if the addition of concurrent visual feedback, via a tablet computer, would increase adherence to an intensive upper limb home exercise program in stroke survivors.

A secondary aim was to assess the feasibility of the use of upper limb accelerometry as a method of monitoring upper limb activity during a home exercise program in stroke survivors.

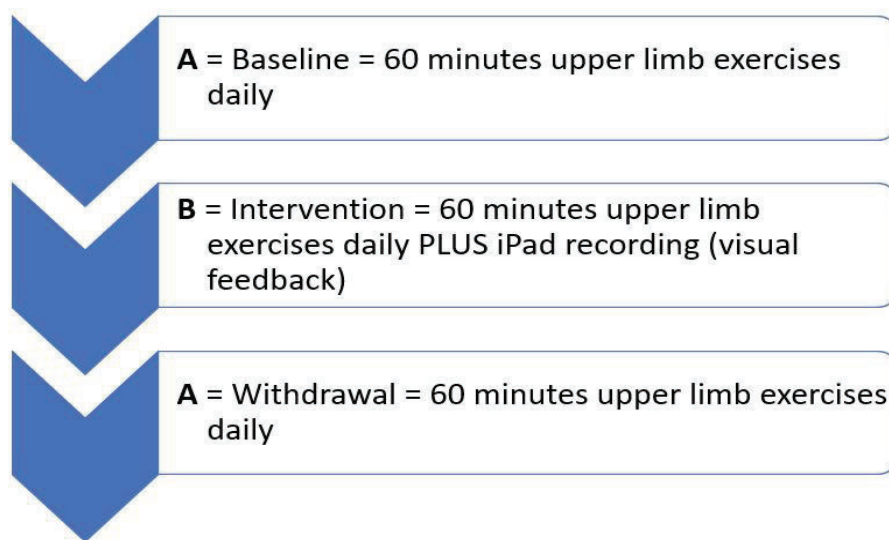
## **4.2 Methods**

Ethical approval for this study was granted by The Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC EC00188). Ten participants were recruited from the Flinders Medical Centre – Rehabilitation and Palliative Division. All participants provided written informed consent. Criteria for inclusion were diagnosis of stroke (>3 months), completion of formal rehabilitation, and being able to pick up a small block with the stroke-affected hand. Stroke survivors were excluded if they were less than 18 years old, had a Mini-Mental State Examination score (MMSE) of less than 24 out of 30 (Cockrell & Folstein, 2002), were non-English speaking (or



absence of an English-speaking carer), or had a visual deficit preventing technology use. After participants' eligibility screening and written informed consent, baseline outcome measures were collected to provide an understanding of the demographics of the participants. Measures were the Fugl-Meyer Assessment (FMA) (Fugl-Meyer et al., 1975), Modified Rankine Score (0-6) (Wilson et al., 2002), Motor Activity Log-14 (MAL-14) (Uswatte et al., 2005), Self-Efficacy for Exercise Scale (Resnick & Jenkins, 2000), the Box and Block test (BBT) (Cromwell, 1976), the line bisection test (Lopes et al., 2007), and a Technology Use Questionnaire (developed by the authors, see Appendix 8).

A single-case series design was employed (Ottenbacher, 1986) with an A-B-A design. A single-case series design was chosen as it allows for detailed testing of the efficacy of an intervention on a chosen outcome. In single-case experiments, many sequential measurements are recorded for each participant. After an initial baseline period, an intervention is applied and the effect of this intervention relative to the baseline values is investigated. Following the intervention phase, there is a follow-up phase which features the withdrawal of the intervention. Figure 4-1 illustrates the outline of the A-B-A phases implemented in this study.



**Figure 4-1 Phases of ABA study design in single-case experiment**

Participants in this study were visited at home by the researcher. Following the completion of baseline measures, the participants were instructed in a tailored home program that was based on the Graded Repetitive Arm Supplementary Program (GRASP) (Harris, Eng, Miller & Dawson, 2009), and were asked to practice their program for a total of 60 minutes each day, six days per week for four weeks. Participants were provided with a recording sheet to record the amount of time spent exercising during each session.

### **4.2.1 Intervention (tablet computer use)**

During the intervention phase (weeks 2 and 3), participants were provided with a tablet computer (Apple model A1474) and were asked to video record each exercise session using the MoviePro app, a video recording app that was downloaded onto the tablet computer. This required participants to tap on a single mobile app, pressing a Record button at the start and end of each session. The tablet computer was set up in front of the participant so that they were able to see themselves exercising and they were instructed to look at the screen as they exercised. Participants also recorded the start and finish times of each exercise session on a recording sheet provided. This enabled verification of accelerometry data if it was required.

### **4.2.2 Measurements**

Participants were provided with two wrist-worn accelerometers (Actigraph, Pensacola, FL) and were instructed to don these before their exercise session and to remove them after each exercise session. The Actigraph, a lightweight accelerometer that resembles a wristwatch, measures the movement of the upper limb through acceleration, which is the change in speed with respect to time. Data from two or three axes of movement are combined to provide the output.

The outcome measure used to evaluate adherence in this study was active time when wearing the accelerometer. At the completion of the study the researcher downloaded recordings from the Actigraph devices. Data was analysed using the Actilife Software, version 6.13.3, and Actigraph active time was calculated for each exercise session.

To evaluate the feasibility of accelerometry use as a method to measure adherence, The System Usability Scale (SUS), a 1 to 5 Likert scale that measures participants' experience with using the technology, was completed post-intervention (Bangor, Kortum & Miller, 2008). Additionally, the researcher kept a logbook, recording any issues that arose with the technology.

### **4.2.3 Data Analysis**

Changes in the amount of activity recorded on the accelerometers from the baseline phase to the 'tablet intervention' phase indicated whether adherence to exercise increased in response to the inclusion of the tablet. In addition, any changes in accelerometer recorded activity following removal of the tablet in the follow-up phase provided extra information to inform the interpretation of the data.

In accordance with standards related to single-case series research where the participant acts as their own control, five measures were analysed in the baseline phase and the mean and standard deviation of measures were calculated to account for the level (mean score) and trend (slope) of the five measures, before the introduction of the tablet (Kratochwill et al., 2010). Active wear time data were then analysed using the two standard deviation (2 SD) band method which has been

recommended for the analysis of single-case series designs (Ottenbacher, 1986; Crosbie, McDonough, Gilmore & Wiggam, 2004; Cashman, Mortenson & Gilbert, 2014). If two or more successive data points within the intervention phase fell outside the 2 SD band (i.e. outside the 95% confidence limits), changes from baseline to the intervention were considered statistically significant. Rigour of the methodology was enhanced by replication of the design on 10 different occasions with 10 different participants. This method of evaluation enables variability of performance to be factored into the analysis (Nourbakhsh & Ottenbacher, 1994).

### 4.3 Results

Table 4-1 presents the baseline demographics of participants who were involved in the study. The mean age of participants was 58.1 years and there was a mean time of 2.2 years since stroke. When using the affected hand, the mean score for the Box and Block Test was 28.3 (range, 0-65) blocks. The mean score for self-efficacy was 7.9/10 (range, 5.9-10).

**Table 4-1 Participant demographics at baseline**

Subject	Age	MMSE	FMA	MAL14	Self - Efficacy	MRS	BBT (affected)	BBT (unaffected)	Time since stroke (months)	Time since rehabilitation (months)
1	64	26	63	7.2	6.4	2	16	29	58	20
2	52	29	62	5.6	10.0	2	65	81	6	4
3	63	28	62	5.6	8.5	3	32	59	13	6
4	65	27	32	5.0	5.9	3	0	57	24	21
5	65	30	62	4.5	7.4	3	19	63	14	9
6	70	29	33	4.7	10.0	2	2	68	7	3
7	21	30	55	4.7	6.1	2	20	32	110	57
8	62	30	64	7.1	7.5	2	45	64	24	.5
9	56	30	65	7.9	9.7	2	48	54	3	1
10	63	30	35	5.1	7.3	3	36	60	5	4

*MMSE: Mini-Mental State Examination (0-30); FMA: Fugl-Meyer Assessment (0-66); MAL14: Motor Activity Log-14 (0-10); Self-Efficacy: Self-efficacy for Exercise Scale (0-10)  
MRS: Modified Rankine Score (0-6); BBT: Box and Block test*

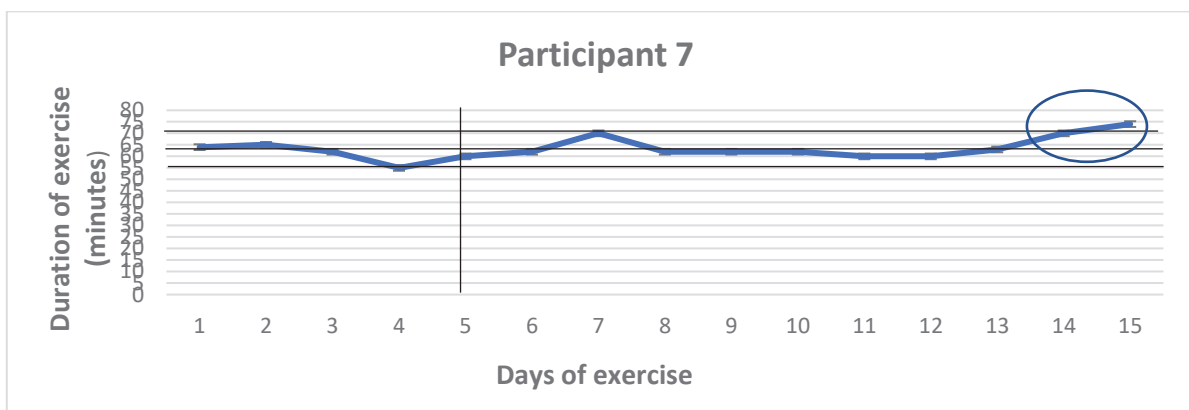
#### **4.3.1 Aim 1: To determine if the addition of concurrent visual feedback, via a tablet computer, will increase adherence to an upper limb home exercise program in people with stroke**

Overall, a significant effect was observed in 4 out of the 10 cases (participants 1, 5, 7, and 10), as demonstrated by 2 successive data points occurring outside the 2 SD band during the intervention phase, meaning that these participants performed a significantly greater amount of exercise when they were using the tablet computer to provide feedback. These results are represented in Figure 4-2.

Furthermore, one participant (participant 9) showed a statistically significant reduction in performance at follow-up when the tablet computer was removed (Figure 4-3). Participant 1 also demonstrated a statistically significant increase in exercise during the follow-up period.

Nine participants reported that they enjoyed the tablet computer and found it beneficial in terms of giving feedback and improving engagement. Participant 1 reported that he did not like the experience of using the tablet computer as he felt like he was being watched. However, despite this discomfort, he still reported a perception that being recorded improved his adherence.

When the time since stroke was investigated, the two participants with the longest time since their strokes (participant 1 = 58 months; participant 7 = 110 months), both showed a statistically significant change, as demonstrated by 2 successive data points occurring outside the 2 SD band during the intervention phase. Furthermore, when the level of motor ability was explored, four of the six non-responders to the tablet intervention (participants 2, 3, 8, and 9) had recorded a relatively high Box and Block test score.



**Figure 4-2** Data points through baseline, intervention, and follow-up for Participants 1, 5, 7, and 10 (significant results circled with 2 consecutive data points outside 2 SD range) (Incomplete data for P 7 due to device malfunction)



**Figure 4-3 Data points through baseline, intervention, and follow-up for Participant 9 (significant result circled with 2 consecutive data points outside 2 SD range)**

#### **4.3.2 Aim 2: To assess the feasibility of the use of upper limb accelerometry as a method of monitoring upper limb activity**

Accelerometry acceptability was measured via the System Usability Scale. The mean score for the System Usability Scale was 96.5 out of 100, indicating a high level of usability.

The accelerometer devices provided objective data representing exercise times. However, there were several problems in terms of data collection. Issues that arose included missing data (participants 4, 9, and 10); despite reportedly charging the devices, data were missing during the last three days of exercise in Participants 4 and 9. One device malfunctioned during the final week for Participant 10. Two participants forgot to put devices on and/or off (participants 2 and 5), on one occasion for each participant. A further two participants forgot to charge the accelerometers (participants 1 and 7), and participant 7 had no recorded data after day 15. Two participants were unable to put the device on the non-affected wrist without assistance (participants 4 and 6). There were no issues with accelerometry utility or data collection in participants 3 and 8.

### **4.4 Discussion**

This study demonstrated that using a tablet computer as a tool to promote adherence (via real-time feedback and video recording) to an intensive upper limb home exercise program can be a useful technique for some stroke survivors. Hence health professionals should assess individual patient factors such as level of motivation, access to and familiarity with technology, and level of motor impairment when considering this method of technology use.

A significant improvement in the amount of exercise performed was observed in four of the 10 participants who completed the study. Additionally, a further participant showed a statistically significant reduction in performance at follow-up when the tablet computer was removed. Most participants reported positive feelings towards the approach. These findings are consistent with those reported by Gilmore and Spaulding who found greater satisfaction in participants who received video feedback during a functional task (Gilmore & Spaulding, 2007). Furthermore, in a randomised controlled trial investigating adherence to exercise in people with stroke, Emmerson and colleagues (Emmerson, Harding & Taylor, 2016) compared paper-based home exercises to home exercises filmed on an electronic tablet. Whilst there were no significant between-group differences in adherence, the authors stated that a potential benefit could be the accuracy of the movement and feedback aspect of the video use and suggested that this may be evaluated in further studies.

There were no technical issues reported with tablet computer use and all participants managed to operate the devices without any assistance or with minimal assistance from a carer. Findings align with other research that describes features of tablet computers, such as a wide touch screen platform, that allows for ease of use in people with stroke (Ameer & Ali, 2017), and qualitative data that reported tablet computers as easy to use, acceptable and engaging (White, Janssen, Jordan & Pollack, 2015). Therefore, despite beliefs that older adults (Gitlow, 2014) and adults with cognitive impairments (Rosenberg, Kottorp, Winblad & Nygård, 2009) experience difficulties with technology, this was not the case in this study.

A ceiling effect was observed in those participants who were highly motivated to participate in the prescribed amount of activity from the beginning of the study; meaning there was less 'room for improvement' and hence no statistically significant effect was evident during the intervention period. Testing the effect of the tablet computer on the adherence of a less motivated group of participants would be valuable. Four of the participants who did not show a significant change with the intervention were the participants who had recorded a relatively high score on the Box and Block test. It may be that the visual feedback provided when using the tablet may be more sought out and utilised when a patient has less motor control, and therefore provides greater benefits. The two participants in this study who presented at the longest time since stroke demonstrated a significant change with the intervention. It may be that this technology is most effective when stroke survivors are in the chronic phase of recovery, but this needs to be considered with caution.

Most of the participants in this study had enough upper limb movement to enable them to independently don and doff the accelerometers. Two participants, who had a higher level of

impairment, required carer assistance to put the devices onto their non-affected wrists. Some practical issues with utility arose throughout this study. At times participants reported that they forgot to don/doff the accelerometers. Additionally, two participants forgot to charge the devices. Potential interventions to promote the reliability of accelerometry use should be considered and may include the use of scheduling applications and phone text reminders. This small study has demonstrated that there are issues that may reduce the utility of home-based accelerometry use in people with stroke. The main advantage of using the accelerometers was that they provided accurate data on exercise time.

#### **4.5 Strengths and limitations**

A strength of this study was the use of accelerometers which provided objective data on the actual amount of exercise performed. The study sample was small and could be considered motivated, having consented to a 4-week motor retraining program, which may have influenced adherence to the prescribed activity. It would be valuable to explore the effect of this intervention in a less adherent group, particularly in those stroke survivors that health professionals struggle to engage in self-directed exercise.

A qualitative component to this study would have enabled a greater exploration of participants' experiences. Furthermore, as participants in a single-case design act as their own controls, data can only be considered individually, and group analysis cannot be reported statistically. A lack of a control group in this study is a weakness as it limits the ability to generalise findings to a wider population. Using a tool (tablet computer) to influence adherence, that is also intended to measure adherence, could be considered a limitation of this study. However, in this single-case series, the primary measurement tool used for analysis of exercise duration was the accelerometer device.

#### **4.6 Implications for future practice and research**

Some stroke survivors were more adherent when using a tablet computer which provided visual feedback of their upper limb home exercise sessions. Given the small number of participants overall, further research using a larger sample is warranted to confirm findings from this single-case series. The results of this study have demonstrated that the impact of technology on motivation is not fully understood and warrants further investigation.

This study has demonstrated that the use of tablet technology as a means of providing extrinsic motivation may be a factor that can enhance adherence to home exercise programs in stroke survivors. In addition, the results of the feasibility study reported in Chapter 3 demonstrated that variables including social support and level of impairment may influence adherence. However, to fully understand factors influencing adherence and comprehensively address Aim 2, a more rigorous in-depth analysis is required. The next study is a qualitative exploration of adherence to



an intensive exercise program in a group of stroke survivors.

# **CHAPTER 5 WHAT ARE THE FACTORS INFLUENCING ADHERENCE TO INTENSIVE EXERCISE PROGRAMS IN STROKE SURVIVORS?: A QUALITATIVE STUDY**

This chapter answers Aim 2 of the thesis, “To explore barriers and enablers to exercise adherence in stroke survivors”. This chapter describes a qualitative study and is presented with minor changes for thesis formatting from the publication, ‘Just that four-letter word hope: stroke survivors’ perspectives of participation in an intensive upper limb exercise program; a qualitative exploration’ (Levy et al., 2021), published in *Physiotherapy Theory and Practice* (in press).

Chapters 3 and 4 described a feasibility study and single-case series which explored technology use during intensive upper limb home exercise programs in stroke survivors. Findings from both studies indicated that there are factors such as the amount of social support and level of impairment that may influence adherence to intensive upper limb home exercise programs. However, to fully understand factors influencing adherence and comprehensively address Aim 2, a more in-depth and rigorous analysis was required. Hence, the candidate chose to conduct a qualitative exploration of adherence to an intensive exercise program in a group of stroke survivors.

As the lead author for the publication, the candidate’s contribution was 80% of this chapter. The candidate developed the research questions and methodology with the guidance of supervisor NL. The candidate conducted 50% of the interviews and analysed the data with the assistance of an external researcher, Lauren Christie. Co-author and supervisor NL assisted in data analysis. All co-authors were involved in editing and proof-reading the manuscript. Each author has consented to the inclusion of this work in the thesis, as per the submission of thesis form.

## **5.1 Introduction**

Higher therapy doses have been associated with better outcomes following stroke (Kwakkel et al., 2004; Lohse, Lang & Boyd, 2014; Veerbeek et al., 2014). Schneider and colleagues (Schneider, Lannin, Ada & Schmidt, 2016) found that when extra rehabilitation aimed at reducing activity limitations is added to usual rehabilitation, it improves activity in people following stroke. The amount of extra rehabilitation that needs to be provided is large, with this systematic review reporting at least an extra 240% was needed to achieve a beneficial effect. However, due to a range of service-specific factors including staffing, resource, and time constraints (Janssen, Klassen, Connell & Eng, 2020; Juckett, Wengerd, Faieta & Griffin, 2020), providing higher doses of therapy in practice is challenging and evidence has shown there may be low adherence to participation in higher intensity therapies in some stroke survivors (Kwakkel, 2006). The capacity of

stroke survivors to adhere to intensive exercise programs is an important contributing factor to the feasibility and acceptability of delivering intensive programs in practice. Therefore, an exploration of the factors that influence adherence to intensive exercise programs is warranted.

A recent national, multicenter Phase III randomized controlled trial (The InTENSE trial) investigated the effects and cost-benefit of adding evidence-based motor training (i.e. extra rehabilitation) to botulinum toxin-A injections to muscle/s which cross the wrist. The program incorporated 10 weeks of motor training aimed at reducing weakness (electrical stimulation and progressive resistance exercises), whereby participants were encouraged to practice at home for 60 minutes per day, every day for 10 weeks (Lannin et al., 2020). Participants were asked to monitor and document the amount of time they spent exercising per session on a 'record of practice'. This home therapy program was supported by a combination of centre-based sessions with health professionals, home visits, and phone calls. Health professionals were provided with targeted training to enable the successful implementation of the intervention, and coaching techniques developed from motivational interviewing principles were utilised to enhance participant active involvement and confidence. Within the InTENSE study, participants within the intervention arm demonstrated a high level of adherence to this intensive daily practice regimen (ranging from 62% to 87% of the protocolised amount of practice), despite having significant upper limb impairment (Lannin et al., 2020).

Factors that predicted adherence to home-based therapies were explored in a recent systematic review that included a range of patient populations, including people with chronic low back pain, osteoarthritis, and falls (Essery, Geraghty, Kirby & Yardley, 2017). Within that review, self-motivation, self-efficacy, previous adherence to exercise, and the social supports available to the person were all important predictors of adherence to home-based therapy (Essery, Geraghty, Kirby & Yardley, 2017). However, to date, there has been limited research exploring barriers and enablers to adherence to post-stroke rehabilitation programs, particularly intensive programs, from the perspective of stroke survivors.

Understanding factors that influence stroke survivors' adherence to intensive exercise programs following stroke could facilitate the identification of barriers and enablers and assist health professionals to develop programs that promote adherence. Therefore, the purpose of this study was to: (1) explore the experience of stroke survivors who had participated in an intensive exercise program and (2) identify barriers and enablers to adherence to intensive exercise programs following stroke.

## **5.2 Methods**

### **5.2.1 Design, participants, and recruitment**

An exploration of experiences of, and motivators and barriers to, participation in intensive exercise was undertaken in a cohort of stroke survivors. A qualitative descriptive design using semi-structured interviews was conducted (Atkins et al., 2017).

Following the completion of the motor training program component of the InTENSE trial, participants were invited to take part in an interview exploring their experiences of receiving intensive evidence-based motor training following botulinum toxin-A injections. To be eligible for this qualitative study, participants must have completed the motor training intervention of the InTENSE trial and be able to consent to an interview. Exclusion criteria included having insufficient conversational English skills to complete the interview and being unable to provide informed consent to an interview. Written informed consent was obtained from participants prior to their interview. Ethical approval was obtained from the Alfred Ethics Committee (442/14) and the Southern Adelaide Clinical Human Research Committee (259.15).

An initial 10 interviews were conducted with a diversity of sampling across sex, age (working age versus non-working age), and in-home support (lives alone versus lives with others). After these 10 interviews, the coding framework was developed and refined by two authors and a further 10 interviews were conducted. Data saturation was defined prior to commencing these final 10 interviews as being when no new material emerged from three consecutive interviews.

### **5.2.2 Interview procedures**

Semi-structured interviews were conducted using an interview guide that focused on participating in an intensive exercise program (see Appendix 9 for a copy of the guide). This guide was piloted by an independent interviewer and the initial two interview transcripts were reviewed collaboratively with senior author NAL before the prompts were refined, and a further eight interviews were then completed. Following the development of the coding framework, the final 10 interviews and coding proceeded together (DeJonckheere & Vaughn, 2019). To refine the interview guide, our prompts were informed by the Transtheoretical Model of Behaviour Change (Romain, Chevance, Caudroit & Bernard, 2016) to explore beliefs, attitudes, and supports influencing exercise adherence to the intensive upper limb program, which had been a key theme emerging from the open coding of the first 10 interviews.

The Transtheoretical Model of Behaviour Change was selected as it permitted the interviewer to explore each participant's readiness to act on a new behaviour (Schutz et al., 2017) - in this case, the intensive exercise program. The model provides constructs such as stages of change which

include contemplation and action, processes of change which include self-re-evaluation, levels of change which identify the complexity of presenting barriers to change, self-efficacy, and decisional balance which reflects weighing up the pros and cons.

For example, concerning the area 'enlisting social support,' participants were asked:

*"How did your carer or support person encourage you to participate in the program? How did they assist you with the exercises?"*

This schedule was a guide only, and the interviewer was responsive to answers from interviewees. All interviews were conducted individually and in the participants' residence. Following written, informed consent, semi-structured interviews were conducted by either the first author (TL) or a second independent interviewer (initial 10 interviews) who had no other involvement with the study. Interviews were audio-recorded and field notes were taken which provided additional information about participants' social circumstances, home environment, and mood throughout the interview. The interviews took approximately 40 minutes to complete and were conducted between September 2018 and July 2019. Following each interview, audio recordings were transcribed verbatim by a professional transcription service, deidentified with pseudonyms applied to all transcripts, and each participant was allocated a participant number.

### **5.2.3 Interview and research personnel**

TL is a physiotherapist and health services researcher with over 30 years of clinical experience, primarily in neurological rehabilitation. TL conducted the last 10 of the 20 interviews and contributed to the analysis once interviews were transcribed and de-identified. TL had previously worked clinically with several participants during the InTENSE clinical trial.

LCh is an occupational therapist and health services researcher with over 10 years of clinical experience, primarily in neurological rehabilitation, and previous experience in qualitative research methods and implementation studies. LCh did not conduct any of the interviews, however, contributed to analysis once interviews were transcribed and de-identified.

NAL is an occupational therapist who holds a PhD in neuroscience/health and a post-graduate qualification in implementation science. She has over 20 years of clinical and research experience. NAL contributed to analysis once the interviews were transcribed and de-identified.

### **5.2.4 Analysis**

Using an inductive approach to thematic analysis, two authors (TL and LCh) coded the transcripts using NVivo data management software (version 12). The transcripts from three interviews were coded collaboratively by the two authors to develop the coding framework. Following this, four

subsequent interviews were double coded independently. Results were compared and discussed to clarify coding differences and the coding framework was further refined; when researchers coded the same response to different codes, these differences were resolved through discussion.

To explore the experiences of participation in an intensive exercise program, TL read all manuscripts multiple times to achieve familiarity with the data and then analysed all the transcripts using a thematic analysis approach. TL and LCh then met to review the generated codes and clustered them into four key categories that described participants' experiences. The presence of these categories was systematically checked across each of the transcripts. Then, to explore barriers and enablers to adherence after initial thematic coding, two authors (TL and LCh) deductively mapped these codes to the domains of the Theoretical Domains Framework (TDF) (Atkins et al., 2017) and the Capability, Opportunity, Motivation-Behaviour (COM-B) model of behaviour change (Michie, Van Stralen & West, 2011). The Theoretical Domains Framework is a validated framework that can be used to investigate and address implementation problems. The Capability, Opportunity, Motivation-Behaviour model can be used in conjunction with the Theoretical Domains Framework as a framework for understanding behaviour. Discrepancies were discussed with an author with expertise in the Theoretical Domains Framework and the Capability, Opportunity, Motivation-Behaviour model (NAL), and a consensus was reached.

## 5.3 Results

### 5.3.1 Participants characteristics

Twenty people with stroke who had participated in an intensive upper limb exercise program were interviewed. A carer was included in the interview for one participant with mild communication difficulties who requested to have a support person present. Data saturation occurred at interview eighteen, as subsequent interviews did not contribute to the development of additional themes. Table 5-1 illustrates details of participants' characteristics including age, sex, time since stroke, side of hemiplegia, and level of motor ability.

**Table 5-1 Profile characteristics of participants (n=20)**

Participant characteristic	n (%)
Sex	
Male	16 (80%)
Female	4 (20%)
Age	
20-39	4 (20%)
40-59	4 (20%)
60+	12 (60%)
Time between stroke and study participation	
0-23 months	5 (25%)
24-47 months	5 (25%)
48 months +	10 (50%)
Side of hemiplegia	

Left	13 (65%)
Right	7 (35%)
Motor training program undertaken	
Passive movements (e.g. electrical stimulation)	13 (65%)
Gross motor movements	4 (20%)
Manipulation / grasp movements	3 (15%)

### **5.3.2 Experience of participation in an intensive upper limb exercise program**

Participants described factors relating to: the physical experience of participation, including the intensity and duration of the exercise program; social factors, including the support received from family and the role of the health professional; the behavioural experience, including their expectations of participation and feelings experienced during participation; and the environment, including access to the hospital and how they structured their exercise programs. Many of the factors identified within these key areas were also considered as barriers and enablers to adherence and are subsequently presented in the Theoretical Domains Framework and Capability, Opportunity, Motivation-Behaviour model analysis. Figure 5-1 represents an illustration of these findings.

### **5.3.3 Summary of the Theoretical Domains Framework and Capability, Opportunity, Motivation-Behaviour model: key barriers and enablers to adherence to an intensive upper limb exercise program**

From the thematic coding of the data, twenty-five themes (seven barriers and eighteen enablers) were identified and mapped onto the six Capability, Opportunity, Motivation-Behaviour model components and 10 of the 14 Theoretical Domains Framework domains. The Theoretical Domains Framework domains were “physical skills”, “environmental context and resources”, “beliefs about consequences”, “emotion”, “memory, attention and decision-making processes”, “social influences”, “social/professional role and identity”, “reinforcement”, “optimism” and “goals”. These findings are represented using the Theoretical Domains Framework domains and Capability, Opportunity, Motivation-Behaviour model in Table 5-2.

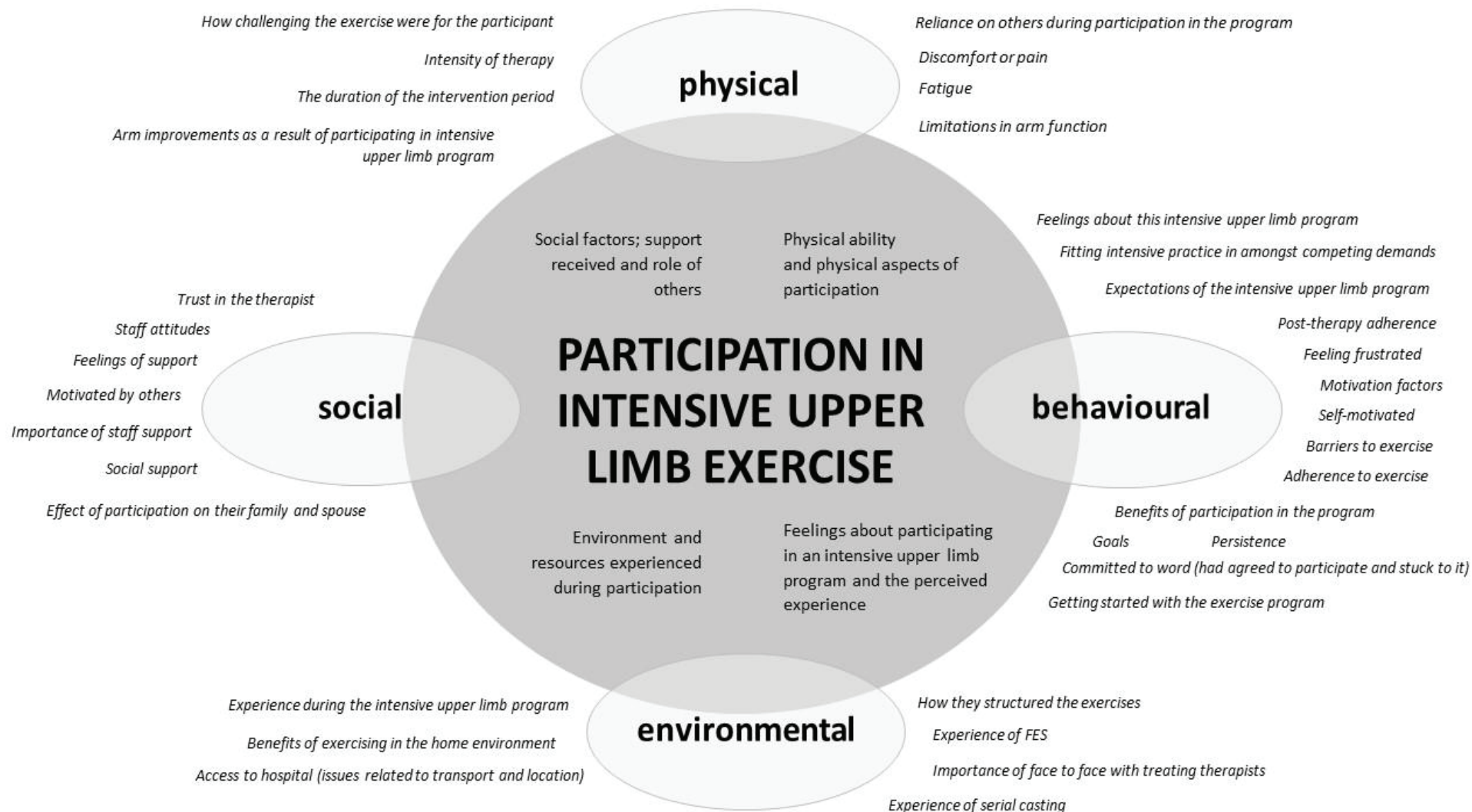


Figure 5-1 Experiences of participants, identified from the interviews



**Table 5-2 Barriers and enablers to participation in an intensive upper limb exercise program mapped to Theoretical Domains Framework domains and Capability, Opportunity, Motivation-Behaviour model**

<b>TDF</b>	<b>COM-B</b>	<b>THEMES – KEY BARRIERS</b>	<b>EXEMPLAR QUOTE</b>
<b>Physical skills</b> <i>An ability or proficiency acquired through practice</i>	<b>Capability-Physical</b> <i>Skills, abilities, or proficiencies acquired to perform the behaviour</i>	Challenging exercise	06: <i>a lot of the exercises were very difficult for me to do. There was a couple that I would skip because they were too hard</i>
		Discomfort or pain	04: <i>as soon as I feel pain, I would just stop</i>
		Reliance on others	14: <i>after I've tried it, the carers come along and amend where I've stuffed up.... I always need carers to help me to initiate them</i>
		Fatigue	14: <i>when I was really tired it was hard to get them all done....it was really a major problem</i>
<b>Beliefs in consequences</b> <i>Acceptance of the truth, reality, or validity about outcomes of a behaviour in each situation</i>	<b>Motivation-Reflective</b> <i>Self-conscious planning and beliefs about the behaviour</i>	Fitting it all in	06: <i>sometimes we didn't do 60 minutes because we were busy. We might have an appointment but often if we had to go out, I would try and do the exercises later</i>
<b>Emotion</b> <i>A complex reaction pattern, involving experiential, behavioural, and physiological elements, by which the individual attempts to deal with a personally significant matter or event</i>	<b>Motivation-Automatic</b> <i>Desires and impulses to perform the behaviour</i>	Feeling frustrated	13: <i>I get frustrated because I can't do it. And I know my hand won't do it, and I think well why I should do it</i>
<b>Environmental context and resources</b> <i>Any circumstance of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence, and adaptive behaviour</i>	<b>Opportunity-Physical</b> <i>Environmental context and resources to allow performance of the behaviour</i>	Access to hospital	01: <i>the hard thing was the visits to the hospital ... travelling to and from took a long time</i>

<b>TDF</b>	<b>COM-B</b>	<b>THEMES – KEY ENABLERS</b>	<b>EXEMPLAR QUOTE</b>
<b>Social influences</b> <i>Those interpersonal processes that can cause individuals to change their thoughts, feelings, or behaviours</i>	<b>Opportunity – social</b> <i>Social influences such as social pressure, norms, conformity, social comparisons</i>	Feelings of support	02: <i>the support was very positive; lots of guidance initially also, with exercises. I felt like I was able to get help when I needed it</i>
		Motivated by others	04: <i>the support is a positive thing. Even though you feel inside yourself, "I really can't do this," but they're saying, "You're right, you can do this" - it's easy to get down when you're by yourself sort of thing</i>
		Importance of social support	16: <i>if he wasn't around it would have been awful – he gave physical support but also enormous mental support'</i>
		Importance of therapy staff	14: <i>each week when we would rehash what we'd done, and where the improvements were, it was reaffirming</i>
		Trust in therapist	08: <i>as I said before, so whatever someone says to me I just do it. I didn't question it and I still don't question it even today because they know what they must do whereas me, I don't know</i>
<b>Social/professional identity</b> <i>A coherent set of behaviours and displayed personality qualities of an individual in a social or work setting</i>	<b>Motivation-Reflective</b> <i>Self-conscious planning and beliefs about the behaviour</i>	Accountability	14: <i>when you give your word for something, people are going to rely on you. You can't let people down</i>
		Motivation factors	11: <i>I wanted to be able to use my arm again. I was an avid golfer, so I wanted to get back to playing golf if I could. And so that was my motivation, or one of them. That was my main motivation</i>
		Attitude to exercise	04: <i>my attitude was, "Well, you've got to do this to - it's not going to get better by itself"</i>
		Self-motivated	06: <i>60 minutes was achievable because I am very determined and motivated</i>
<b>Environmental context/resources</b> <i>Any circumstance of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence, and</i>	<b>Opportunity-Physical</b> <i>Environmental context and resources to allow performance of the behaviour</i>	Benefits home environment	20: <i>being in the comfort of my own house I think, yeah that was a definite plus</i>

<i>adaptive behaviour</i>			
		How structured exercises	16: <i>I generally had brekkie first and have a bit of a clean-up and then get into it. Depending if we had anything on. You know, you'd squeeze it in to wherever</i>
		Benefits of face to face contact	14: <i>because you can go through the exercises with them and show them some positive results. Because somehow or another they seem to get more out of you and it's encouraging</i>
		Record of practice	01: <i>just every day I would write down what time I started and how many repetitions I was doing and just every day I would try and break my record</i>
<b>Reinforcement</b> <i>Increasing the probability of a response by arranging a dependant relationship, or contingency, between the response and a given stimulus</i>	<b>Motivation-Automatic</b> <i>Desires and impulses to perform the behaviour</i>	Committed to word	14: <i>I kept going because I signed up for 12 weeks. My word is my bond</i>
		Routine practice	04: <i>you just get into a routine and you just did it. Once you go through the - probably the first week or two would have been the hardest - but then you just did it. You did it at certain times - even did it for probably longer because you worked out - it took me one session to do half a book and if I didn't quite reach that, I kept going. No, you just get into the routine of it</i>
<b>Optimism</b> <i>The confidence that things will happen for the best or that desired goals will be attained</i>	<b>Motivation-Reflective</b> <i>Self-conscious planning and beliefs about the behaviour</i>	Feeling hopeful	06: <i>just that four letter word, hope. Probably more hoping for some recovery with my arm or hand</i>
<b>Goals</b> <i>Mental representations of outcomes or end states that an individual wants to achieve</i>	<b>Motivation-Reflective</b> <i>Self-conscious planning and beliefs about the behaviour</i>	Goals	14: <i>you've got to have goals. My goal now is to be able to use my arm to play the piano and to hold a cup with this left arm</i>
<b>Memory, attention, decision processes</b> <i>The ability to retain information, focus selectively on aspects of the environment and choose between two or more alternatives</i>	<b>Capability-psychological</b> <i>The capacity to engage in the necessary thought processes to perform the behaviour</i>	Persistence	14: <i>you're going to do better next time, you got to keep trying. If there was something I couldn't do, just a little bit, then you make a mental note of it so that when you do it next time, you try harder</i>

### 5.3.3.1 Barriers

#### Capability (COM-B component)

##### *Physical skills (TDF domain)*

In terms of “physical skills,” participants talked about the difficulties they had in performing some of the exercises. Despite this challenge, most participants would persist and continue to attempt the exercises. However, a small number of participants described that if the exercises were too hard they would move onto the next exercise or cease their practice.

*‘Some of the exercises were impossible to do...if I came across a hard exercise, I didn’t do it otherwise I would get frustrated sitting at the table. I tried and tried and tried and I just decided myself that was no good’ (participant 13)*

Participants described some feelings of guilt at having to rely on people to help with their exercises. This was predominantly in the form of physical assistance to set up the exercises or to transport the participant to the clinic visits. Subsequently, participants expressed concern about the strain being placed on their family members or carers during the program and described this in terms such as ‘guilt’ and ‘burden’.

*‘It was very hard for me because Brian wasn’t here all the time to help me do the exercises. It was difficult because I needed him to put the electrodes on each time. Also, he would push me to get them done’ (participant 14)*

Fatigue was identified as a barrier to adherence. Participants highlighted a relationship between exercise and fatigue and used terms such as ‘bombed’ and ‘exhausted’. For some, this was physical fatigue and for others a ‘brain fatigue’ from concentrating. Many participants described that if fatigue occurred, they would cease the exercises and rest.

*‘In the early days it was exhausting, and I would finish for a half an hour rest. There was one or two days early on that I wanted to collapse. It was usually tiredness that would make me stop exercising’ (participant 17)*

A few participants described some pain or discomfort which stopped them from adhering to the exercise program. At times, the pain was described as related to the content of the exercise program, however, some participants discussed pre-existing pain related to the stroke which may have restricted their participation.

*‘With his stroke, he gets headaches easy, so when he was concentrating for so long and so hard, we had to cut things short a couple of times, or a few times actually because of the headaches. But*

*that didn't stop us or deter him from wanting to participate in it' (carer, participant 09)*

## **Opportunity (COM-B component)**

### ***Environmental context and resources (TDF domain)***

Many participants described positive experiences relating to the visits to the clinic, however, some found access to the hospital to be a barrier. Most of the participants who described access to the hospital as a barrier were living more remotely and the travel into the clinic was time-consuming and for some, a potential burden on family members or carers.

*'When I had to attend the hospital on a regular basis, I thought this is a damn nuisance, I've got to go down there that often. It was very difficult to get transport down. But I pushed through it and we got there eventually' (participant 01)*

## **Motivation (COM-B component)**

### ***Beliefs in consequences (TDF domain)***

Fitting the hour of daily practice into an already full schedule was a significant challenge for many participants. Despite this challenge, several of these participants described working hard to achieve the recommended amount of practice i.e. one hour per day. The issue of timing of the program was raised, with some participants believing that they may have gained more benefit if the program had been available at a later stage in their recovery when they had fewer commitments. However, other participants believed they would have received greater benefits if this program had been available earlier in their post-stroke journey.

*'The thing that stopped me exercising on some days was I was busy - just family things like lunches, birthdays, but also appointments like doctors, physio, speech. Then I would maybe get to the exercises about half the time' (participant 07)*

### ***Emotion (TDF domain)***

The level of difficulty with the exercises led to significant feelings of frustration in some participants. Frustration was an emotion that was expressed by many participants who felt that they were exercising very hard but not making significant improvements in arm movement.

*'Some of them were very difficult, in fact almost impossible, for me to do and that frustrated the hell out of me. As time went on and the minimal improvement I was getting made it very frustrating. Then the motivation declined as the frustration increased' (participant 11)*

### **5.3.3.2 Enablers**

#### **Capability (COM-B component)**

##### ***Memory, attention, decision processes (TDF domain)***

Participants described being persistent with their exercise program despite facing various barriers. The participants discussed pushing themselves and continuing to try even when they found the exercises difficult, were tired, or were not experiencing improvements in arm function. Many participants expressed that they did not want to 'give up' and they kept up with the exercises even when they were aware that they were not improving.

*'I've seen patients in the past who have given up when they have had potential and it's really sad. And sometimes I would think that could be me and so I kept at it. I knew I can. I stuck at it. If there was something I couldn't do I would make a mental note of it so next time I would try harder'*  
(participant 14)

#### **Opportunity (COM-B component)**

##### ***Social influences (TDF domain)***

A common enabler to adherence discussed by participants was the feeling of support experienced during the exercise program. Participants described feeling that staff were readily available when they needed them and provided guidance and encouragement. This support was felt through follow up phone calls and face to face contact. Participants highlighted an important relationship between therapist support and ongoing adherence.

*'The support was great because if I have someone with me, I have got the motivation plus if I do something wrong, I have the feedback. Without the support it wouldn't have worked for me, it was the most important thing for me'* (participant 10)

*'Having an appointment with someone was really important. Knowing it was going to be a good experience even though it was hard work, having pleasant people around you who are trying to help'* (participant 11)

Participants also described having trust in the therapists and in the research process which further enabled adherence to the program. Many participants talked about the importance of believing that ongoing adherence may lead to the ultimate 'pay-off'.

*'In your head you are thinking this is pointless, but the therapist explained to me that it was helping and so I had faith and kept going for that reason'* (participant 12)

*'I would keep doing it because you have programmed it for 12 weeks, you must have done that for a reason. When you set up a program like this it takes months of planning so you must have picked 12 weeks for a reason' (participant 14)*

Social support was highlighted by many participants to be an important enabler to adherence. However, several participants discussed that tensions in relationships, such as differing views on how to execute the exercises, meant that their social support networks, such as family, could sometimes be a barrier to exercise adherence. For example, one participant described that he always exercised when his wife was at work because she became too impatient with him. Furthermore, in terms of motivation, some participants described being motivated by other people, namely the health professionals, family members, and carers. This was an important enabler, particularly for those participants who could not motivate themselves. Whereas some considered themselves to be self-motivated and driven, many participants described the benefits of having others to motivate them.

*'My daughter and wife were both there to 'nag' me and if they hadn't, I think I would have done less. I think it would be hard to do this sort of exercise if you lived alone' (participant 07)*

*'I needed the therapists because I live alone and there's no motivation. They reminded me that to learn you must follow up. I am the sort of person that if I don't feel the whip, I do what I want not what I am supposed to do' (participant 10)*

### ***Environmental context and resources (TDF domain)***

When discussing the 'environmental context' participants described the benefits of being able to exercise in their home environment. This included allowing the visiting health professional to make modifications to the exercise set-up, reducing the negative aspects of needing to access the hospital, being comfortable in the environment, and being able to manage fatigue.

*'It's easier to be at home if I'm really tired, or I've had a fall or something. When I did it at home, I didn't have all the tiring walking before I did the exercises and I could fit the exercise in when I had time' (participant 17)*

In terms of 'face to face' visits in the hospital with the treating health professionals, many participants identified this as an enabler to exercise adherence. This contact allowed the health professional to make modifications and progressions to the participants' exercises, provide motivation and encouragement, and provided participants with a positive experience through increased social contact.

*'The contact with the therapists was really important, it was a motivation because I had a time to keep. Later in the trial where there was less contact with staff I struggled with motivation. I think the energy improves because you've got somebody to drive you. We got along pretty well and had a laugh. They were so good' (participant 11)*

Several participants described structuring their exercise regime in an individualised manner to fit in with their lifestyle and to maximise their participation. For example, some participants found splitting the hour program into two halves useful, describing that this strategy allowed an opportunity for their body and brain to rest. Another participant explained that they always started with the easier exercises and progressed to the more challenging ones as a strategy.

*'I generally had breakfast and then got into it. Depending if we had anything on, I would squeeze it in wherever. I usually went back to the hard ones at the end. Sometimes I split it up because we had something else to do. Also breaking it up rested the brain a little bit' (participant 16)*

When discussing 'resources' many participants identified the 'record of practice' as an enabler. This allowed participants to keep track of their performance but also served as a motivator; one participant commented that he would reflect on his record and at times "felt embarrassed" that he hadn't ticked it.

*'The record helped because you look back and think, oh I did all that. I had it all written down so I knew where I'd finished up and could just go on from there. Keeping a record allowed me to see and feel the improvement – you've got to be motivated yourself' (participant 16)*

## **Motivation (COM-B component)**

### ***Social/professional identity (TDF domain)***

Maintaining a positive attitude to exercise was considered by many participants to be an enabler to adherence. Whilst many participants described being disappointed at not seeing the gains being made during the program, most continued to adhere fully and displayed a 'don't give up' or 'nothing to lose' attitude.

*'As I was preparing to exercise, I would feel I was going to work. It was very difficult but worthwhile if your mental state is good. If somebody is a positive person, it would be really good - you need a good head space. Just try and stay positive and try and keep doing it' (participant 11)*

Participants identified a range of external factors as possible motivators, such as exercising with music on or the television in the background. Furthermore, identifying a goal and having that in the back of their mind was suggested to be motivating.



*'If people aren't motivated, try music or something that takes your mind off what you're doing and something you really enjoy. I was working at the time and I couldn't do that fine movement up high so I just thought about that when I was exercising – this will make it easier and I will be able to do it' (participant 04)*

*'My mind just says keep going. I just make it part of my routine by myself, I just do it. I initiate things myself; I don't rely on Bob. It's easy, just get going' (participant 03)*

Feeling accountable to the health professionals was a significant enabler to adherence. Many participants felt that as they had agreed to participate, they were obligated to continue for the full duration and intensity of the program. Several participants commented that they did not want to let down the treating health professionals or researchers.

*'I didn't want to let you down and I thought "well you've got to do this - it's not going to get better by itself". If I didn't complete it, I would be letting myself down and you down as well. I couldn't skip it because I knew you were going to check up on me. The therapists are putting a lot of effort in' (participant 04)*

### **Reinforcement (TDF domain)**

The issue of committing to their word was identified by participants as a critical factor enabling adherence. Once participants had agreed to participate and signed a contract, they wanted to see the program through to the end.

*'I would keep going otherwise I would think I'd let people down by bothering to even start. I put my hand up to say, "I'm going to have a go". So, you make that commitment and you've got to do it. I was personally obligated to continue, and I wanted to finish what I set out to do' (participant 06)*

Furthermore, a common enabler was establishing a routine practice time.

*'It became part of my evening ritual I suppose. I did it at the same time every day and it became part of my routine. Once it became my routine, I just did this for the time, one hour each day. Then it's a lot easier' (participant 05)*

### **Optimism (TDF domain)**

Many participants considered feeling hopeful was an important enabler of adherence. Some expressed that they maintained a sense of hope throughout the exercise program, despite very little benefit being noted. Many of these participants believed this prevailing sense of hope reflected their underlying personality.

*'I just had a lot of hope for it, I just wanted to get my arm moving basically. It was more of a hope thing than an expectation. I was hoping to get movement back in my arm. I thought, oh man, wouldn't that be wonderful to be able to straighten those fingers' (participant 16)*

*'I think that's me. You can give up – lie down and everything runs over you, or you can get up and keep going' (participant 06)*

### **Goals (TDF domain)**

Setting clear and individualised goals was considered by many participants to be an enabler to adherence. Some goals were specific to improvements in movement whilst other participants identified goals related to an activity such as making soup and playing golf. Participants highlighted a relationship between setting goals and ongoing motivation.

*'My goal was that I could walk better and get my arm to sit down by my side. I would have this in the back of my mind when I was exercising' (participant 04)*

## **5.4 Discussion**

Stroke survivors who practiced a large amount over a 10-week period were able to share the barriers and enablers to adherence to intensive exercise. Their perspectives contribute to our understanding of both why and how people with stroke may adhere to intensive exercise programs, even in the absence of noticeable improvements in arm function. Participants described that their adherence was influenced by their physical experience of participation, social factors, their behavioural experience, and the environment. The structured nature of the training program and set practice times were important enablers to adherence for many participants. This finding was supported by the main trial results that suggest the protocol of home exercises supported by clinic-based sessions, home visits, telephone calls, an individualised manual, and training log is effective at supporting people to practice, at least within a trial (Lannin et al., 2020).

Social support from a carer, loved one or health professional was critical to enhance exercise adherence. Similarly, the role of 'family members/friends' in the delivery of exercises was highlighted in a qualitative study by Galvin and colleagues, who reported family members were under-utilised and willing to participate in the delivery of exercise programs (Galvin et al., 2011). When prescribing exercise programs, health professionals should consider how much support is available from others as well as how willing the support person is to assist, as both factors may influence adherence to the prescribed program. It is also important to consider who is providing support and what their capabilities and other commitments may be. For example, in this study, many of the older participants were being cared for by their spouse, whereas several of the

younger participants were relying on support from a parent or external care provider. In these circumstances, the carer may not have the time to provide support for exercise programs if they are balancing other work and family commitments. Furthermore, whilst social support was a key enabler to adherence, for several participants in this study it was described as a barrier as the carer relationships were not always positive. These findings are consistent with those of Clark and colleagues (Clark et al., 2015) who found that caregivers of stroke survivors, who were undertaking an arm rehabilitation program, reported some of the most challenging aspects of their carer role included “constantly pushing him” (p. 194) and “watching the stroke survivor deal with the frustration of trying to use his or her arm” (p. 192), with these elements then contributing to relationship conflict. On the other hand, carers reported the most positive elements of their carer role included “seeing improvement in arm movement” (p. 192) (Clark et al., 2015).

Considering the importance of social support as a positive influence on exercise adherence, intensive rehabilitation programs must consider and plan for the individual circumstances of the stroke survivor and carer when developing exercise programs. Programs must also ensure that adequate education and support is provided not only to the stroke survivor but to their carer as well so that the carer may be able to undertake the role of a support person. A recent feasibility study has suggested that provision of carer education on topics including communication, creating an autonomous, supportive environment, and problem-solving can support stroke survivor adherence to intensive upper limb retraining and reduce reported levels of family conflict (Blanton et al., 2019). Furthermore, Maclean and colleagues identified that patients who understood the nature and purpose of rehabilitation were more likely to be considered highly motivated (Maclean, Pound, Wolfe & Rudd, 2000). Hence, ensuring stroke survivors and their carers, who are participating in a home-based exercise program, are provided with education and information about their condition and exercise program is important and may enhance motivation.

Our findings also suggest that adherence to exercise may be enhanced by ongoing support through face to face contact with health professionals, with participants valuing positive interactions with the therapy team. Consistent with the findings of Signal and colleagues (Signal et al., 2016), participants within this study described valuing the health professionals’ clinical expertise, that health professionals motivated them, and that the health professionals believed in their capacity to improve. Participants discussed placing a great deal of trust and belief in the health professionals’ word. A significant relationship exists between positive patient-therapist relationships and improved physical outcomes (Adams, 2017), and a satisfactory patient-therapist relationship is an essential component of rehabilitation success (Peloquin, 1990).

Health professional engagement has been considered to influence patient engagement in rehabilitation (Bright et al., 2017). Health professional engagement is influenced by the health

professionals' knowledge, confidence, and perceptions of the patient's engagement (Bright et al., 2017). Within this current study, the cohort of stroke survivors received therapy from health professionals with experience in delivering evidence-based upper limb retraining to a stroke population. This level of experience may have had a positive influence on exercise adherence and contributed to the participants' high levels of engagement. Additionally, this positive relationship was a source of 'hope' for some participants. Bright and colleagues found that patients who had a positive relationship with their practitioner, despite some experiencing challenges with their therapy program and not seeing the purpose of therapy, tolerated and continued with therapy in the hope that they may see improvement (Bright et al., 2017). This is consistent with the findings within our current study and highlights the critical responsibility of health professionals to develop strong therapeutic relationships with clients and support patient engagement throughout their stroke recovery.

Stroke survivors have described looking for hope of functional recovery in the early phase post-stroke (one week) and needing information that is framed positively to help them maintain a positive outlook about their future (Visvanathan et al., 2019). Stroke survivors have also described how they may lose trust in health professionals if given information during the early stages post-stroke that is considered to be negative or discouraging (Visvanathan et al., 2019). Many stroke survivors remain hopeful of recovering their pre-stroke level of functioning six months or more after a stroke (Kulnik, Mohapatra, Gawned & Jones, 2018; Visvanathan et al., 2019), and describe how this hopeful outlook helps them stay determined. However, some also said that upon reflection they wished they had been given realistic information about their recovery early after their stroke to help prepare for their future. Whilst hope has been found to support motivation and engagement, there can be a challenge for health professionals when balancing providing realistic information, whilst maintaining hope, known as the 'hope-information paradox' (Lou, Carstensen, Jørgensen & Nielsen, 2017). Consistent with the findings of Kulnik and colleagues (Kulnik, Mohapatra, Gawned & Jones, 2018), our study highlights the powerful role that health professionals and researchers play in both providing hope and information. Whilst it is acknowledged that maintaining hope is linked to ongoing participation, health professionals need to find a balance, delivering information in a way that gives hope for a possible positive outcome, in a realistic way (Schutz et al., 2017).

Participants in the study who had a greater level of impairment, that is, they were unable to complete even gross upper limb movements, described the greatest challenges in exercise adherence. Understandably, these challenges included difficulty performing the exercises, increased physical and mental fatigue, increased frustration, and reduced levels of motivation. Post-stroke fatigue is common, with a recent cohort study of stroke survivors four to six weeks post-stroke finding that almost half (43%) reported clinically significant levels of fatigue (Drummond et al., 2017). Stroke survivors six months post-stroke have also described physical and mental

exertion as triggers for fatigue (Hawkins et al., 2017). Consistent with the findings of Hawkins and colleagues (Hawkins et al., 2017), the pacing of activities was a common strategy used by participants in this current study to ensure they met the recommended amount of practice each day. Future research should consider the impact of fatigue when designing the structure of intensive rehabilitation programs as well as the potential impact of fatigue on outcomes.

Participants in this study found the timing of the intensive exercise program to be both a barrier and an enabler. Current clinical guidelines recommend people with stroke commence therapy as soon as possible (Stroke Foundation, 2017c) and rehabilitation should be structured to provide as much practice as possible within the first six months after stroke (Emmerson, Harding & Taylor, 2019). However, in this study participants with more recent strokes were amongst those who discussed the greater difficulty in fitting in the amount of exercise prescribed as they still had other rehabilitation commitments and medical appointments. Therefore, the timing of intensive exercise programs in people following stroke should consider the evidence regarding recovery, but also the ability of the participants to commit to the intensity required and options for tailoring programs to meet the needs of individuals.

In this study, a common enabler to adherence was a sense of feeling accountable to the health professionals, in addition to participants being committed to their word. This finding gives support for the use of behavioural contracts and is supported by extensive evidence developed in the Constraint-Induced Movement Therapy (CIMT) literature. Behavioural contracts that form a component of an adherence-enhancing package during CIMT implementation have been described as promoting accountability for adhering to the protocol and have been associated with better outcomes for several months after CIMT (Morris, Taub & Mark, 2006; Takebayashi et al., 2013). During this study, motivational interviewing techniques were utilised during participants' clinic visits. Motivational interviewing is a specific talk-based therapy, originally developed to help people with addictions, which has become a technique utilised across a broad range of health fields, including stroke, to build patients' intrinsic motivation (Watkins et al., 2007). There has been evidence associating behavioural support (i.e. through motivational interviewing) with adherence to exercise programs in the falls population (Arkkukangas, Söderlund, Eriksson & Johansson, 2018). In the candidate's qualitative study, motivational interviewing principles were used to support self-efficacy and increase awareness of the importance of adhering to the recommended exercise program. Several key enablers identified can be linked to the use of motivational interviewing during the clinic visits, including feelings of support, being motivated by others, and the importance of the therapy staff.

This comprehensive analysis of the perceptions of why this group of stroke survivors undertook a large amount of independent practice provides unique insights into how physiotherapists and

occupational therapists could support intensive motor training. Deductive coding to the Theoretical Domains Framework and Capability Opportunity Motivation-Behaviour model adds strength to this study, allowing findings to be interpreted within a behaviour change theoretical framework. From the key findings, health professionals can develop strategies to increase adherence to intensive exercise programs in people with stroke. Encouraging the support of family members is recommended as a key strategy to increase adherence, however, personalising therapy programs may also be a method to improve adherence. Developing exercise programs that target these relevant barriers and enablers will maximise the amount of upper limb rehabilitation practice undertaken, and these findings should be considered when designing research trials and therapy protocols.

## **5.5 Strengths and limitations**

In terms of strengths, in this study we used validated, theoretically informed frameworks of behaviour change to both inform the development of the interview schedule, The Transtheoretical Model of Behaviour Change (Romain, Chevance, Caudroit & Bernard, 2016) and to guide data analysis, the Theoretical Domains Framework and the Capability Opportunity Motivation-Behaviour model of behaviour change (Michie, Van Stralen & West, 2011; Atkins et al., 2017).

A potential limitation of the study was that, due to limited resources (lack of funded interpreter services), this study excluded individuals who had insufficient conversational English skills to complete the interviews. This exclusion criterion may have reduced the candidate's capacity to report on the potential impact of language as a barrier or enabler to adherence to intensive exercise programs.

A limitation of this study was that participants had consented to the InTENSE trial, indicating a level of commitment to the intensive program and exercise protocol. It would be valuable to further explore these issues in stroke survivors who may have low adherence to exercise.

Whilst the selection processes for study participants may introduce a potential risk of bias, importantly we selected participants from multiple study sites that had demonstrated high levels of adherence to their intensive exercise programs, despite having significant upper limb impairment. Therefore, these findings provide important insights for health professionals on strategies that may support engagement and adherence, including for stroke survivors with very poor upper limb muscle strength and control.

## **5.6 Implications for future practice and research**

The findings from this study have implications for health professionals working with stroke survivors. Overall this study has identified factors that may impact the stroke survivors' adherence

to intensive upper limb exercise programs. This information adds knowledge to guide the development of exercise programs that take these potential barriers into account. Based on these findings, Chapter 7 of this thesis will use the Behaviour Change Wheel (Michie, Van Stralen & West, 2011) to develop strategies for addressing the key modifiable barriers that have been identified.

Many participants in this qualitative study described the important role that carer support played in enabling ongoing adherence to the intensive upper limb exercise program. Based on these findings, the next study moves on to explore how involving carers early in stroke rehabilitation may improve the stroke survivor and carers' understanding of the importance of, and participation in, ongoing exercise

## **CHAPTER 6 ENGAGING CARERS DURING THE INPATIENT REHABILITATION OF STROKE SURVIVORS: A PILOT IMPLEMENTATION STUDY**

This chapter answers Aim 2 of the thesis, “To explore barriers and enablers to exercise adherence in stroke survivors”. This chapter describes an implementation study and is presented with minor changes for thesis formatting from the submitted manuscript, ‘Development and facilitation of an exercise-based group for stroke survivors and their carers: the Carers Count group’ (under review, Disability and Rehabilitation).

Chapter 5 described a qualitative study that explored barriers and enablers to intensive upper limb home exercise programs in stroke survivors. Findings indicated that, for many stroke survivors, the level of social support provided may influence adherence to intensive upper limb home exercise programs. Whilst it is evident that carer involvement in rehabilitation following stroke can have positive effects, there is a lack of research exploring different approaches to achieving early engagement of carers. Hence, the candidate chose to conduct a pilot implementation study exploring the development, facilitation, and evaluation of the Carers Count group, an exercise-based group for stroke survivors and their carers.

As the lead author for the publication, the candidate’s contribution was 80% of this chapter. The candidate developed the research aims and methodology with the guidance of all supervisors. The candidate developed the study resources and conducted the intervention. The candidate conducted all participant interviews and supervisor KL assisted with the focus group and data analysis. All co-authors were involved in editing and proof-reading the manuscript.

### **6.1 Introduction**

There are significant barriers to delivering high doses of therapy in environments where resources are scarce (Kwakkel, 2006; Kaur, English & Hillier, 2012), thus health professionals may need to consider alternative methods of service delivery to augment the amount of practice undertaken by people with stroke. One method which has been proposed to increase the dose of therapy is involving carers in exercise training within the ward environment (Liu et al., 2016; Van Den Berg et al., 2016; Vloothuis et al., 2016). Carers have been defined as “the spouse or partner, family members, friends, or “significant others” who provide physical, practical, or emotional support to someone after their stroke” (p. 1852) (Luker et al., 2017).



The contribution of carers to post-stroke care is recognised worldwide. The majority (80%) of patients who survive the acute phase of stroke remain impaired physically or cognitively and need ongoing carer support (Pont et al., 2020). The role of the carer has been highlighted in early supported discharge and ambulatory rehabilitation models including rehabilitation at home, early hospital discharge, and increasing use of telerehabilitation (Lou et al., 2017; Laver et al., 2020). Because of the recognition of the key role of carers within long term stroke rehabilitation, clinical practice guidelines now recommend that carers are actively engaged in the process of rehabilitation from the outset (Stroke Foundation, 2017c). Despite this guideline recommendation, carers of stroke survivors report that they feel excluded from inpatient rehabilitation (Morris et al., 2015) and are underutilised within rehabilitation wards (Galvin, Cusack & Stokes, 2009).

A systematic review exploring carers of stroke survivors' experiences, needs, and preferences, recommended that rehabilitation programs should foster an inclusive environment to support and prepare carers for their new role post-discharge (Luker et al., 2017). Furthermore, this review reported that carers have a strong desire to be recognized as stakeholders in the stroke survivors' recovery and called for the development of systems to enable an active carer role. While there have been studies that have investigated carer-mediated exercise programs with inpatients (Vloothuis et al., 2019) and group programs with community-dwelling stroke survivors (Marsden et al., 2010), it remains unclear if delivering a group in an inpatient setting is feasible or beneficial.

Based on guideline recommendations that better patient outcomes can be achieved through increasing the amount of practice undertaken by people with stroke (Veerbeek et al., 2014; Schneider, Ada & Lannin, 2019) and including carers in rehabilitation (Vloothuis et al., 2019), a group program was developed and implemented. Many studies have reported challenges in the implementation of new programs within hospital settings, even when the intervention has a sound evidence base. Identifying factors that influence the implementation and sustainability of a new program is an important process (Luker et al., 2016). Therefore, the purpose of this study was to design and facilitate a new group, the Carers Count group, to promote the inclusion of carers within an exercise-based group and increase the amount of practice undertaken by people with stroke.

The study aims were to:

- (1) Develop and evaluate an exercise-based group for stroke survivors and their carers for delivery on a stroke rehabilitation ward,
- (2) use implementation strategies to embed the group within usual ward care, and
- (3) evaluate the outcomes of the intervention using implementation, service, and client outcomes.

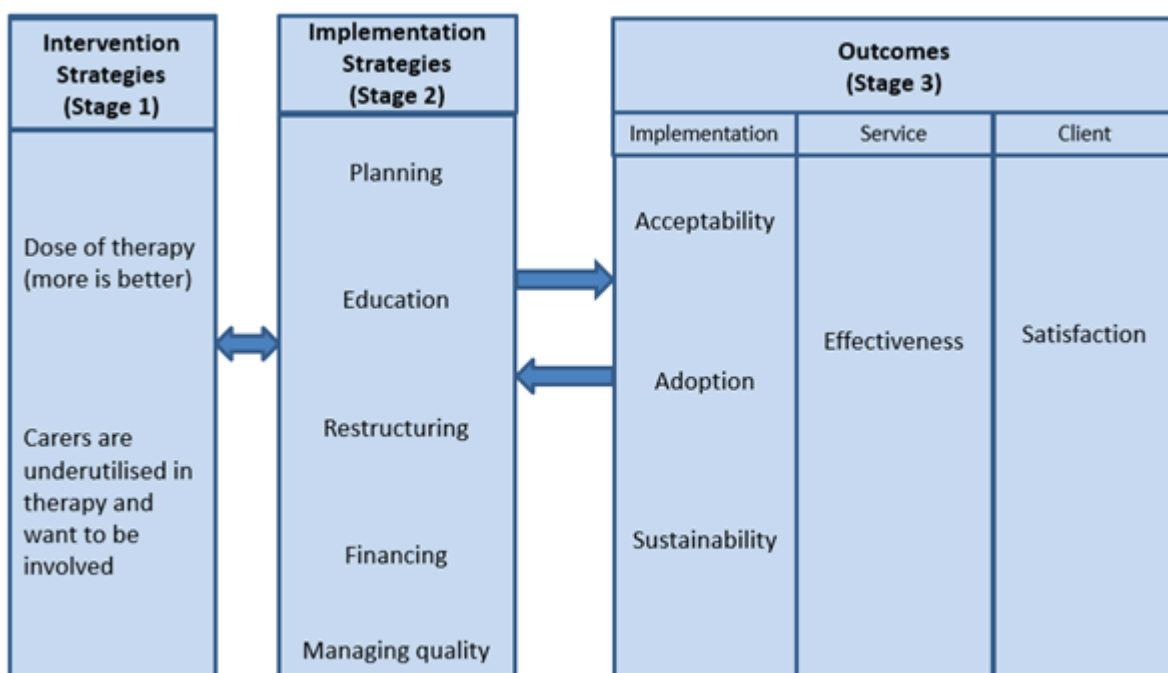
This study was conceptually guided by Proctor’s framework for implementation research (Proctor et al., 2009) which includes three main stages:

Stage 1) Development of the intervention: the selection of evidence-based practice.

Stage 2) Development of implementation strategies: the development of strategies to implement the intervention.

Stage 3) Program evaluation: outcome measurements which include implementation outcomes, service outcomes, and client outcomes.

Figure 6-1 displays our approach within this framework.



Model based on Proctor et al 2009 ; Implementation Research in Mental Health Services: an Emerging Science with Conceptual, Methodological, and Training challenges, *Adm Policy Ment Health*. 2009 January ; 36(1)

**Figure 6-1 Carers Count study; representation of stages of the study based on the Proctor framework**

Ethics approval for this study was provided by the Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC) (HREC/19/SAC/83).

## **6.2 Methods**

### **6.2.1 Stage 1: Development of the Intervention**

To develop the program, the evidence for carer involvement in stroke rehabilitation was examined, ranging from expert opinion and personal experiences through to systematic reviews (see Search strategy, Appendix 10).

The scoping of the literature identified four key findings, which were:

- Carers want to be involved in rehabilitation but are underutilised (Galvin, Cusack & Stokes, 2009; Luker et al., 2017)
- Some stroke survivors lack intrinsic motivation and engagement in rehabilitation can be low (Rapoliene, Endzelyte, Jaseviciene & Savickas, 2018; Kurniawati, Rihi & Wahyuni, 2020)
- A large proportion of stroke survivors rely on a carer following discharge from hospital (Hall, Crocker, Clarke & Forster, 2019; Kokorelias et al., 2020)
- Overall, there was a gap in the literature exploring inpatient rehabilitation interventions that actively involve carers.

After meeting with the allied health team to discuss these findings, a potential approach to involving carers in rehabilitation was identified. During this meeting, the researchers sought to develop the health professionals' perceptions of the carers' unmet needs and discussed the potential role of a group on the inpatient ward. In addition, a consumer representative, who was the spouse of a stroke survivor, was included in the planning to further explore current limitations in the involvement of carers on the inpatient ward.

#### ***6.2.1.1 Intervention objectives:***

The intervention development group (research team, allied health team, and consumer representative) agreed that the aims of the Carers Count group were:

1. To engage carers in the rehabilitation of the stroke survivor, and
2. To increase adherence to exercise of the stroke survivor, both during their inpatient stay and following this, when they were discharged from the hospital.

#### ***6.2.1.2 Eligibility:***

Stroke survivors were considered to be eligible for the Carers Count group if they had a predicted length of stay of greater than 10 days, had a carer who was able to participate in the group, and were English speaking (or had a carer who was able to translate). To ensure participants could

attend at least two sessions in total, this length of stay was considered an important inclusion criterion. The first 30 participants eligible for this study were included in the analysis. The stroke survivors and their carers provided written informed consent.

### **6.2.1.3 Intervention description:**

The Carers Count group was conducted three times per week on the inpatient stroke ward and components of the group included exercises (individually tailored and performed as a group), education regarding neuroplasticity including the viewing of an audio-visual resource, the use of coaching techniques, and music. There was a focus on engaging activities and having fun.

Further details outlining the Carers Count group are presented in Table 6-1.

**Table 6-1 Content of the Carers Count intervention**

<b>INTERVENTION ELEMENT</b>	<b>DESCRIPTION OF INTERVENTION</b>
<b>Purpose</b>	<ul style="list-style-type: none"> <li>• To engage carers early in rehabilitation, aiming to assist with the process of discharge and life after the hospital.</li> <li>• Intended to be a fun and engaging environment using music and games to enhance enjoyment.</li> <li>• To enhance the stroke survivor's understanding of the importance of practice for recovery.</li> </ul>
<b>Setting</b>	<ul style="list-style-type: none"> <li>• An inpatient stroke subacute rehabilitation ward.</li> <li>• A rehabilitation gym with all participants seated around the parallel bars. This enabled participants to exercise in sitting, to practice functional activities such as sit to stand, and to exercise safely in standing.</li> </ul>
<b>Frequency</b>	<ul style="list-style-type: none"> <li>• Three times per week (Monday, Wednesday, and Friday afternoons from 4-5 pm).</li> </ul>
<b>Personnel</b>	<ul style="list-style-type: none"> <li>• Two health professionals (including physiotherapists, occupational therapists, and allied health assistants).</li> <li>• Once per week, a music therapist attended.</li> </ul>
<b>Participants</b>	<ul style="list-style-type: none"> <li>• Minimum of two stroke survivors and their carers present (total, n=4). Maximum of seven stroke survivors and their carers (total, n=14).</li> </ul>
<b>Content</b>	<ul style="list-style-type: none"> <li>• Most exercises were completed with the health professionals leading and with the stroke survivors sitting in wheelchairs with their carer next to them.</li> <li>• Exercises included active and assisted arm and leg movements, as well as resisted exercises with the use of small dumbbells and TheraBand.</li> <li>• For those participants who were able to stand safely at the bars, there were some standing functional exercises including sit-to-stand practice, marching, and squats.</li> <li>• Each participant had an individually prescribed exercise program (designed by their treating physiotherapist) and at stages throughout the group they would perform these, with their carers support, under the supervision of the health professionals.</li> <li>• A music therapist was present for one session each week and on the other</li> </ul>

	<p>sessions, participants were asked to nominate their favourite songs which were included on a playlist. The music therapist who sang and played guitar, used rhythm and beat to engage the participants and had several small musical instruments that the participants could play.</p> <ul style="list-style-type: none"> <li>• Coaching techniques, developed from motivational interviewing principles, were utilised to enhance the active involvement and confidence of the carers.</li> </ul>
<b>Resources</b>	<ul style="list-style-type: none"> <li>• Ongoing reinforcement about the principles of neuroplasticity and the importance of practice in stroke rehabilitation. After each participants' initial session they were able to view a video resource about neuroplasticity.</li> <li>• All participants were provided with an exercise diary which they brought to each session. This book contained their individual exercise programs and provided them with further information about neuroplasticity principles and suggestions about ways to increase individual practice.</li> </ul>
<b>Key elements</b>	<ul style="list-style-type: none"> <li>• Music, exercises performed as a group and led by the health professionals, individually prescribed exercises with the carer participating as the coach, and information about the principles of neuroplasticity through viewing an educational video recording.</li> </ul>

## 6.2.2 Stage 2: Development of Implementation Strategies

The facilitation and evaluation of the Carers Count group commenced first with the selection of promising evidence-based strategies (Boyd, Powell, Endicott & Lewis, 2018) to enhance the sustainability of the program within the clinical setting (Kokorelias et al., 2020).

Implementation strategies were considered across five broad categories: planning, educating, financing, restructuring, and quality management (Powell et al., 2012). Table 6-2 highlights the categories and specific implementation strategies used to develop the Carers Count group intervention.

**Table 6-2 Implementation strategies and method of adoption**

<b>Implementation strategy category</b>	<b>Project methods</b>
<p><b>Planning</b></p> <p><i>Gather data, select strategies, build buy-in, initiate leadership, develop relationships</i></p>	<ul style="list-style-type: none"> <li>• Reviewed evidence to determine the gap in the literature; conducted a literature review and synthesised key themes.</li> <li>• Met with Ward Management team to assess readiness to implement the group and support; an initial meeting to outline the plan and a subsequent meeting to explain processes.</li> <li>• Held meetings targeted to team members and management, fortnightly throughout the study period.</li> <li>• Identified and prepared champions to help support the intervention.</li> <li>• Involved consumer representative in all phases of the planning and implementation, provided a key voice for the carers.</li> </ul>

	<ul style="list-style-type: none"> <li>• Tailored intervention to address potential barriers identified by the team at a focus group and fortnightly meetings.</li> <li>• Staged implementation scale-up by commencing with a small group for the initial week of the study period.</li> </ul>
<b>Educating</b>  <i>Inform stakeholders about the innovation</i>	<ul style="list-style-type: none"> <li>• Had health professionals shadow other health professionals with greater experience.</li> <li>• Conducted ongoing training of all staff participating in the group.</li> <li>• Used media (posters) to promote the group.</li> <li>• Prepared stroke survivors and carers to be active in their care and ask questions, through small group discussions at the end of the group.</li> <li>• Developed clear written document of procedures.</li> <li>• Distributed educational materials (posters and brochures).</li> <li>• Developed easy to use manuals and other supporting materials, involving consumer representative.</li> </ul>
<b>Restructuring</b>  <i>Altering staff, professional roles, physical structures, data systems</i>	<ul style="list-style-type: none"> <li>• Revised roles amongst professionals who could provide the intervention; specifically delegation of tasks to other team members.</li> <li>• Modified the records system to allow the collection of accurate data on the intervention; involved creating an acronym for easy identification of participation in Carers Count.</li> <li>• Updated participant timetables to incorporate the group.</li> </ul>
<b>Financing</b>  <i>Provide resources for training and support</i>	<ul style="list-style-type: none"> <li>• Applied for and received funding (Allied Health seeding grant) to support the development of resources.</li> </ul>
<b>Managing quality</b>  <i>Systems to evaluate and enhance the quality of care, ensure fidelity</i>	<ul style="list-style-type: none"> <li>• Developed tools for quality monitoring (surveys).</li> <li>• Sought participant/consumer feedback; informally during the group, via survey, and in follow-up interviews.</li> <li>• Provided health professionals with ongoing supervision.</li> </ul>
<b>Attending to the policy context</b>  <i>Clinical innovation through accredited bodies and systems</i>	<ul style="list-style-type: none"> <li>• Not applicable.</li> </ul>

### 6.2.3 Stage 3: Program evaluation

The **implementation outcomes** of acceptability, adoption, and sustainability (Boyd, Powell, Endicott & Lewis, 2018) were assessed using a focus group of participating staff members, surveys of stroke survivors and their carers, and a record of participant recruitment and attendance.

Effectiveness (**service outcome**) was evaluated by calculation of the time spent in physical rehabilitation on the group days compared to the non-group days.

Satisfaction (**client outcome**) was evaluated through interviews of the stroke survivors and their carers. Interviews were conducted face to face in the participants' place of residence, and were audio recorded and transcribed.

A detailed description of these methods of evaluation is presented in Table 6-3.

A summary of these three stages, activities and timelines incorporated, and personnel involved are presented in Table 6-4.

**Table 6-3 Study evaluation outcomes and methodology**

<b>OUTCOME AND RELEVANT STUDY ARM</b>	<b>SAMPLE SIZE</b>	<b>FOCUS</b>	<b>METHODOLOGY</b>
<b>ACCEPTABILITY AND SUSTAINABILITY</b>			
<i>Focus group</i>	7 health professionals (2 physiotherapists, 2 occupational therapists, 2 allied health assistants, and 1 nurse)	Questions probed perspectives about positive and negative aspects of the group, potential strategies to support sustainability, and potential barriers.	Held one month after the commencement of the group, we invited 10 staff to participate with the purpose of reviewing the progress of the group implementation. The focus group was facilitated by 2 researchers who used probing questions to provide the depth of content. The focus group was audio-recorded and transcribed, and the lead researcher read the transcripts multiple times and conducted a topical analysis of the content.
<i>Surveys</i>	30 stroke survivors and 30 carers	Questions explored benefits of attending the group, satisfaction with the support received, and the amount of burden experienced.	Surveys were filled out at the completion of the participants final group session.
<b>ADOPTION</b>			
<i>Patient flow and attendance</i>	Not applicable	Information on eligibility, consent, and attendance was collected.	Data were collected by the researchers including the number of sessions attended and reasons for non-attendance. The researcher collected additional data including the total number of admissions to the ward, the total number of eligible stroke survivors, reasons for non-eligibility, number consented, reasons for non-consent, and the number of withdrawals.
<b>EFFECTIVENESS</b>			
<i>Dosage</i>	Not applicable	Information on the dose of therapy (time spent in physical	Data were extracted from the electronic medical records which contain individually entered clinical times, and all document durations that had been supervised by a physiotherapist on the day of record, including 1:1 physiotherapy sessions,



		therapy) was collected.	hydrotherapy, and the technology/robotics gym, were added together. Demographic data to describe participants and understand additional factors that may have affected participation was collected from the electronic medical records. The demographic data included age, carer age, and date of stroke.
<b>SATISFACTION</b>			
<b><i>Interviews</i></b>	18 stroke survivors and their carers	Questions probed perspectives about positive and negative aspects of the group, suggestions for change	<p>Semi-structured interviews with a sample of participants (the first 18 participants discharged from the ward) were performed by the same researcher. An interview schedule was informed by the Transtheoretical Model of Behaviour Change (Romain, Horwath &amp; Bernard, 2018) to explore experiences of participation in the group and feelings about their experiences since discharge. The Transtheoretical Model of Behaviour Change assesses an individual's readiness to act on a new behaviour and is composed of constructs such as stages of change, processes of change, and self-efficacy. Questions included the following.</p> <ul style="list-style-type: none"> <li>• <i>How did attending the group help your understanding of the importance of ongoing exercise after stroke?</i></li> <li>• <i>Did you receive benefits from having your carer attend the group with you, and if so, what were they?</i></li> <li>• <i>What barriers did you experience that impacted on your participation in the group?</i></li> </ul> <p>All interviews were conducted with the stroke survivor and carer together and were predominantly completed face to face (16/18). The interviews took approximately 30 minutes to complete. The interviews were audio-recorded and transcribed. TL read all transcripts multiple times to achieve familiarity with the data. The data was analysed in two steps. In step 1, TL analysed the transcripts and generated significant codes. In step 2, TL reviewed the codes with another key investigator (KL) and codes were grouped into categories. The presence of these categories was systematically checked across each of the transcripts.</p>

Table 6-4 Stages of Carers Count, activities, timelines and personnel

Month number

	1	2	3	4	5	6	7	8	9	10
<b>Proctor Stage 1 = Intervention strategies</b>										
<i>Activity:</i> literature search and analysis <i>Stakeholders:</i> research team	√									
<i>Activity:</i> met with consumer representative to determine carer needs <i>Stakeholders:</i> research team, consumer representative		√								
<i>Activity:</i> met with allied health team and ward management committee to determine unmet needs <i>Stakeholders:</i> research team, allied health team, ward management committee		√								
<i>Activity:</i> implementation of the intervention (Carers Count) <i>Stakeholders:</i> research team, allied health team, patients, and carers				√	√	√	√	√	√	
<b>Proctor Stage 2 = Implementation strategies</b>										
<i>Activity:</i> planning of processes for implementation <i>Stakeholders:</i> research team		√	√							
<i>Activity:</i> developed assessment tools, including surveys and focus group guide, then applied for ethics <i>Stakeholders:</i> research team	√	√	√							
<i>Activity:</i> application for funding for resource development <i>Stakeholders:</i> research team	√									
<i>Activity:</i> development of resources, including outline of procedures, education materials <i>Stakeholders:</i> research team		√	√							
<i>Activity:</i> met with allied health team including music therapist to discuss goals, processes and format <i>Stakeholders:</i> research team, music therapist		√								
<i>Activity:</i> distributed posters and pamphlets to the ward <i>Stakeholders:</i> research team			√							
<i>Activity:</i> met ward management committee to outline processes <i>Stakeholders:</i> research team, ward management committee			√							
<i>Activity:</i> met consumer representative to outline final processes and resources <i>Stakeholders:</i> research team, consumer representative			√							
<i>Activity:</i> identified 2 champions within allied health team, to help support the intervention <i>Stakeholders:</i> research team, allied health team			√							
<i>Activity:</i> training and ongoing support of staff <i>Stakeholders:</i> research team, allied health team			√	√	√	√	√	√		
<i>Activity:</i> fortnightly meetings to monitor progress and modify as required <i>Stakeholders:</i> research team, allied health team				√	√	√	√	√	√	
<b>Proctor Stage 3 = Outcomes</b>										
<i>Activity:</i> patient and carer surveys on discharge <i>Stakeholders:</i> research team, patients and carers				√	√	√	√	√	√	√
<i>Activity:</i> weekly collection of recruitment, eligibility, and attendance data <i>Stakeholders:</i> research team				√	√	√	√	√	√	
<i>Activity:</i> focus group <i>Stakeholders:</i> research team, allied health team					√					
<i>Activity:</i> follow-up interviews, one month after discharge <i>Stakeholders:</i> research team, patients, and carers					√	√	√	√	√	√

## 6.3 Results

### 6.3.1 Participant characteristics

The 30 stroke survivors who attended this group, between October 2019 and March 2020, were aged 60-98 years with an average age of 77. There were 22 (73%) male stroke survivors.

The 30 carers recruited were aged 48-80 with a mean age of 66 years. Seventy percent of carers attending were the spouses of the stroke survivor. Additionally, some stroke survivors' children attended as carers (27%) and one participant had a close friend attend.

### 6.3.2 Outcomes

#### 6.3.2.1 Implementation outcomes (measuring acceptability, sustainability, and adoption)

##### 6.3.2.1.1 Focus group

Staff were very positive about the group, especially the fun and engaging nature of it, and felt it raised morale on the unit. This was expressed in terms such as *“everyone’s in such a good mood just knowing that the carers and the patients are having fun and that’s fulfilling from a staff perspective as well”*.

Staff felt involvement of carers in the group would help the stroke survivor transition back into the community and it would give carers more confidence and awareness of how to communicate and help in terms of care and exercises. For example, one participant described that attending the group would enable carers to *“increase their confidence and competence in providing care; if they have increased confidence in managing at the beginning, then the chances are they more able to maintain their caregiving.”*

The staff could see great benefits in the peer support element of the group, both for the stroke survivors to motivate each other and for the carers to support each other. It was reported that *“carers support each other, on that emotional level”*.

Some staff were concerned that attending the group may be a burden for some carers as they were experiencing a lot of other stressors and *“had enough on their plate”*. There was also concern that carers of the more impaired stroke survivors may find it difficult as they would compare their family member to others who were making better progress.

##### 6.3.2.1.2 Surveys

All participants (stroke survivors and carers) in the group completed the survey. Responses are outlined in Table 6-5. Overall, the feedback was positive. All stroke survivors (100%) were aware of

the benefits of attending the group, were satisfied with the support given by the staff, and felt they benefited from the interaction with other participants. Additionally, they all believed the group gave their carer more confidence in how to support them following discharge.

**Table 6-5 Survey responses, stroke survivors and carers (n=60), expressed as n (%)**

	<b>Strongly agree</b>	<b>Agree</b>	<b>Neutral</b>	<b>Disagree</b>	<b>Strongly disagree</b>
<b>I am aware of the benefits of attending the group for myself and my family member</b>					
Patient	13 (43%)	17 (57%)			
Carer	22 (73%)	8 (27%)			
<b>I am satisfied with the amount of support given by the staff member present</b>					
Patient	22 (73%)	8 (27%)			
Carer	20 (67%)	10 (33%)			
<b>I believe attending the group has given me/my carer more understanding of my family member's/ability</b>					
Patient	12 (40%)	18 (60%)			
Carer	13 (43%)	17 (57%)			
<b>I believe attending the group has given me/my carer more confidence in how to support my family member/me when we leave hospital</b>					
Patient	9 (30%)	17 (56%)	4 (14%)		
Carer	14 (46%)	12 (40%)	4 (14%)		
<b>I believe that one benefit of the group is the socialisation aspect</b>					
Patient	15 (50%)	10 (33%)	5 (17%)		
Carer	21 (70%)	9 (30%)			
<b>I found attending the group added to the level of stress I was dealing with at the time</b>					
Patient				6 (20%)	24 (80%)
Carer				10 (33%)	20 (67%)

### 6.3.2.1.3 Participant recruitment and attendance

A detailed record of ward admissions, eligibility, and consent was kept throughout the study.

Across the 30 participants a total of 37 groups were missed. Participants attended an average of eight (range, 2-22) groups each. Participants missed an average of 1.2 groups each (range, 0-6), with 19 participants attending all groups held during their admission. Participant flow is presented in Figure 6-2.

In addition, adherence was recorded by maintaining a logbook throughout the study. The most frequent reasons for non-attendance were the carer being unavailable (28%) and the stroke

survivor being unwell (22%). Other reasons were fatigue (14%), conflicting appointments (10%), refusal due to a lack of motivation (8%), low mood of the stroke survivor (8%), and miscellaneous reasons, such as having visitors (10%).

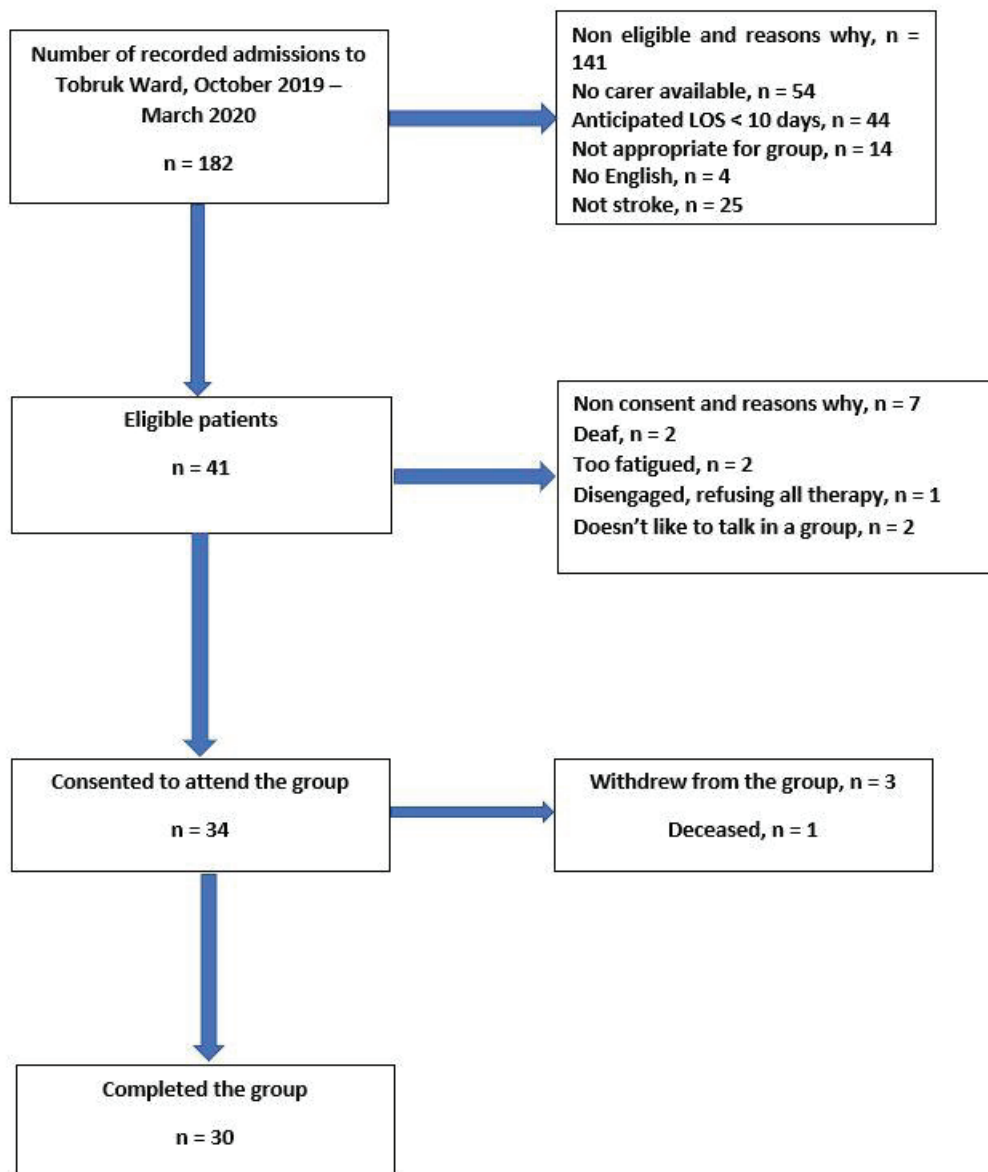


Figure 6-2 Participant flow through the study

### 6.3.2.2 Service outcomes

The amount of time spent in physiotherapy supervised sessions was calculated for each participant. Overall, the mean time spent in physiotherapy supervised sessions on group days was 95 (60-140) minutes and on non-group days was 59 (30-105) minutes. A paired t-test revealed a significant difference between dosage on group days and non-group days ( $p < .001$ ).

### 6.3.2.3 Client outcomes

A total of four categories were generated from the interview data. These categories were 'something to look forward to', 'we were in it together', 'not so isolated', and 'perceived benefits'. Exemplar quotes illustrating these themes are presented in Table 6-6.

**Table 6-6 Themes and quotes from participant and carer interviews**

Main theme	Exemplar quotes
<b>Something to look forward to (overall experience of participation)</b>	
	<i>"it was very positive; it was great seeing others in the same boat and it was fun. It had a lightness to it and a few laughs"</i>
	<i>"you're in this dark hole and you don't know what the future is and then you go to this group which was all light and happy"</i>
<b>We were in it together (shared experience with family members)</b>	
	<i>"it's great to have the family involved, to make the person aware what's happening to the other person"</i>
	<i>"I felt as though I'm not in it on my own, another part of my family is there with me"</i>
<b>Not so isolated (shared experiences with other participants)</b>	
	<i>"You didn't feel so alone. Because you realised there were other people who were in your situation. Other wives that were supporting their husbands who had problems. I just thought that it just brought you a certain, it just brought you some comfort to know that you weren't alone"</i>
	<i>"it was really good to see Bob with other people who were the same as him, encouraging him, they said "oh you're doing so well"</i>
	<i>"you're a social person, you like to be with people .... just being with other people would encourage mum to keep going"</i>
<b>Perceived benefits</b>	
	<i>"when they get home the carer knows what they're capable of doing and what they should be doing and can work on that and improve it"</i>
	<i>"it's important to understand that every little bit helps and doing it regularly, you know you can sort of see the light at the end of the tunnel"</i>
	<i>"In the group I was doing a little bit more of the prompting and so that's really helped since I've come home, because I now know how to do that a bit more without being so blunt, as she keeps telling me I keep telling her what to do"</i>

## 6.4 Discussion

Using a staged approach to intervention development (Proctor et al., 2009), an exercise-based group program for inpatient stroke survivors and their carers was developed and facilitated on the inpatient ward. Including the carers was associated with an increase in the amount of time spent participating in physical exercise. The evaluation showed the importance of providing an engaging environment for participants, enabling increased opportunity for physical exercise and dose of therapy, and providing support and education for people with stroke and their carers. These

findings may assist other services to promote carer involvement with an exercise-based group, which may, in turn, increase the amount of practice undertaken by people with stroke. Importantly, there was no carer burden or adverse events reported amongst our participants.

Studies that simultaneously evaluate a clinical intervention and implementation strategies have been promoted as allowing more rapid translation of research into practice (Curran et al., 2012; Kemp, Wagenaar & Haroz, 2019). Curran and colleagues (Curran et al., 2012) identified recommended conditions for using this type of design, including circumstances when minimal risk is associated with the clinical and implementation strategies, and in situations where the intervention and/or implementation strategy to be tested are not complex in terms of organisational changes necessary to support it. The implementation effectiveness study design chosen allowed co-design and pragmatic testing of a new approach on an inpatient ward. It provided valuable information on which aspects of the program were likely to be sustained.

Within this study, we used a range of intervention strategies that were classified under five of the categories proposed by Powell and colleagues (Powell et al., 2012): planning, educating, restructuring, financing, and managing quality. This 'multifaceted approach' is supported by findings of a recent systematic review exploring the effectiveness of implementation strategies for promoting evidence-informed interventions in allied healthcare. This review concluded that multifaceted interventions, including the use of opinion leaders, follow-up education, and educational meetings are the most effective in implementing evidence-based recommendations (Goorts, Dizon & Milanese, 2020).

It has been reported that a critical component of implementation studies is attention to implementation outcomes (Proctor et al., 2011), and using some of the key implementation outcomes identified in the Proctor model (acceptability, sustainability, and adoption) has given strength to this study evaluation (Farrell, Norton, Adsul & Hursting, 2019). Acceptability and sustainability were assessed through surveys and a focus group, and findings of both were positive, suggesting a favourable effect of the chosen implementation strategies on the implementation outcomes.

An important finding of this study was the limited number of people who were eligible for the approach, with only 22.5% of stroke survivors admitted to the ward being eligible to participate. The main reasons for non-eligibility were lack of carer availability (38%) and a predicted length of stay of fewer than 10 days (31%). In this study, to ensure participants could attend at least two sessions in total, length of stay was considered an important inclusion criterion. However, offering the group to participants irrespective of their predicted length of stay (i.e. including less than 10 days) would enable a greater number of participants. Throughout this study, there was a high

number of sessions (n=37) that were missed by participants. Fifty percent of non-attendance was either due to the carer being unavailable or the stroke survivor being unwell. In this study cohort, 70% of the carers participating were spouses of stroke survivors. However, out of the 10 sessions not attended due to carer unavailability, seven of these occurred when the carer role was taken by the child of the stroke survivors. It may be that the children of the stroke survivors had other demands on their time such as caring for small children and employment. Hence, when planning interventions that involve carers, health professionals should consider both the availability and relationship of the carers as this may impact the level of engagement and attendance.

An evidence-based intervention is a health-focused intervention, practice, policy, or guideline with evidence demonstrating its capacity to change a health-related behaviour (Chambers, Vinson & Norton, 2018). As a component of the effectiveness of the intervention (service evaluation), this study has shown that participation in the group led to increased dosage of physiotherapy supervised time. National clinical guidelines recommend providing as much scheduled therapy as possible to stroke survivors (Stroke Foundation, 2017c), however, it is extensively reported that recommendations are not being met (Janssen et al., 2014). Additional therapy provided using current approaches is expensive and many health services are at capacity in terms of therapy provision. In this current study, the staff:participant ratio was approximately 2:4 and participants received on average an extra 50 minutes of therapy, three times per week. Two staff were necessary to ensure the safety of participants during standing activities and to support carers during the facilitation of individual exercises. The capacity to provide an increase in therapy time with this staff to patient ratio suggests this group intervention may be an efficient method of therapy delivery, however, it must be acknowledged that some health services will not have access to this staffing ratio. It is important to consider resource-efficient methods to augment the intensity of rehabilitation, and this study has demonstrated that involving carers in an exercise group is one potential method of achieving this target.

In the current study, client outcomes, reported through interview responses, were extremely positive. The group was described as fun and uplifting, and many participants emphasised the important role that the social aspect and music played in this experience. The importance of the social aspect of rehabilitation has been explored as a major source of motivation (Borghese et al., 2013). Similar to the Carers Count study, positive patient experiences and learning 'to smile a lot more' by being with other stroke survivors were reported by stroke survivors participating in group art therapy (Beesley et al., 2011). Another study that explored the impact of an arts-based therapy program on an inpatient ward (Higgins, Mckeivitt & Wolfe, 2005) produced some findings which were similar to our study. The authors reported some stroke survivors found the program to be a relaxing contrast to the demands of rehabilitation and several stroke survivors suggested the focus



being on 'entertainment' rather than disability allowed them to 'be themselves'. Music was a central element of the Carers Count group and was emphasised by many participants as being integral to the experience. There is extensive research exploring the benefits that music can have in stroke rehabilitation. Music therapy has been described as a medium in which to engage stroke survivors positively and has been associated with improved mood and cognition (Kershaw, 2019), arm function, speech, gait, and social interactions (Street et al., 2020).

Whilst including carers in the rehabilitation of stroke survivors is recommended in stroke guidelines, the issue of carer burden needs consideration. A study by Ilse and colleagues explored carer strain at two, four, and six months post-stroke (Ilse et al., 2008). In this study (Ilse et al., 2008), at two months, most patients were still in the rehabilitation environment and 28% of carers were assessed as being under strain. In contrast to this, several studies that have assessed the strain of carers involved in carer-assisted programs have reported a reduction in stress with involvement in the programs delivered (Carr & Sheperd, 1987; Geyh et al., 2004). In our focus group, an issue of concern identified by staff members was the potential carer burden, however, this was not identified through carer surveys or interview responses. Whilst the participants in this study did not report carer burden, it is important to note that the main reason for non-eligibility in this study and non-attendance of eligible participants was a lack of carer availability. Thus, it may be that carers of participants who were considered non-eligible for this study (due to carer unavailability), had a higher degree of carer burden.

This study reported positive findings across implementation, service, and client outcomes. This is in contrast to other studies that have reported that the implementation of new programs within hospital settings is difficult, even when the intervention has a sound evidence base (Nordin, 2019). Several factors have been identified that may specifically challenge the successful implementation of physical activity programs into rehabilitation, including the multidisciplinary setting, the heterogeneous population, and changes at a professional and institutional level (Hoekstra et al., 2014). Barriers identified in implementing a new intervention in a hospital setting include a lack of established interdisciplinary team, inadequate staffing levels, and the implementation environment, described as being the "fast-paced, high acuity, discharge driven culture" of acute hospitals (p. 5) (Luker et al., 2016). This contrasts with the intervention in the current study which, for a sample of inpatient stroke survivors, was implemented successfully in a stable multidisciplinary team within a supportive rehabilitation environment.

## **6.5 Strengths and limitations**

A strength of this study is that the candidate used an evidence-based implementation framework in the design, implementation, and evaluation of the Carers Count group. In addition, a co-design

approach was incorporated as a consumer representative was involved in the development of the Carers Count group.

This was a pragmatic study performed on a ward with limited resources and there are some limitations. Whilst a consumer representative was involved in the development stage of the Carers Count group, the program was largely designed by staff. While a co-design process with health professionals, carers, and stroke survivors would have been ideal, engaging the health professionals in a new approach to therapy delivery was the focus.

Whilst an objective of the study and focus of the follow-up interviews was to increase adherence to exercise of the stroke survivor, adherence was explored in participant interviews and no direct measure of adherence was included in the evaluation. As no direct measure of adherence was included, limited conclusions could be drawn on the impact of the approach on exercise adherence. Furthermore, allied health team members conducting the group received training and ongoing supervision from the research team and 'champions', however, there was not a formal assessment process of the fidelity of the intervention session over time.

A large number of stroke survivors admitted to the inpatient ward during the study period were considered ineligible as they did not have a carer available or a carer who was willing to participate. Whilst interviews were conducted at one-month post-discharge, further follow-up data was not collected, hence no conclusions could be made regarding the long-term benefits of attending the group.

Whilst a significant difference in the total time spent in physical rehabilitation on group versus non-group days was reported, this measure does not account for additional factors that may impact participation in physical rehabilitation (for example fatigue and the need for a 'day off'). Furthermore, due to the male-dominated sample in this study (over 70%), a larger, controlled trial would be required to enable the generalisability of findings.

There is potential for bias in this study as follow-up interviews were conducted with the stroke survivor and carer together; this may have impacted the responses given to questions such as reported carer burden.

Exploring sustainability through consideration of adaptations including addition, deletion, expansion, reduction, or substitution of various intervention components (Rabin et al., 2008) would be an area for further investigation. Whilst the authors were initially unable to assess long-term sustainability due to restrictions placed on the group during the Covid-19 pandemic, a strength of this study is that, following a lifting of Covid-19 restrictions and further team meetings and review, the Carers Count group has sustained with minor modifications and is currently embedded within

normal practice on an inpatient stroke rehabilitation ward.

## **6.6 Implications for future practice and research**

Our evaluation demonstrated that it is possible to develop novel modes of delivery that include the carers of stroke survivors within the inpatient hospital environment. In this study, the use of multifaceted implementation strategies produced a favourable effect on implementation outcomes, including acceptability and adoption. Furthermore, the intervention that was implemented, the Carers Count group was described as an engaging experience and provided positive outcomes in terms of increased dose of therapy and client satisfaction.

The Carers Count group has demonstrated that the carers of some stroke survivors are willing to be involved in early post-stroke rehabilitation. Participants in the study indicated that they had a greater understanding of recovery following stroke and the need for ongoing adherence to prescribed home exercise programs. Health professionals should assess the capability and willingness of the individual carers to be involved and develop programs that enable as much carer participation as possible.

This thesis has explored barriers, including lack of social support, to stroke survivors' participation in intensive home-based exercise programs. To enable a practical application of these research findings, in the next chapter the candidate aimed to identify appropriate behaviour change strategies and inform the development of a guide for health professionals to improve adherence to home-based exercise programs in stroke survivors.

# **CHAPTER 7 USING A BEHAVIOUR CHANGE MODEL TO DEVELOP A GUIDE FOR HEALTH PROFESSIONALS TO USE WHEN PRESCRIBING EXERCISES FOR STROKE SURVIVORS**

This chapter addresses Aim 3 of this thesis, “To identify appropriate behaviour change strategies and inform the development of an intervention/approach to improve adherence to home-based exercise programs in stroke survivors”.

Throughout this thesis, the candidate has investigated factors that influence adherence to intensive exercise programs in stroke survivors. In Chapter 5 the candidate used the Capability, Opportunity, Motivation-Behaviour model (COM-B) to understand and categorise themes influencing adherence to intensive exercise programs. In this chapter the candidate chose to use the COM-B model and the Behaviour Change Wheel to develop a guide for health professionals to use when prescribing exercise programs for stroke survivors, aiming to maximise adherence.

As the main author developing this guide, the candidate’s contribution was 90% of this chapter. The candidate developed the research aim and methodology with the guidance of all supervisors. The candidate synthesised findings from Chapter 5 with the assistance of supervisor KL. The candidate worked with a graphic artist to develop the final infographic. All co-authors were involved in editing and proof-reading the guide.

## **7.1 Background and Purpose**

Evidence suggests that a positive relationship exists between the dose of therapy provided and motor recovery after stroke, meaning that health professionals should try and provide as much therapy as possible (Veerbeek et al., 2014; Schneider, Lannin, Ada & Schmidt, 2016). Home-based exercise programs enable therapy to occur beyond inpatient rehabilitation (Coupar et al., 2012a; Brown et al., 2015), and self-managed home exercise programs are frequently prescribed by physiotherapists working with stroke survivors. When prescribing home exercise programs, health professionals should consider potential barriers to participants’ adherence. A systematic review reported that self-motivation, self-efficacy, previous adherence behaviour, and social support are relatively strongly associated with adherence to home-based therapies (Essery, Geraghty, Kirby & Yardley, 2017). The authors recommended that prior assessment of these domains is undertaken to identify potential barriers to adherence.

There is an acknowledgment that theory should be used to inform intervention and using a theoretical approach to exercise prescription may provide a unique way of tailoring a home program to each stroke survivor, to maximise adherence (Marley, 2017). However, health

professionals have reported that they have limited knowledge of behaviour change theories, and this has been confirmed in systematic review evidence (Alexanders, Anderson & Henderson, 2015). This systematic review included four studies in which health professionals believed they received insufficient psychological training (including in communication skills and 'theories') during their undergraduate degree and were welcoming of further training (Alexanders, Anderson & Henderson, 2015). An increased understanding of behaviour change theories "can help health professionals tailor their interventions appropriately and therefore potentially provide outcomes that are more effective" (p. 1007) (Hartley, 2019).

Based on the evidence that adherence to exercise is challenging for many stroke survivors (Marley, 2017), and that, despite evidence of their effectiveness, many health professionals lack knowledge in the application of behaviour change models (Alexanders, Anderson & Henderson, 2015), this chapter aims to outline the process of using a behaviour change model to develop a unique guide that is specifically designed for health professionals working with stroke survivors.

## **7.2 Position and Rationale**

### **7.2.1 The Behaviour Change Wheel and Capability, Opportunity, Motivation-Behaviour model**

The Behaviour Change Wheel, developed in 2011 by Michie and colleagues (Michie, Van Stralen & West, 2011), provides a comprehensive framework as it incorporates elements of 19 behaviour change frameworks from a systematic review into an overarching model of behaviour. At its hub, the Behaviour Change Wheel identifies capability, opportunity, and motivation (the Capability, Opportunity, Motivation-Behaviour model) as the main components interacting to drive behaviour. The Capability, Opportunity, Motivation-Behaviour model has been identified as an ideal model when describing adherence to health behaviours and has been recommended as a guide for adherence researchers and health professionals involved in the care of non-adherent patients (Jackson, Eliasson, Barber & Weinman, 2014).

The Behaviour Change Wheel was developed to aid intervention design and improve the process of intervention evaluation (Michie, Atkins & West, 2014). There are three main stages to consider when using the Behaviour Change Wheel for guiding intervention design: (1) understand the behaviour; (2) identify intervention options; and (3) identify content and implementation options (Atkins & Michie, 2015). These stages and how they relate to adherence are illustrated in Figure 7-1.

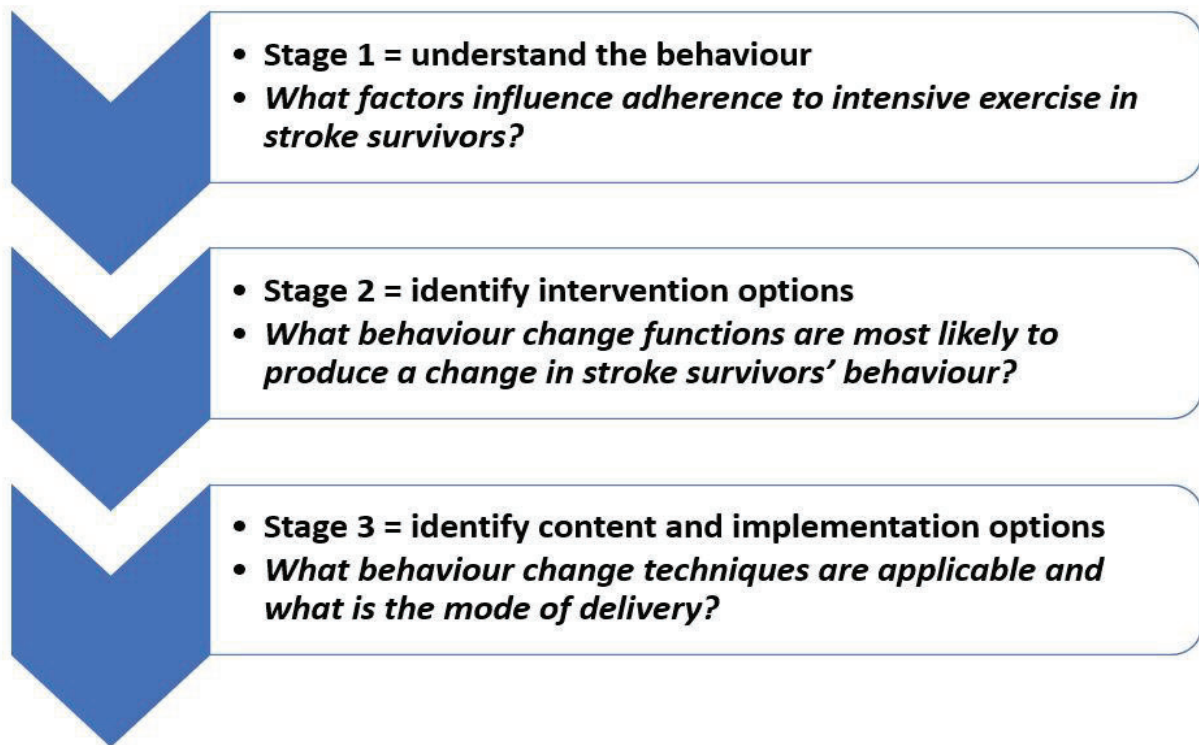


Figure 7-1 Three main stages when using the Behaviour Change Wheel

## 7.2.2 An example of using a Behaviour Change model to guide exercise prescription

### 7.2.2.1 Stage 1: Understand the behaviour

In Stage 1, health professionals make a 'behavioural diagnosis' of what needs to happen for the desired behaviour to occur. The method chosen to define the target behaviour will depend on the target population and could include interviews, the use of expert opinion, focus groups, or surveys. Categorising findings according to a behavioural model can help identify strategies to minimise the barriers to the behaviour (Govender et al., 2017), and the candidate recommends that health professionals conduct qualitative research, based on a theoretical model, to explore the behaviour.

As reported in Chapter 5, to develop an understanding of the barriers to exercise adherence in stroke survivors, we conducted semi-structured interviews with 20 stroke survivors who had participated in an intensive upper limb therapy trial (Lannin et al., 2020). After initial thematic coding, two authors deductively mapped these codes to the domains of the Capability, Opportunity, Motivation-Behaviour model of behaviour change to explore the barriers to adherence experienced by stroke survivors (Michie, Van Stralen & West, 2011). This analysis showed common barriers for this population were that the exercises were too difficult, stroke survivors experienced fatigue, there was a lack of social support, and these are presented with additional barriers in Chapter 5 of this thesis and Table 7-1.

**Table 7-1 Barriers and enablers to participation in an intensive upper limb exercise program mapped to Capability, Opportunity, Motivation-Behaviour model**

<b>COM-B</b>	<b>THEMES – KEY BARRIERS</b>	<b>EXEMPLAR QUOTE</b>
<b>Capability-Physical</b> <i>Skills, abilities, or proficiencies acquired to perform the behaviour</i>	Challenging exercise	06: <i>a lot of the exercises were very difficult for me to do. There was a couple that I would skip because they were too hard</i>
	Discomfort or pain	04: <i>as soon as I feel pain, I would just stop</i>
	Reliance on others	14: <i>after I've tried it, the carers come along and amend where I've stuffed up.... I always need carers to help me to initiate them</i>
	Fatigue	14: <i>when I was really tired it was hard to get them all done....it was really a major problem</i>
<b>Motivation-Reflective</b> <i>Self-conscious planning and beliefs about the behaviour</i>	Fitting it all in	06: <i>sometimes we didn't do 60 minutes because we were busy. We might have an appointment but often if we had to go out, I would try and do the exercises later</i>
<b>Motivation-Automatic</b> <i>Desires and impulses to perform the behaviour</i>	Feeling frustrated	13: <i>I get frustrated because I can't do it. And I know my hand won't do it, and I think well why I should do it</i>
<b>Opportunity-Physical</b> <i>Environmental context and resources to allow performance of the behaviour</i>	Access to hospital	01: <i>the hard thing was the visits to the hospital ... travelling to and from took a long time</i>
<b>COM-B</b>	<b>THEMES – KEY ENABLERS</b>	<b>EXEMPLAR QUOTE</b>
<b>Opportunity – social</b> <i>Social influences such as social pressure, norms, conformity, social comparisons</i>	Feelings of support	02: <i>the support was very positive; lots of guidance initially also, with exercises. I felt like I was able to get help when I needed it</i>
	Motivated by others	04: <i>the support is a positive thing. Even though you feel inside yourself, " I really can't do this," but they're saying, "You're right, you can do this" - it's easy to get down when you're by yourself sort of thing</i>

	Importance of social support	16: <i>if he wasn't around it would have been awful – he gave physical support but also enormous mental support'</i>
	Importance of therapy staff	14: <i>each week when we would rehash what we'd done, and where the improvements were, it was reaffirming</i>
	Trust in therapist	08: <i>as I said before, so whatever someone says to me I just do it. I didn't question it and I still don't question it even today because they know what they must do whereas me, I don't know</i>
<b>Motivation-Reflective</b> <i>Self-conscious planning and beliefs about the behaviour</i>	Accountability	14: <i>when you give your word for something, people are going to rely on you. You can't let people down</i>
	Motivation factors	11: <i>I wanted to be able to use my arm again. I was an avid golfer, so I wanted to get back to playing golf if I could. And so that was my motivation, or one of them. That was my main motivation</i>
	Attitude to exercise	04: <i>my attitude was, "Well, you've got to do this to - it's not going to get better by itself"</i>
	Self-motivated	06: <i>60 minutes was achievable because I am very determined and motivated</i>
<b>Opportunity-Physical</b> <i>Environmental context and resources to allow performance of the behaviour</i>	Benefits home environment	20: <i>being in the comfort of my own house I think, yeah that was a definite plus</i>
	How structured exercises	16: <i>I generally had brekkie first and have a bit of a clean-up and then get into it. Depending if we had anything on. You know, you'd squeeze it in to wherever</i>
	Benefits of face to face contact	14: <i>because you can go through the exercises with them and show them some positive results. Because somehow or another they seem to get more out of you and it's encouraging</i>
	Record of practice	01: <i>just every day I would write down what time I started and how many repetitions I was doing and just every day I would try and break my record</i>
<b>Motivation-Automatic</b> <i>Desires and impulses to perform the behaviour</i>	Committed to word	14: <i>I kept going because I signed up for 12 weeks. My word is my bond</i>
	Routine practice	04: <i>you just get into a routine and you just did it. Once you go through the -probably the first week or two would have been the hardest - but then you just did it. You did it at certain times - even did it for probably longer because you worked out - it took me one session to do half a book and if I didn't quite reach that, I kept going. No, you just get into the routine of it</i>
<b>Motivation-Reflective</b> <i>Self-conscious planning and beliefs about the</i>	Feeling hopeful	06: <i>just that four letter word, hope. Probably more hoping for some recovery with my arm or hand</i>



<i>behaviour</i>		
<b>Motivation-Reflective</b> <i>Self-conscious planning and beliefs about the behaviour</i>	Goals	14: <i>you've got to have goals. My goal now is to be able to use my arm to play the piano and to hold a cup with this left arm</i>
<b>Capability- psychological</b> <i>The capacity to engage in the necessary thought processes to perform the behaviour</i>	Persistence	14: <i>you're going to do better next time, you got to keep trying. If there was something I couldn't do, just a little bit, then you make a mental note of it so that when you do it next time, you try harder</i>

### 7.2.2.2 Stage 2: Identify intervention options

Having made the 'behavioural diagnosis,' the next stage is to begin building the behaviour change intervention. Stage 2 involves identifying the relevant behaviour change functions that may address the capability, opportunity, and motivation factors that could be influencing the behaviour (i.e. specifically, reduced adherence to intensive home exercise programs in people with stroke).

Intervention functions are defined as “broad categories of means by which an intervention can change behaviour” (p. 108) (Michie, Atkins & West, 2014). Therefore, once barriers to adherence were identified and mapped to the Capability, Opportunity, Motivation-Behaviour model, the candidate selected the relevant behaviour change intervention functions. Overall, there are nine intervention functions identified in the Behaviour Change Wheel guide (Michie, Atkins & West, 2014): education, persuasion, incentivism, coercion, training, restriction, environmental restructuring, modelling, and enablement.

In selecting the appropriate behaviour change functions, the candidate followed the recommended links between the Capability, Opportunity, Motivation-Behaviour model and the intervention functions, as “identified by a group of experts in a consensus exercise”, and presented in the Behaviour Change Wheel guide (p.113) (Michie, Atkins & West, 2014). Six of these functions were considered relevant and were mapped to the behaviours identified in Stage 1 (i.e. barriers identified through the Capability, Opportunity, Motivation-Behaviour model). The six functions and definitions are presented in Table 7-2.

**Table 7-2 Relevant behaviour change functions and definitions**

<b>Relevant behaviour change function</b>	<b>Definition</b>
<b>Enablement</b>	Increasing means/ reducing barriers to increase capability or opportunity i.e. beyond education and training or environmental restructuring
<b>Education</b>	Increasing knowledge or understanding
<b>Persuasion</b>	Using communication to induce feelings or stimulate action
<b>Training</b>	Imparting skills
<b>Environmental restructuring</b>	Changing the physical or social context
<b>Modelling</b>	Providing an example for people to aspire to

*Source: The Behaviour Change Wheel: a guide to designing interventions, Michie, Atkins & West, 2014*

Following the selection of behaviour change functions, the candidate developed practical

intervention strategies for each specific function relevant to the modifiable barriers, as recommended in the Behaviour Change Wheel Guide, page 119 (Michie, Atkins & West, 2014). For example, concerning the barrier of the level of challenge (Capability – Physical), the factor to consider before prescribing exercises was ‘does the person have the physical ability to perform the exercises?’ One of the relevant behaviour change functions identified to address this issue was enablement and the specific intervention strategy was to ‘modify and individualise the exercises to ensure the person can perform them’. Concerning the barrier of the exercise environment (Opportunity – Physical), the factor to consider before prescribing exercises was ‘does the person have an appropriate space to set-up and perform their exercises?’ The relevant behaviour change function identified to address this issue was environmental restructuring and the specific intervention strategy was ‘to perform a check of the environment, in person or via telehealth’. Concerning the barrier of making exercises routine (Motivation – Automatic), the factor to consider before prescribing exercises was ‘does the person have adequate strategies to make participation a routine practice?’ One of the relevant behaviour change functions identified to address this issue was enablement and the specific intervention strategy was ‘utilises support strategies (for example, diaries, phone prompts, alarms)’.

This process was repeated for each modifiable barrier identified, as presented in Table 7-3. From this analysis a guide for health professionals was developed, as presented in Figure 7-2.

### ***7.2.2.3 Stage 3: Identify content and implementation options***

Stage 3 involves identifying content and implementation options, through the selection of appropriate behaviour change techniques that will facilitate the desired change. A behaviour change technique is defined as “an observable, replicable and irreducible component of an intervention designed to alter or redirect causal processes that regulate behaviour”, and includes techniques such as ‘goal setting’ and ‘feedback’ (p. 82) (Michie et al., 2013). This stage was considered to be beyond the scope of this study as it was not an essential component of the process of developing a guide for health professionals. However, throughout the research within this thesis, behaviour change techniques such as motivational interviewing and goal setting have been adopted. Different settings and implementation projects will need to incorporate this stage into their specific study design.

**Table 7-3 Barriers to participation in exercise, mapped to the COM-B model, relevant behaviour change functions, and intervention strategies**

Theme	Factors to consider during assessment (prior to exercise prescription)	Relevant behaviour change functions and intervention strategies
<b>Capability</b>		
<b>Physical</b>	Does the person have the physical ability to perform the exercises?	<ul style="list-style-type: none"> <li>• <b>Modelling / Training</b> &gt; Demonstrate, instruct and have a practice run of exercises</li> <li>• <b>Enablement</b> &gt; Modify and individualise the exercises to ensure the person can perform them</li> </ul>
	Can the person move safely around the environment?	<ul style="list-style-type: none"> <li>• <b>Environmental restructuring</b> &gt; Perform a check of the environment (in person or telehealth)</li> <li>• <b>Education</b> &gt; Educate the person about safety considerations of performing the exercise program and provide clear resources that include environmental considerations</li> </ul>
	Does the person experience fatigue?	<ul style="list-style-type: none"> <li>• <b>Enablement</b> &gt; Discuss strategies to manage fatigue. For example, a daily planner to ensure person completes exercises at times of minimal fatigue</li> </ul>
	Does the person experience pain?	<ul style="list-style-type: none"> <li>• <b>Enablement</b> &gt; Incorporate some pain management strategies into program. For example, timing exercises with pain relief medication for optimal performance</li> </ul>
<b>Psychological</b>	Does the person understand the purpose of continuing to perform an exercise program?	<ul style="list-style-type: none"> <li>• <b>Enablement</b> &gt; Discuss person's goals</li> <li>• <b>Education / Persuasion</b> &gt; Reinforce principles of neuroplasticity and importance of practice, provide explanatory resources</li> </ul>
	Does the person have the cognitive ability to follow instructions and perform the exercises?	<ul style="list-style-type: none"> <li>• <b>Education</b> &gt; Ensure written instructions are clear, accessible and avoid the use of jargon</li> <li>• <b>Enablement</b> &gt; Enlist external support (family, carer, or friend) to assist exercise participation</li> </ul>
	Will the person remember to perform the exercises?	<ul style="list-style-type: none"> <li>• <b>Enablement / Education</b> &gt; Utilise memory support strategies (for example diaries, phone prompts, alarms)</li> </ul>
	Will the person be able to maintain concentration and attention to enable them to complete the exercises?	<ul style="list-style-type: none"> <li>• <b>Environmental restructuring</b> &gt; Reinforce the importance of a quiet environment with minimal distractions, provide a 'short and sharp' program</li> </ul>

<b>Opportunity</b>		
<b>Social</b>	If required, does the person have someone available to assist them with the exercises?	<ul style="list-style-type: none"> <li>• <b>Enablement</b> &gt; Enlist social support when available &gt; If lack of available support, consider alternative supports such as phone reviews or telehealth</li> <li>• <b>Training</b> &gt; Provide training to carers who will be supporting the person with their exercises</li> </ul>
<b>Physical</b>	Does the person have an appropriate space to set-up and perform their exercises?	<ul style="list-style-type: none"> <li>• <b>Environmental restructuring</b> &gt; Perform a check of the environment, in person or via telehealth</li> </ul>
	Does the person need any equipment to complete their exercise program?	<ul style="list-style-type: none"> <li>• <b>Training / Environmental restructuring</b> &gt; Provide equipment as needed and ensure person can use it effectively and safely</li> </ul>
	Does the person have time each day to enable them to perform their exercises? (consider amount of other commitments)	<ul style="list-style-type: none"> <li>• <b>Enablement</b> &gt; Discuss with person their commitments and problem-solve ways to fit exercise into their schedule, encourage routine practice times &gt; Consider use of a weekly planner or diary</li> </ul>
<b>Motivation</b>		
<b>Automatic</b>	Does the person understand the importance of ongoing exercise?	<ul style="list-style-type: none"> <li>• <b>Education / Persuasion</b> &gt; Reinforce principles of neuroplasticity and importance of practice, provide resources</li> </ul>
	Does the person have adequate strategies to make participation a routine practice?	<ul style="list-style-type: none"> <li>• <b>Enablement / Education</b> &gt; Utilise support strategies (e.g. diaries, phone prompts, alarms)</li> <li>• <b>Enablement</b> &gt; Discuss with person their commitments and problem solve ways to fit exercise into their schedule</li> </ul>
	Does the person become frustrated when performing exercises?	<ul style="list-style-type: none"> <li>• <b>Modelling</b> &gt; Provide person with some strategies for managing frustration (for example, deep breathing techniques)</li> <li>• <b>Enablement</b> &gt; Modify and individualise the exercises to ensure the person can perform them (hence reducing the frustration)</li> </ul>
<b>Reflective</b>	Is the person motivated to continue with an exercise program?	<ul style="list-style-type: none"> <li>• <b>Persuasion / Enablement</b> &gt; Consider if the person has intrinsic motivation, and if not consider strategies to motivate extrinsically. Examples would be incorporating favourite hobbies into the exercise program, using music to engage</li> </ul>
	Is the person confident in their ability to participate in an ongoing exercise program?	<ul style="list-style-type: none"> <li>• <b>Persuasion / Enablement / Training</b> &gt; Does the person have an adequate level of self-efficacy? If not, provide them with reassurance and support and feedback on their performance</li> </ul>

	Does the person have goals?	<ul style="list-style-type: none"><li>• <b>Enablement</b> &gt; Set clear goals, including 'pie in the sky' goals, break down goals into steps</li></ul>
	Does the person understand the consequences of not exercising?	<ul style="list-style-type: none"><li>• <b>Education / Persuasion</b> &gt; Reinforce principles of neuroplasticity and importance of practice, provide explanatory resources</li></ul>

# MAXIMISING ADHERENCE TO HOME EXERCISE PROGRAMS FOR PEOPLE WITH STROKE: A GUIDE TO APPLYING A BEHAVIOUR CHANGE MODEL

The information contained in this clinician guide is based on the Behaviour Change Wheel and the Capability, Opportunity, Motivation - Behaviour model, and the synthesis of findings from a qualitative exploration of stroke survivors' experiences of participating in an intensive exercise program. (Michie et al. 2011)

SOCIAL

**Factors to consider during assessment (prior to exercise prescription)**

If required, does the person have someone available to assist them with the exercises?

**Relevant behaviour change functions and intervention strategies**

**Enabling**

- Enlist social support when available
- If lack of available support, consider alternative supports such as phone reviews or telehealth

**Training**

- Provide training to carers who will be supporting the person with their exercises

PHYSICAL

**Does the person have an appropriate space to set-up and perform their exercises?**

**Environmental restructuring**

- Perform a check of the environment in person or via telehealth

PHYSICAL

**Does the person need any equipment to complete their exercise program?**

**Training/Environmental restructuring**

- Provide equipment as needed and ensure person can use it effectively and safely

PHYSICAL

**Does the person have time each day to enable them to perform their exercises? (Consider amount of other commitments)**

**Enabling**

- Discuss with person their commitments and problem solve ways to fit exercises into their schedule, encourage routine practice times
- Consider use of a weekly planner or diary



Timina Levy, Kate Javis, Maggie Ellington, Natasha Linnin, Maria Croft  
 Michie, S., Van Stralen, M., and West, R. The behaviour change wheel: a new method for characterizing and designing behaviour change interventions. *Implementation Science*, 2011

## 1. CAPABILITY

PHYSICAL	<p><b>Factors to consider during assessment (prior to exercise prescription)</b></p> <p>Does the person have the physical ability to perform the exercise?</p>	<p><b>Modelling/Training</b></p> <ul style="list-style-type: none"> <li>Demonstrate, instruct, and have a practice run of exercises</li> </ul>	<p><b>Engagement</b></p> <ul style="list-style-type: none"> <li>Modify and individualise the exercise to ensure the person can perform them</li> </ul>
	<p>Can the person move safely around the environment?</p>	<p><b>Environmental restructuring</b></p> <ul style="list-style-type: none"> <li>Perform a check of the environment in person or telehealth</li> </ul>	<p><b>Education</b></p> <ul style="list-style-type: none"> <li>Educate the person about safety considerations of performing the exercise program and provide clear resources that outline safety aspects</li> </ul>
	<p>Does the person experience fatigue?</p>	<p><b>Enabling</b></p> <ul style="list-style-type: none"> <li>Discuss strategies to manage fatigue (e.g. a daily planner to ensure person completes exercise at times of minimal fatigue)</li> </ul>	
	<p>Does the person experience pain?</p>	<p><b>Enabling</b></p> <ul style="list-style-type: none"> <li>Incorporate some pain management strategies into program (e.g. timing exercises with pain relief medication for optimal performance)</li> </ul>	

PSYCHOLOGICAL	<p>Does the person understand the purpose of continuing to perform the exercise program?</p>	<p><b>Enabling</b></p> <ul style="list-style-type: none"> <li>Discuss person goals</li> </ul>	<p><b>Education/Persuasion</b></p> <ul style="list-style-type: none"> <li>Reinforce principles of neuroplasticity and importance of practice; provide explanatory resources</li> </ul>
	<p>Does the person have the cognitive ability to follow instructions and perform the exercises?</p>	<p><b>Education</b></p> <ul style="list-style-type: none"> <li>Insure written instructions are clear, accessible and avoid the use of jargon</li> </ul>	<p><b>Enabling</b></p> <ul style="list-style-type: none"> <li>Enlist external support (family, carer or friend) to assist exercise participation</li> </ul>
	<p>Will the person remember to perform the exercises?</p>	<p><b>Enabling/Education</b></p> <ul style="list-style-type: none"> <li>Utilise memory support strategies (e.g. diaries, phone prompts, alarms)</li> </ul>	
	<p>Will the person be able to maintain concentration and attention to enable them to complete the exercises?</p>	<p><b>Environmental Restructuring</b></p> <ul style="list-style-type: none"> <li>Reinforce the importance of a quiet environment with minimal distractions, provide a 'short and sharp' program</li> </ul>	



## 3. MOTIVATION

AUTOMATIC	<p><b>Factors to consider during assessment (prior to exercise prescription)</b></p> <p>Does the person understand the importance of doing ongoing exercises?</p>	<p><b>Education / Persuasion</b></p> <ul style="list-style-type: none"> <li>Reinforce principles of neuroplasticity and importance of practice, provide resources</li> </ul>	
	<p>Does the person have adequate strategies to make participation a routine practice?</p>	<p><b>Enabling / Education</b></p> <ul style="list-style-type: none"> <li>Utilise support strategies (e.g. diaries, phone prompts, alarms)</li> </ul>	<p><b>Enabling</b></p> <ul style="list-style-type: none"> <li>Discuss with person their commitments and problem solve ways to fit exercises into their schedule</li> </ul>
	<p>Does the person become frustrated when performing exercises?</p>	<p><b>Modelling</b></p> <ul style="list-style-type: none"> <li>Provide person with some strategies for managing frustration (e.g. deep breathing techniques)</li> </ul>	<p><b>Enabling</b></p> <ul style="list-style-type: none"> <li>Modify and individualise the exercises to ensure the person can perform them (hence reducing the frustration)</li> </ul>

REFLECTIVE	<p>Is the person motivated to continue with an exercise program?</p>	<p><b>Persuasion / Enabling</b></p> <ul style="list-style-type: none"> <li>Consider if the person has intrinsic motivation, and if not consider strategies to motivate extrinsically (e.g. incorporating favourite hobbies into the exercise program, using music to engage)</li> </ul>	
	<p>Is the person confident in their ability to participate in an ongoing exercise program?</p>	<p><b>Persuasion / Enabling / Training</b></p> <ul style="list-style-type: none"> <li>Does the person have an adequate level of self-efficacy? If not, provide them with reassurance and support and feedback on their performance</li> </ul>	
	<p>Does the person have goals?</p>	<p><b>Enabling</b></p> <ul style="list-style-type: none"> <li>Set clear goals, including 'pie in the sky' goals, break down goals into steps</li> </ul>	
	<p>Does the person understand the consequences of not exercising?</p>	<p><b>Education / Persuasion</b></p> <ul style="list-style-type: none"> <li>Reinforce principles of neuroplasticity and importance of practice; provide explanatory resources</li> </ul>	

Figure 7-2 Health professional guide, based on the BCW, COM-B model and synthesis of qualitative study (Chapter 5)

### 7.3 Discussion

Based on the evidence that using theory in the design of therapy and exercise programs can enable health professionals to understand barriers and enablers to exercise, the candidate used the Behaviour Change Wheel and Capability, Opportunity, Motivation-Behaviour model to develop a guide for health professionals to use when prescribing exercise programs for stroke survivors (Michie, Van Stralen & West, 2011). The candidate encourages health professionals to follow this guide and believes this may increase health professionals' confidence in applying behaviour change theory into practice when prescribing exercises for stroke survivors.

Whilst there is an acknowledgment that theory should be used to inform intervention, intervention designers and researchers face challenges in selecting and applying the most appropriate theory (Marley, 2017). In a study exploring health professionals' attitudes and practices relating to health promotion knowledge, McMahon and Connolly (McMahon & Connolly, 2013) reported less than half of survey responders believed they had sufficient knowledge of behaviour change theory. The authors concluded that due to the minimal inclusion of behaviour change models, interventions were poor in design, delivery, and evaluation.

It has been reported extensively, and over a long period of time, that approaches to home exercise prescription have been typically 'atheoretical' (Morris & Williams, 2009). In a survey-based study investigating practices of physiotherapists and occupational therapists in prescribing upper limb exercises to people after stroke, Connell and colleagues reported that only 13.5% of respondents considered factors such as cognition, family support, and motivation when deciding whether to prescribe a program (Connell, McMahon, Eng & Watkins, 2014). Exercises were generally prescribed in an ad hoc manner, mainly relying on verbal communication. Additionally, a review of how physiotherapy students prescribe exercises was incorporated into a qualitative study exploring students' learnings around behaviour change and health promotion (Barradell & Bruder, 2019). The authors observed a tendency for students to simply view exercise prescription as a selection of exercises, with less consideration for instruction and demonstration, which led to missed opportunities to review and reassess the clients' progress. Our guide, developed from a theoretical background, provides physiotherapists and occupational therapists with a comprehensive model to work from when prescribing home exercises for stroke survivors.

A lack of understanding regarding behaviour change principles can limit outcomes and recovery (Vallis et al., 2018). Vallis and colleagues (Vallis et al., 2018) reported that "behaviour change theories and interventions have been developed and evaluated in experimental context; however, most healthcare providers have little training, and therefore low confidence in, behaviour change counselling" (p. 1). These findings highlight the need for a more comprehensive approach to



exercise prescription, including consideration of potential barriers to adherence and strategies to address these barriers. This chapter addresses the current limitation when specifically considering health professionals' prescription of home exercises for stroke survivors.

## **7.4 Strengths and limitations**

This was a pragmatic study focused on introducing a usable tool suitable for health professionals (physiotherapists and occupational therapists) working with stroke survivors. In this study, the candidate used a theoretical behaviour change framework to inform the analysis of the data and development of the guide, which could be used by health professionals when developing exercise programs for stroke survivors (Michie, Atkins & West, 2014). The aim was to use known barriers and theory to prompt health professionals to consider strategies to address barriers, aiming to maximise exercise adherence.

This health professional tool was developed from findings of interviews of participants who were largely adherent. It would be valuable to explore barriers and enablers, and subsequently develop strategies to address findings in stroke survivors who have low levels of adherence.

The strength of this study was the development of a useful resource for sharing knowledge with health professionals. Limitations of this approach include a lack of detailed information on the usability of the infographic as this was not formally assessed. Furthermore, there was a lack of co-design in the guide development, including in the development of the recommended intervention strategies.

## **7.5 Implications for future practice and research**

Whilst the candidate believes this infographic could form a component of an 'adherence tool-kit', which is an intervention recommended by the World Health Organisation to address adherence in chronic health conditions (World Health Organisation, 2003), a more comprehensive translational study is indicated. The initial phase of this study would include a qualitative exploration of health professionals' knowledge and use of behaviour change models to better inform the need for tool development. The candidate recommends using a co-design process with health professionals and stroke survivors, working from the point of framing the opportunity, developing preparedness, setting priorities, designing the tool, and evaluating the effect (Dimopoulos-Bick et al., 2019).

## CHAPTER 8 DISCUSSION

This thesis presents a series of studies that sought to better understand and increase adherence to exercise in stroke survivors. This research has important implications for health professionals as the treatment of chronic disease is a growing worldwide problem with consequences including poor health outcomes and increased health care costs (World Health Organisation, 2003). There is a significant financial cost of poor adherence and the World Health Organisation reports that improving adherence may be the best investment for managing chronic conditions effectively (World Health Organisation, 2003). Condition-related factors can influence adherence and it is therefore important to explore factors specific to the disease or health condition. As adherence to exercise in stroke survivors has been reported to be low (Tiedemann et al., 2012; Miller et al., 2017), a comprehensive understanding of related factors is warranted. This will enable health professionals to develop resources to address adherence in this population.

The purpose of this research was to evaluate methods of measuring adherence to exercise in stroke survivors, to explore factors influencing adherence to intensive exercise programs in stroke survivors, and to use a behaviour change framework to develop a guide for health professionals to use when prescribing home exercise programs. This thesis included six complementary studies that had a specific research question and corresponding aim (Figure 8-1). This chapter will (a) summarise the overall key findings of each study (section 8.1), (b) outline the original contribution of this research (section 8.2), compare findings from these studies to previous research (section 8.3), (c) discuss implications of this research (section 8.4 and 8.5), and outline strengths (section 8.6), and limitations (section 8.7) of the research.

As outlined in Figure 8-1, the overall aims of the research presented within this thesis were:

**Aim 1: (a)** To systematically explore methods of measurement of exercise adherence in stroke survivors.

**(b)** To assess the feasibility of using technology as a method of measurement of exercise adherence in stroke survivors.

**Aim 2:** To explore barriers and enablers to exercise adherence in stroke survivors participating in an intensive intervention.

**Aim 3:** To identify appropriate behaviour change strategies and inform the development of an intervention/approach to improve adherence to home-based exercise programs in stroke survivors.

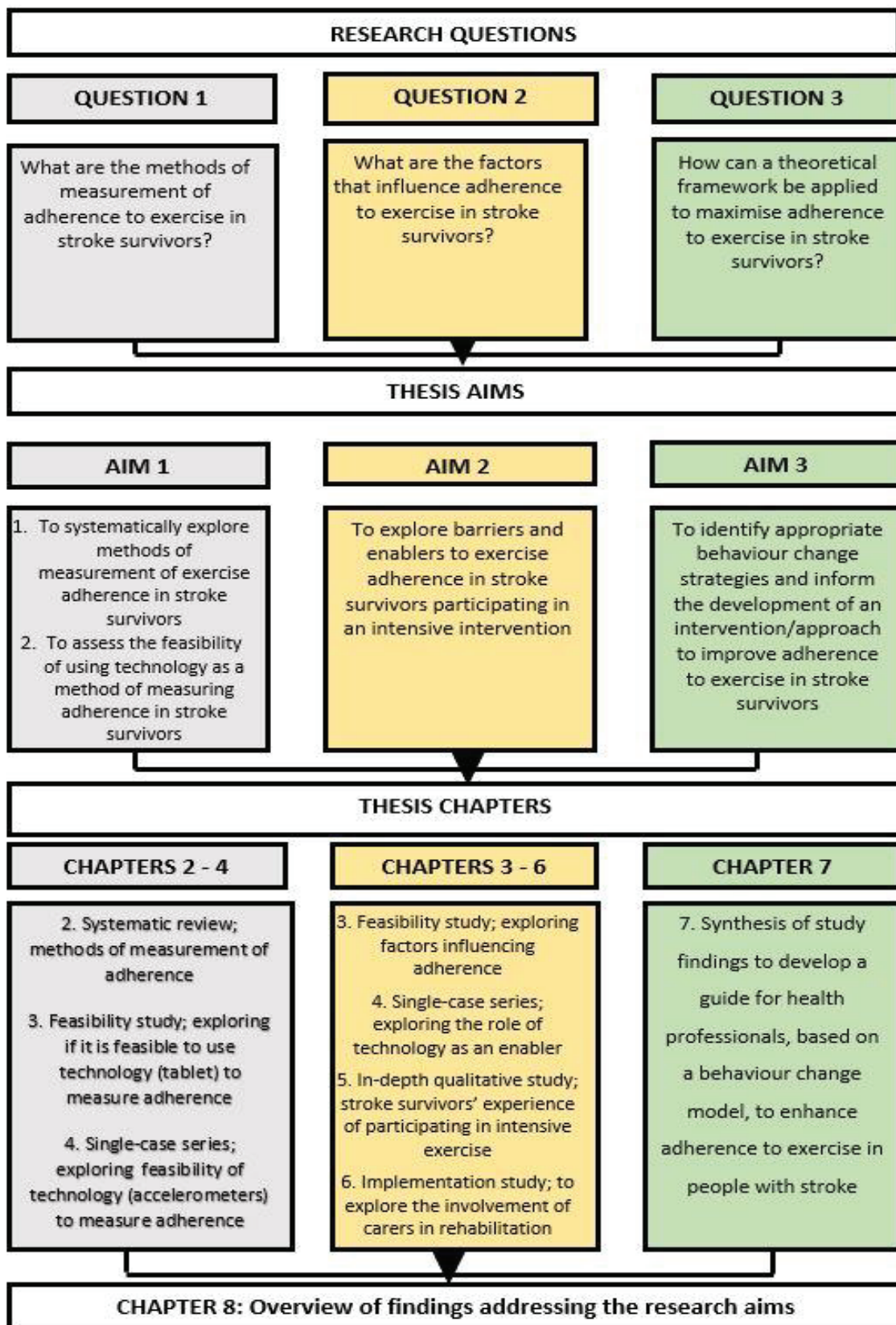


Figure 8-1 Structure of the thesis with research questions, thesis aims, and chapters

## **8.1 Summary of findings and how research aims have been addressed**

### **8.1.1 Aim 1 (a): To systematically explore methods of measurement of exercise adherence in stroke survivors**

The systematic review identified seven methods of measurement commonly used: diaries, logbooks, a record of practice, journals, surveys, questionnaires, and the Physical Activity Scale for Individuals with Physical Disabilities. However, none of the included measurement methods had published psychometric evaluation. Diaries and logbooks were the most frequently used adherence measurement methods, however, there was a lack of standardisation when utilising these tools. Overall, it was found that there is a lack of a uniform method of measurement of adherence to exercise or physical activity recommendations in the stroke population. Furthermore, it was recommended that to increase confidence in adherence reports, health professionals should supplement self-report measures with objective data collection methods.

### **Aim 1 (b): To assess the feasibility of using technology as a method of measurement of exercise adherence in stroke survivors**

Technologies to monitor adherence were described in Chapter 1 and two technologies were examined for their feasibility within these studies. Chapter 3 explored the use of a tablet device which has the advantage of being inexpensive and readily available to most health professionals. This study showed that monitoring of stroke survivors' exercise sessions using video recordings via a tablet computer was feasible and may prove more accurate than self-report. The benefits included the ability to monitor those participants who were considered less likely to adhere, such as those with less social support or the more physically impaired. The video playback enabled the health professional to assess the quality of the participant's exercise and provide feedback on performance, as well as check the accuracy of self-report. Whilst there were advantages to this 'off the shelf approach', the main drawback from the health professional's perspective was the amount of time taken to analyse the videos. To improve clinical utility a modified approach to video analysis, such as analysing 'snapshots' of video recordings, was recommended.

In Chapter 4 the feasibility of using upper limb accelerometers as a method of monitoring upper limb exercise adherence was explored. Whilst the accelerometers provided objective data of exercise times, there were several problems with utility including missing data and device malfunction which may limit usability for health professionals working with stroke survivors in ambulatory settings.

Both Chapters 3 and 4 provide insight into the benefits of technology use as an accurate method of adherence monitoring, as well as some of the challenges with clinical utility. With technologies emerging and changing, health professionals are likely to need to repeatedly assess clinical utility.

The approaches demonstrated in this thesis, the System Usability Scale and the Self Efficacy for Exercise Scale, could be replicated by health professionals. It is recommended that health professionals and researchers stay aware of new technological developments and consider potential stroke-specific barriers when determining usability.

### **8.1.2 Aim 2: To explore barriers and enablers to exercise adherence in stroke survivors participating in an intensive intervention**

Findings from Chapters 3, 4, and 5 highlighted several barriers that influenced adherence to exercise programs in stroke survivors. These factors could all be classified according to the COM-B model, that is the capability, opportunity, and motivation to perform the exercises. The amount of social support and the level of physical impairment were key factors that influenced adherence to exercise programs. Other barriers identified in Chapter 5 were the stroke survivors having a busy schedule of appointments and therefore difficulty finding time for exercise, feeling frustrated by the exercises, and having to rely on others to assist. There were many enablers to adherence identified including exercising at routine times, keeping a record of practice, setting goals, and having ongoing face to face contact with the health professional. The importance of the health professional was also described in terms of the stroke survivors 'giving their word,' or feeling accountable to the health professional. For many stroke survivors a key driving factor was having a sense of hope that adherence to their motor training program would lead to rewards, such as improved movement and abilities.

Several participants described the difficulty with staying motivated and often needed others, such as the health professional or carer, to help motivate them. Some stroke survivors appeared to lack intrinsic motivation and benefited from extrinsic factors to motivate. In Chapter 4 the role of technology as a form of extrinsic motivation was explored with the introduction of a tablet device. This work showed that the use of visual feedback on performance enhanced adherence to a home-based exercise program for some stroke survivors.

As social support was identified as an important factor in determining adherence, the role of the carer was explored in more detail. The Carers Count study was a pilot study that involved the design, implementation, and evaluation of an exercise-based group involving carers and the stroke survivor, early in the inpatient rehabilitation phase. In qualitative interviews, the overall experience of participation was rated as very valuable by the majority of the stroke survivors and carers. Several of the carers reported that being involved early in rehabilitation gave them increased confidence for when the stroke survivor was discharged from the hospital, a greater understanding of the importance of ongoing exercises to enhance recovery, and increased knowledge and confidence in how to assist the stroke survivor with their ongoing exercises. In this pragmatic evaluation a limited number of stroke survivors (22.5% of ward admissions) were eligible for this

approach. As the main reason for ineligibility was lack of an available carer (38%), it may be that health professionals need personalised approaches and multiple programmes to encourage early practice in all stroke survivors. In the Carers Count study, for no additional cost, the candidate and ward staff were able to develop and implement a creative approach to extra practice.

### **8.1.3 Aim 3: To identify appropriate behaviour change strategies and inform the development of an intervention/approach to improve adherence to home-based exercise programs in stroke survivors**

Using a behaviour change model to analyse the barriers to exercise adherence in stroke survivors, a visual guide/infographic was developed for health professionals to use when prescribing exercises. The Behaviour Change Wheel and Capability, Opportunity, Motivation-Behaviour model were used to analyse modifiable barriers identified in the qualitative study, presented in Chapter 5. Relevant behaviour change functions were identified, and practical intervention strategies were developed for each behaviour change function. This analysis was then developed into a visual infographic, aiming to provide health professionals with a framework for developing exercise programs that maximise adherence. This process, and the health professional guide, is presented in Chapter 7.

## **8.2 Original contribution to the research**

The work within this thesis has advanced knowledge about adherence to intensive exercise in stroke survivors in several important ways, as outlined below.

1. It has provided robust evidence of an evidence gap. There is currently a lack of valid and reliable tools to monitor adherence in stroke rehabilitation. In the absence of such tools, health professionals should use objective data collection methods, such as activity monitors, to supplement stroke survivor self-report.
2. This research has demonstrated that 'off the shelf' technology, in the form of a tablet computer, can be used by health professionals to objectively monitor stroke survivors' exercise practices. Furthermore, this method of technology use can also benefit the stroke survivor in terms of providing extrinsic motivation.
3. To date there has been a lack of research focused on understanding stroke survivors' participation in *intensive* upper limb exercise programs and this research has revealed that there are key barriers and enablers, including the level of physical impairment, level of motivation, the amount of social support, and the ability to maintain hope, that should be considered by health professionals working with stroke survivors.
4. A group developed to engage carers in rehabilitation (and promote increased adherence to exercise on discharge) is feasible and of value to carers.

5. The candidate used a behaviour change model to produce a theory-informed infographic guide to enable health professionals to develop exercise programs that support adherence, which aids in dissemination of the findings of this research.

## **8.3 Comparison to previous research**

### **8.3.1 Methods of measurement**

This research reported that the most frequently used methods of measurement of adherence to exercise in research studies in the stroke population were diaries and logbooks. This is consistent with a similar review (Donoso Brown et al., 2020) which also found a reliance on self-report methods as well as the emergence of technology ranging from pedometer to computer applications. Self-report poses several limitations such as recall bias and a lack of accuracy (Donoso Brown et al., 2020). Whilst self-report can be cost-efficient and easy to administer, evidence has shown that health professionals should not feel confident that what is reported is an accurate reflection of the actual amount of practice. This was highlighted by Prince and colleagues who found low to moderate correlations between self-report and direct measures of adherence (Prince et al., 2008).

The lack of valid and reliable tools is not unique to this population. Frost and colleagues reported similar findings with a broader population (Frost et al., 2017), where diaries were the most frequently reported measures and were often combined with an additional measure, including questionnaires and interviews. Other studies identified in Chapter 2 also report the use of additional methods of monitoring, such as face to face meetings, combined with self-report (Winstein et al., 2003; Gunnes, Indredavik & Askim, 2015; Koh et al., 2015; Bonnyaud et al., 2018). Based on these findings, health professionals should consider the use of a multi-faceted approach to adherence measurement, combining self-report with additional methods, such as activity monitors, to enhance accuracy and improve confidence in the use of self-report measures.

### **8.3.2 The role of technology**

#### ***8.3.2.1 Technology as a measurement tool***

The use of technology presents another method of measurement that health professionals can adopt to accurately monitor practice and complement self-report measures. In this research, the use of a direct measurement device enabled the candidate to accurately report on exercise adherence as well as analyse the accuracy of participants' self-reported exercise times. In Chapter 3, four of the 10 participants showed a large difference between self-reported and tablet-recorded exercise times. This suggests that the technology will be useful for some, but not all, rehabilitation participants.

Video recording and playback (as applied in Chapter 3) was a relatively simple process. Warland

and colleagues (Warland et al., 2019) highlighted the importance of using technology that is simple to set up and operate to enable independent use, as a lack of confidence with technology could be a barrier to adherence. Others have used similar approaches to the method described in Chapter 3, including Simpson and colleagues (Simpson et al., 2020) who used a remote monitoring system, pairing a tablet device to sensors. Whilst this intervention demonstrated a more sophisticated use of a tablet device, the authors reported that a key component of the system was the monitoring and provision of feedback by the health professional. As per the findings in Chapter 3, the authors reported that as all participants were able to use the system, the technology may be beneficial to the general stroke population. Hence, whilst the tablet computer use described in Chapter 3 was less sophisticated than other studies have implemented, the simple nature of the intervention enabled the majority of the stroke survivors to use it independently, and health professionals should therefore consider this as a potential measurement tool.

Accelerometry is emerging as a technology and may offer a valid and acceptable way of measuring adherence (Hayward et al., 2016). In this research (Chapter 4), the candidate downloaded accelerometry data and calculated the active time for each exercise session. This methodology, supported in a recent publication (Lang, Waddell, Klaesner & Bland, 2017), involved calculating the time of limb use by observation of when the activity count was above zero. However, it was time-consuming and would be difficult to apply in clinical settings. Other studies (Michielsen et al., 2012; Bailey, Klaesner & Lang, 2014; Lemmens et al., 2015; Chin et al., 2019) have used accelerometers in a more sophisticated manner including using Bilateral Magnitude and Magnitude Ratio to enable an exploration of activity intensity, investigate specific upper limb activities, and to evaluate the contribution of each upper limb to activity. Hence, accelerometers can be used for a more advanced assessment of the upper limb post-stroke, however this was considered to be beyond the scope of the study aim. In Chapter 4 there were several challenges reported with accelerometry use, including missing data and participants forgetting to charge and don/doff the devices. Issues with the clinical utility of accelerometers, including missing data, have been reported elsewhere (Narai, Hagino, Komatsu & Togo, 2016; Bhatnagar et al., 2020), and it may be that accelerometers are more suited for advanced assessment and research purposes.

### ***8.3.2.2 Technology as a tool to enhance adherence***

Chapter 4 extended the exploration of tablet use for exercise adherence by investigating the role of the tablet as a means of influencing adherence to exercise. Following stroke, if intrinsic feedback mechanisms are impaired it is important to introduce external sources of feedback (Van Vliet & Wulf, 2006). Concurrent visual feedback can be used to provide extrinsic feedback and the candidate found that, for some stroke survivors, this intervention did enhance adherence to exercise. Visual feedback was also reported as an important component of doing exercises in the ActiveABLES study (Olafsdottir et al., 2020).



Several participants in the studies reported in Chapters 3 and 4 reported an awareness that the researcher may be checking up on their exercise practice. Other authors have reported that adherence may be enhanced by participants' being aware of their practice being monitored (Bennell et al., 2019; Simpson et al., 2020). Based on the studies presented in Chapters 3 and 4, the use of tablet computers as a means of providing 'real-time' visual feedback should be considered, especially in stroke survivors who are considered to be lacking intrinsic motivation.

### **8.3.2.3 Challenges with technology use**

In both Chapter 3 and Chapter 4 the candidate discovered factors which influenced the usability of technology for both health professionals and stroke survivors. Factors included the extra time taken to set-up and monitor the equipment, intermittent equipment failure, cost, and reliance on others to set-up and implement successfully. These findings are comparable to other studies of technology-based interventions which have reported that the integration of technologies into clinical practice and uptake by patients will depend on factors such as ease of use, accessibility, time burden, and cost (Jonkman, van Schooten, Maier & Pijnappels, 2018; Nussbaum et al., 2019). In Chapter 3 the candidate reported that over 10 weeks the researcher was contacted three times to assist with technical difficulties. This suggests that this technology was reliable and easy to use when compared to other studies that have reported more challenges with technology use, with one study reporting that over four weeks the researcher was contacted 19 times to assist with technical difficulties (Olafsdottir et al., 2020). With the increased use of telehealth in rehabilitation, tablet devices are being introduced to many stroke survivors as a means of providing home-based rehabilitation. Based on the candidate's findings that some stroke survivors needed support with the tablet device, health professionals should carefully assess individual stroke survivors for their ability to operate the equipment, as well as ensuring there is the capacity to support individuals' ongoing use.

Whilst most of the participants enjoyed using the tablet computer, one participant reported that he felt like he was being watched and likened it to 'Big Brother'. Similar responses were reported by two participants in the study conducted by Warland and colleagues (Warland et al., 2019), where concerns regarding the privacy and security of the telerehabilitation system were expressed. Lemmens and colleagues (Lemmens et al., 2015) reported that in addition to being a time-consuming assessment method, the use of patient video recordings intruded on the patients' privacy. These patient-specific factors need to be considered if this form of video monitoring is to be explored.

### **8.3.3 Intensive upper limb exercise programs**

Chapter 5 described a qualitative exploration of adherence factors in stroke survivors who had participated in an intensive intervention (Lannin et al., 2020). Whilst previous studies have explored

exercise adherence in stroke survivors using qualitative methods (Nicholson et al., 2014; Mahmood et al., 2019), these studies have not explored factors specific to *intensive* upper limb exercise programs. Considering the extensive evidence supporting intensive upper limb practice following stroke, a comprehensive analysis of barriers to intensive exercise was warranted. A previous study explored factors influencing the acceptability of a 'high-intensity group-based exercise program for people with stroke' (Signal et al., 2016), however, the study presented in Chapter 5 differed considerably as it incorporated more home-based individual exercise programs at a much higher intensity. Aligning with the findings presented in Chapter 5, Signal and colleagues (Signal et al., 2016) reported the importance of self-motivation and external sources of motivation, the effect of fatigue, and the sense of frustration experienced when the exercises were more challenging. Further barriers and enablers to participation in intensive upper limb exercise programs will be discussed in the following subsections.

### **8.3.3.1 Interpersonal relationships**

The importance of the relationship between the health professional and client (and subsequent impact on adherence) has also been found in other studies (Signal et al., 2016). Signal and colleagues found participants viewed the role of the physiotherapists very positively, placing value in the level of expertise and ability to motivate them during training (Signal et al., 2016). Participants in the qualitative study (Chapter 5) placed a great deal of importance on the health professionals they were working with as a source of information, support, and motivation. This aligns with other studies that have described the need for support, comfort, and external motivation, most likely related to the limited self-efficacy of stroke survivors (Wiles et al., 2008; Simpson et al., 2011), and suggests that health professionals need to appreciate the interpersonal nature of therapy. The importance of the health professional and stroke survivor relationship, and the capacity for ongoing face to face monitoring, were described by many participants in the candidate's study as a critical component in facilitating ongoing exercise adherence. Similarly, in a study exploring stroke survivors' views of post-discharge programs, Wiles and colleagues (Wiles et al., 2008) reported that stroke survivors felt concerned about being 'left to their own devices' without regular contact with health professionals. This finding is consistent with other studies (Nicholson et al., 2014; Signal et al., 2016; Adams, 2017; Mahmood et al., 2019), and emphasises that health professionals should consider methods of ongoing supervision for home-based exercise programs, such as telehealth or face to face visits, to enhance adherence to exercise programs.

Furthermore, stroke survivors have described the health professional connection and encouragement as increasing self-efficacy to exercise (Resnick et al., 2008). In a recent study exploring the feasibility of technology use to connect stroke survivors and health professionals, Simpson and colleagues (Simpson et al., 2020) reported that high adherence rates may be linked to monitoring and provision of feedback by health professionals. In the candidate's qualitative

study, participants described the health professionals in very positive terms, and this level of perceived engagement positively influenced adherence to the exercise intervention. This finding is in line with a qualitative study exploring how practitioner engagement can influence patient engagement (Bright et al., 2017). In this study, Bright and colleagues (Bright et al., 2017) describe that both health professionals and stroke survivors recognise the importance of practitioner engagement and the role it plays in patient engagement.

A further aspect of the therapeutic relationship described by participants in the qualitative study (Chapter 5) was a sense of accountability. Accountability has been defined as “a relationship of control between different parties and has a connection to trust” (p. 13) (Cornelese, 2020), and Oussedik and colleagues (Oussedik et al., 2017) reported that accountability is commonly present in clinical trials. This is especially relevant in trials, such as the InTENSE trial, that incorporate self-report of adherence, as the anticipation of the follow-up and reporting may motivate participants to follow the clinical protocol. These findings have demonstrated that many stroke survivors feel very committed to meeting the expectations of their treating health professional and engaging a ‘contract’ for the amount of home-based practice may be a method to enhance adherence to exercise programs.

Many health services now incorporate a large telehealth component into stroke rehabilitation. This research has highlighted the importance of the relationship between stroke survivors and health professionals, which may be limited with less face to face contact. Hence, when considering the mode of delivery of therapy, health professionals need to ensure this interpersonal connection is not lost in a ‘digital world’. Thus, health professionals should assess whether the individual stroke survivor is likely to engage with therapy delivered via telehealth and adjust the intervention accordingly.

### **8.3.3.2 *The physical challenge***

A significant barrier identified in this research was the amount of difficulty experienced by the stroke survivors when performing the prescribed exercises, due to the severity of their upper limb impairment. This aligns with another study exploring barriers to exercise after stroke, where stroke survivors reported physical impairments experienced following stroke prevented engagement in physical activity (Damush et al., 2007). The importance of ensuring stroke survivors have the physical capability to perform the prescribed exercises is critical and was further highlighted by Simpson and colleagues (Simpson et al., 2011) who reported that being able to master the components of exercise determined what activities the participants chose to perform. This was consistent with Mahmood and colleagues (Mahmood et al., 2019), who reported that failure to accomplish tasks impacted confidence and reduced adherence to exercise. In this qualitative study, Mahmood and colleagues also reported boredom or losing interest in the program by

repeating the same set of exercises each day to be a significant barrier to adherence. Whilst participants in the InTENSE trial were often repeating exercises from the GRASP manual, the intermittent clinic visits enabled programs to be updated and modified, and in the candidate's cohort, boredom was not described as a key barrier. Whilst it may appear obvious that health professionals should prescribe exercises that the stroke survivor can physically manage, many participants in Chapter 5 reported that, despite having tailored programs from experienced staff, the physical challenge was the main barrier to adherence. It may be that health professionals need to take more time to ensure prescribed exercise programs enable successful participation in the exercises, whilst still setting a challenge for the stroke survivor. These findings may also indicate that health professional and stroke survivor views of the 'optimal' challenge level differ.

Cognitive challenges were not raised as a barrier to intensive exercise programs in the stroke survivors. However, the participants in the studies were considered to have no greater than mild cognitive impairment. This is an important consideration for health professionals, as it may be that stroke survivors with greater cognitive impairment need further support and different behavioural strategies to adhere to intensive exercise programs.

### **8.3.3.3 Hope**

Many participants in the qualitative study (Chapter 5) who persisted with exercises despite minimal noted improvements, described a strong belief in the process, or a sense of hope that adherence would lead to benefit. Similar findings have been reported in other studies involving stroke survivors (Visvanathan et al., 2019). Kulnik and colleagues found more specifically that people with stroke reported that it was important to 'keep at it' and not give up on the arm (Kulnik et al., 2018). These findings have demonstrated that adherence is closely linked to hope and that allowing stroke survivors to continue hoping may increase their adherence to exercise programs. Importantly, health professionals should be cautious about assessing stroke survivors' goals as 'unrealistic' or engaging in discussion around 'false hope' as this may lead to reduced motivation to participate and disengagement from rehabilitation.

In Chapter 5 many of the participants who showed minimal physical improvement described that they persisted with their exercises because they remained hopeful for some benefit. It was also noted that some stroke survivors adhered to the recommended amount of practice because they had faith in the process of participating in a research study. In a clinical environment, when not participating in a research study, if stroke survivors show little or no physical improvement despite adhering to therapy programs, health professionals might consider reviewing therapy goals and considering strategies to maintain participation and enthusiasm.

### **8.3.3.4 Habit formation**

Establishing routine behaviours and the structured nature of the intervention were features

described by many participants in the candidate's qualitative study as factors that enhanced adherence. The benefits of creating routine exercise behaviours, culminating in the formation of habit have been reported in the literature. Gardner (2015) described how the formation of exercise habits has benefits in that it is less cognitively demanding and will make it less likely that people will seek unhealthy alternative behaviours. Increasing evidence about habit formation is emerging and more work is needed to determine how health professionals can support exercise adherence behaviours to facilitate the formation of habits in stroke survivors.

### **8.3.4 Social support**

The importance of social support was reported in Chapters 3 and 5 of this thesis. This is consistent with findings in other studies, where participants reported a lack of support from family and friends can be a barrier to physical exercise following stroke (Nicholson et al., 2014; Mahmood et al., 2019; Nussbaum et al., 2019). In a recent qualitative exploration of exercise adherence in community-dwelling stroke survivors, Mahmood and colleagues (Mahmood et al., 2019) reported that a supportive family was the most important factor in promoting exercise adherence, via physical assistance to perform the exercises, encouragement to continue, and providing psychological support. Although the candidate's qualitative study reported similar findings, some negative aspects of social support were also discussed. For some participants there was a sense of guilt at needing to rely on and burden another person to assist, and some participants felt strain caused by a sense of frustration on the caregivers' behalf.

In Chapter 6 the candidate developed, implemented, and evaluated the Carers Count group which was an exercise-based group involving the stroke survivor and their carer. Including carers in the stroke rehabilitation environment is recommended in clinical guidelines (Stroke Foundation, 2017c) and described as contributing to a "3-way partnership together with health care providers and stroke survivors" (p. 1853) (Luker et al., 2017). Past work with carers has shown that they may be able to assist with extra practice, encourage motivation, and help in accessing information (Luker et al., 2016). Furthermore, carers want to contribute to the recovery of the stroke survivor and feel frustrated and disempowered about not being included. The carers in the candidate's intervention group valued the opportunity to be involved in a practical component of the stroke survivors' rehabilitation. To minimise the risk of 'over-dependence' the Carers Count group incorporated coaching techniques and self-management strategies, with a focus on the carer as a coach or facilitator of the stroke survivors' exercise program. This was an important feature of this group as it has been reported that being dependant on a carer may lead to poor adherence, as the stroke survivor may believe that they can only exercise if the carer helps them (Lin et al., 2020). Adopting a similar approach to that taken in the candidate's study, whereby the carer is encouraged to coach and promote the stroke survivors' self-management, should minimise this 'over-dependence' and enhance adherence.

Carers have indicated that knowing about the importance of exercise and understanding how to assist with the exercises are enablers to ongoing participation (Scorrano, Ntsiea & Maleka, 2018). A key goal of the Carers Count group was to increase the carers' understanding and capability to assist with the exercises as it has been reported that some carers lack knowledge and confidence about how to support the stroke survivor with exercises (Billinger et al., 2014; Scorrano, Ntsiea & Maleka, 2018). Other features of the Carers Count group align with many of the important factors identified in a qualitative study by Scorrano and colleagues, including providing external motivation and establishing routine practice times (Scorrano, Ntsiea & Maleka, 2018). Methods recommended for increasing the motivation of stroke survivors include providing information about rehabilitation and accessing patients' cultural norms (Maclean, Pound, Wolfe & Rudd, 2002). The Carers Count group aimed to enhance motivation through the provision of an engaging environment including music, imparting knowledge, and using coaching techniques.

Carer inclusion in rehabilitation is a recommendation of international guidelines (Hebert et al., 2016; Stroke Foundation, 2017c). A recent National Stroke Audit (Stroke Foundation, 2020) recommended improving the provision of information and education to the stroke survivor and their carers, including information on recovery. Researchers have explored the effectiveness of 'dyad' interventions, which are defined as interventions that target both the stroke survivor and the carer, with both being active participants (Bakas, McCarthy & Miller, 2017). Recommendations are that interventions incorporate the development of skills and provide education in an individualised or tailored format. In a comparable setting to the Carers Count group, Kalra and colleagues (Kalra et al., 2004) presented an example of a family and carer dyad intervention. In addition to usual care, the intervention group received instruction on stroke-related problems, positioning, gait facilitation, and 'hands-on' training in facilitation and mobility techniques. Commencing when the rehabilitation needs had stabilised, carers received three to five sessions, and improvements in carer burden and anxiety, and stroke survivor quality of life at three and 12 months were reported. The authors concluded that "the time may be ripe to use a structured program of activities under professional supervision during inpatient rehabilitation, to empower consenting informal caregivers in their future role by teaching them appropriate skills" (p. 5) (Kalra et al., 2004). These recommendations provide support for the content and structure of the Carers Count group. A key novel feature of the Carers Count intervention was delivery in a group setting, with other stroke survivors and their carers. Implementing groups as a method of providing peer support can benefit stroke survivors in terms of social contact, skill learning, receiving advice and information, increasing hope, helping others, and improved self-efficacy (Schwartzberg, 1994; Morris & Morris, 2012). Whilst more work is needed to establish the long-term benefits of participation in the Carers Count group in terms of exercise adherence, health professionals are encouraged to consider the early engagement of carers in the rehabilitation environment, including in a group format.

The studies reported in Chapters 5 and 6 of this thesis have indicated that whilst it is generally a positive relationship, the role of social support is not a straightforward one, and it is not always possible or ideal for 'carers' to be involved in rehabilitation. Health professionals need to assess the stroke survivors and their social support network to determine the potential benefits of, and barriers to, their involvement in rehabilitation. Consideration should be given to factors including who is the support person/carer (i.e. spouse, sibling, child, or friend), what are the other commitments of that support person/carer, are they physically and emotionally capable of being a support person/carer, what is the potential level of the burden they may be experiencing, and does the stroke survivor and their support person/carer want them to be involved in the rehabilitation journey?

### **8.3.5 Behaviour change**

In Chapter 7 the candidate described the process of using the Behaviour Change Wheel (BCW) (Michie, Atkins & West, 2014) and the Capability, Opportunity, Motivation-Behaviour (COM-B) model (Michie, Van Stralen & West, 2011) to develop an infographic guide for health professionals to use when developing exercise programs for stroke survivors. More practical tools to reduce the gap between research and practice are required. The World Health Organisation states that "health providers can have a significant impact by assessing the risk of nonadherence and delivering interventions to optimise adherence" (p. 14) (World Health Organisation, 2003). Aligning with this recommendation, this guide considers potential barriers and recommends strategies to enable health professionals to prescribe exercise programs that maximise adherence.

Other research studies have used the BCW framework to guide intervention development across a range of settings, including studies evaluating and developing exercise-based interventions (Stewart, Power, McCluskey & Kuys, 2019) and adherence-based studies (Ribaut et al., 2020).

## **8.4 Implications for practice**

The work outlined in this thesis has deepened the understanding of factors to consider when developing, implementing, and monitoring intensive exercise programs with stroke survivors.

In the absence of a gold standard measurement tool of adherence, some have suggested that health professionals consider using multi-faceted methods of measurement. Health professionals may have greater confidence in the reliability of the stroke survivors' self-report if it is supported by objective data gained through devices such as activity monitors or using a tablet computer, as outlined in this research. The use of the tablet computer enabled the candidate to accurately evaluate the amount of practice the participants were doing. However, as it was a labour-intensive process, for real-world application health professionals should consider time-efficient methods of activity tracking. One example would be the use of programs such as Physitrak® which

incorporate a remote activity monitoring feature within the platform. To maximise the effect of this program, health professionals would need to embed a method of providing feedback on performance to the stroke survivor. This form of adherence tracking may not be necessary for all stroke survivors, and health professionals should identify those at risk, based on consideration of factors such as level of social support and physical impairment.

Technological advances and innovative programs continue to extend into the area of stroke rehabilitation. This research showed that some stroke survivors are willing to engage with technology, such as tablet computers and accelerometers, and may benefit from its inclusion in their exercise programs. However, health professionals should consider the individual stroke survivor and whether there may be specific characteristics of that person that would limit the effectiveness of technology use. For example, stroke survivors who have minimal social support, or a high degree of physical or cognitive impairment may have barriers to successful use.

Health professionals must consider potential barriers and enablers to adherence when developing home exercise programs. For example, many participants described the importance of having hope as an ongoing motivator for adhering to exercise programs. This aligns with the literature on stroke self-management which identifies the importance of allowing stroke survivors to aspire to the big dream goals by providing a “map towards their overall goal or aspiration” (p. 4) (McKenna et al., 2015). Whilst many health professionals fear giving stroke survivors ‘false hope’, they should be aware that allowing stroke survivors to maintain hope and aspire to their goals can be a source of ongoing motivation, which may lead to increased adherence to ongoing exercise programs.

Another key finding for consideration from Chapter 5 is the value and importance that stroke survivors place on the relationship with the health professional. Whilst developing self-management principles is an important aspect of stroke care, the capacity to ‘check-in’ with a health professional was emphasised as an important enabler to exercise adherence. It has been reported that there are shortcomings in the follow-up needs of stroke survivors (Martinsen, Kirkevold & Sveen, 2015), hence consideration for stroke rehabilitation services that support long-term follow-up with in-person or telehealth contact is warranted. Health professionals should be aware of the importance of this professional relationship and use evidence-based methods, such as coaching principles and motivational interviewing to optimise its influence on adherence.

Participants in the qualitative study (Chapter 5) described feeling bound to their word and having a sense of commitment, and this is an area that health professionals can make use of. When designing exercise programs, health professionals should consider methods to take advantage of this sense of ‘accountability’, such as the use of behavioural contracts. Behavioural contracts are documents that outline an agreement between the health professional and the stroke survivor and have been used extensively with stroke survivors, especially in the implementation of Constraint-



Induced Movement Therapy (Taub et al., 1993).

Throughout this thesis, the importance of social support as an influence on exercise adherence was emphasised. Chapter 6 highlighted that it was possible to develop and implement modes of delivery in rehabilitation that include the carers of stroke survivors, and this intervention was considered enjoyable and beneficial. The interview outcomes described in Chapter 6 reported that both stroke survivors and their carers described positive outcomes of participation in the Carers Count group, including greater understanding and confidence in how to support the stroke survivor following hospital discharge. Thus, health professionals should endeavour to include carers in the stroke rehabilitation journey as early as possible. Carers have traditionally been involved in 'formal' aspects of rehabilitation such as case conferences and discharge planning meetings, but it is apparent that many carers value being involved in a very 'hands-on' way, such as occurred during the Carers Count group. One limitation of the Carers Count study was that many stroke survivors could not attend as they did not have a carer available. To increase accessibility to an intervention such as Carers Count, health services could consider the development of digital resources and the inclusion of carers during telehealth group sessions.

To develop an infographic for health professionals (Chapter 7), the candidate used a systematic process to assess potential barriers to adherence, as recommended in the literature (World Health Organisation, 2003). The guide developed, featured by the Australian Physiotherapy Association during Stroke Week 2020, provides health professionals with evidence-based behaviour change strategies aimed at maximising adherence to prescribed exercise programs. This guide has been disseminated through social media networks and presentation at a state forum in South Australia. The guide has been produced in electronic and print form (poster and pamphlet) and could be used by physiotherapists and occupational therapists working with stroke survivors.

The Capability, Opportunity, Motivation-Behaviour (COM-B) model (Michie, Van Stralen & West, 2011) was used in the research presented within this thesis and was considered to provide a strong foundation for the exploration of adherence. Throughout Chapters 3-6 of this thesis, factors relating to capability, opportunity, and motivation were explored. A description of how the COM-B model can be applied to the findings from the chapters presented in this thesis is included in Table 8-1.

**Table 8-1 Applying the COM-B model to thesis findings**

<b>Thesis chapter</b>	<b>Application of the COM-B model</b>
<b>3</b>	<p><b>Method:</b> Evaluation of factors that may influence adherence to the prescribed exercise program</p> <p><b>Influence of C, O, M:</b></p> <p><b>Capability</b> – the level of impairment influenced adherence</p> <p><b>Capability, Opportunity, Motivation</b> – social support influenced adherence</p>
<b>4</b>	<p><b>Method:</b> Explore the role of concurrent visual feedback (via tablet computer) on adherence to upper limb home exercise program</p> <p><b>Influence of C, O, M:</b></p> <p><b>Motivation</b> – The addition of tablet computer may increase adherence in some stroke survivors</p>
<b>5</b>	<p><b>Method:</b> Evaluation of barriers and enablers that may influence adherence to intensive upper limb exercise program, coded using the COM-B model</p> <p><b>Influence of C, O, M:</b></p> <p><b>Capability</b> – the level of challenge and reliance on others were barriers to exercise</p> <p><b>Opportunity</b> – social support, face to face contact, and trust in health professional were enablers</p> <p><b>Motivation</b> – hope, accountability, and routine practice were enablers</p>
<b>6</b>	<p><b>Method:</b> Explore the implementation of an exercise-based group for stroke survivors and their carers</p> <p><b>Influence of C, O, M:</b></p> <p><b>Capability</b> – increased confidence with post-discharge exercises</p> <p><b>Opportunity</b> – increased amount of physical exercise as participated in group</p> <p><b>Motivation</b> – increased understanding about neuroplasticity, engaging experience</p>

Motivation played a key role across all studies presented in this thesis. It could be considered that many of the participants in Chapters 3-5 were motivated, as they had agreed to participate in intensive exercise programs of four- or ten-weeks duration. However, despite this fact, many issues that occurred with low rates of adherence related to motivation factors. It is reported that stroke survivors may have reduced intrinsic motivation (Rapolienė, Endzelytė, Jasevičienė & Savickas, 2018) and health professionals should develop tools to assess motivation and use strategies to improve motivation. Health professionals can consider using methods of extrinsic motivation presented in this thesis, including the use of concurrent visual feedback, the involvement of the carer, and participation in a fun and engaging group. Furthermore, health professionals should be encouraged to incorporate behaviour change strategies when working with stroke survivors. Examples discussed in this thesis include self-management strategies, individualised goal setting, and enhancement of self-efficacy.

## 8.5 Implications for research

The World Health Organisation (World Health Organisation, 2003) report recommends the development of an 'adherence counselling tool-kit' incorporating information on adherence, assessment tools and strategies to promote change, as well as behavioural tools for creating or maintaining habits. An adherence 'tool-kit', aiming to provide an evidence-based educational resource to improve health professionals' knowledge and confidence with adherence enhancing activities, was successfully tested in the musculoskeletal population (Babatunde, MacDermid & MacIntyre, 2017). This study demonstrates the practical implementation of a 'tool-kit' as recommended by the World Health Organisation (World Health Organisation, 2003), and future research should explore a similar intervention, with the development and testing of tools, for health professionals working with stroke survivors. Whilst studies in this thesis enabled the development of a health professional guide, more research is needed in this area and the development and feasibility testing of resources that target stroke are required. Aligning with the World Health Organisation (World Health Organisation, 2003) recommendations, resources should be theory-based but health professional and stroke survivor friendly.

Chapter 2 highlighted a lack of valid and reliable methods of measurement of adherence for stroke survivors. It is a current research challenge to develop the 'best methods' of adherence monitoring that combine objective measures with non-objective methods such as diaries or questionnaires. An area for ongoing research would be to consider further developing or validating methods identified in Chapter 2 that are considered easy for health professionals to use. For example, Vanroy and colleagues (Vanroy et al., 2014) developed a coded physical activity diary in which the stroke survivors chose the dominant activity performed in 30-minute intervals, all linked to simple codes. It was hypothesised that this form of diary use minimises writing and recall and may be easier for some stroke survivors to use. Developing and validating a coded diary with specific exercise parameters such as duration of time spent exercising or the number of exercises completed would be an area for further investigation. Furthermore, testing the reliability and validity of existing measures and considering the development of new tools is an area that requires further research. The research presented within this thesis demonstrated that there are issues with the utility of upper limb accelerometers in an ambulatory setting, and the development of a more usable device for monitoring upper limb activity is warranted.

The timing of intensive rehabilitation was discussed in Chapter 5 of this thesis and is an area that warrants further investigation. The timing of intervention would be interesting to explore from the aspect of the level of chronicity of impairment and how this correlates to rates of adherence and ongoing recovery. Whilst it is apparent that the brain is most responsive to therapy early post-stroke, functional gains are still possible in a chronic population (Teasell, Bitensky, Salter &

Bayona, 2005; Ward, Brander & Kelly, 2019). However, Chapter 5 presented some barriers to adherence to intensive exercise programs, such as level of impairment, which may be significant in a more chronic population. Fully understanding how adherence rates vary over time would enable health professionals to develop timely and relevant strategies to maximise adherence across the stroke survivors' lifespan. Different behavioural strategies may be more effective at different phases of stroke recovery and this warrants further investigation.

The Capability, Opportunity, Motivation-Behaviour (COM-B) model provided a framework for the exploration of adherence within this thesis. Within the COM-B model, Automatic Motivation is defined as "behaviour that is driven by impulses, emotional reaction or reflexive processes such as a trigger to perform a behaviour that has become habitual" (p. 3) (Govender et al., 2017). There is extensive literature exploring habit formation and habit theory (Gardner & Rebar, 2019). Habitual behaviours should persist even when they no longer serve the initial goal, or when motivation has reduced (Wood & Neal, 2007) and should be independent of intentions and beliefs (Phillips et al., 2016). For long-term adherence to exercise, habits are important as they do not rely on self-regulation and are not subject to the temptation of considering alternatives (Danner, Aarts & de Vries, 2008). Currently, there is no research exploring habit formation for exercise in stroke survivors, and this would be a valuable and interesting extension of adherence studies as it could contribute to more long-term behaviour change.

This thesis sought to explore factors specific to adherence to *intensive* exercise in stroke survivors. Some of the findings of this thesis, such as the importance of social support and physical capability, have been reported in previous studies of adherence to programs that would not be considered *intensive*. To provide health professionals with a greater understanding of the specific factors relating to intensity of prescribed programs, a further study comparing adherence to intensive and non-intensive programs would be beneficial.

Lastly, limited resources meant the Carers Count study was not designed to determine the effect on outcomes such as long-term exercise adherence, functional recovery, or quality of life. Furthermore, the studies in Chapters 3 and 4 did not assess whether increased adherence led to improved upper limb function. Large scale trials of several of the interventions presented in this thesis would enable increased generalisability of findings. In relation to Chapter 6, it would be beneficial to explore the long-term benefits of participation in the Carers Count group, including the effect on ongoing exercise adherence and carer burden. In addition, exploring the efficacy of concurrent visual feedback via the tablet computer (Chapter 4) in a 'less adherent' group of participants, with lower baseline motivation levels, may provide health professionals with an additional motivational tool.

## 8.6 Strengths

A strength of the research presented within this thesis is the mixed methods approach used to explore adherence factors in stroke survivors. The thesis has described qualitative and quantitative methodologies and also presented a pilot study, implemented in a ward environment. Each study has contributed to a comprehensive understanding of adherence to intensive exercise in stroke survivors. The thesis tells a story, whereby each study leads logically into the following study.

The studies within this thesis also explored stroke survivor recovery across a range of timeframes—from early in the rehabilitation journey (Chapter 6) to more chronic (Chapters 3 and 5), and from mildly impaired (Chapter 4) to more severely impaired (Chapters 3 and 5). This broad lens on stroke survivors' adherence to intensive exercise programs provides important information for health professionals working across a range of rehabilitation services, from inpatient to outpatient and community. Another strength of this thesis was that the studies were conducted in a clinical setting. Hence the recommendations made for health professionals can be considered relevant to current clinical practice and are readily translatable into a clinical setting.

The candidate commenced the research with a systematic review (Chapter 2) aiming to identify evidence-based methods of monitoring adherence that could be implemented in the studies that followed. Systematic reviews allow large amounts of evidence to be synthesised and enable generalisability of study findings (Mulrow, 1994). The candidate followed a rigorous process through both phases of the review, further strengthening the findings. Conducting a two-phase systematic review was a strength of this thesis as it enabled the candidate to provide evidence-based recommendations to researchers and health professionals. Chapter 2 highlighted the lack of standardised stroke-specific methods of measurement to exercise and recommended that health professionals should consider using more than one method of adherence monitoring to increase confidence in their findings. Subsequent studies (Chapter 3 and 4) within the thesis adhered to this recommendation, using a combination of self-report and objective measures (tablet computer and accelerometer respectively). This enabled the candidate to confidently report the amount of practice undertaken, in addition to identifying inaccuracies in self-report measures.

Chapter 5 used validated theory-based behaviour change frameworks to guide the qualitative methodology (Michie, Van Stralen & West, 2011; Atkins et al., 2017). It is reported that research that is not theory-informed has limited usefulness (Grant & Osalanoo, 2014), and this strong theoretical framework enabled the presentation of evidence-based findings and recommendations regarding adherence. A strength of this study lies in the population that was interviewed; a group of stroke survivors who had participated in an intensive home-based upper limb exercise intervention, with high levels of adherence despite making minimal physical gains (Lannin et al., 2020). This provided insight for the researchers on factors that may support adherence, including in stroke

survivors with a significant physical impairment who are not benefiting from the intervention. A strong framework (Proctor et al., 2009) and a range of implementation strategies also gave strength to the Carers Count study presented in Chapter 6 of this thesis. This study was evaluated across different domains (Powell et al., 2012) which allowed the candidate to present a broad range of outcome measures for health professionals to consider. Furthermore, conducting this study on an inpatient stroke ward provides clinical relevance and highlights considerations for implementation for health practitioners working in early stroke rehabilitation.

Chapter 7 outlined the process used to synthesise the research findings and develop a guide for health professionals to use when prescribing exercises for stroke survivors. This process was theory-based (Michie, Atkins & West, 2014) and the infographic developed was evidence-based, informative, and visually appealing. The process for analysis of barriers was systematic, as recommended in the literature (World Health Organisation, 2003). The development of this guide involved bringing many of the research findings together to produce a useful and practical resource for health professionals.

Throughout all studies in this thesis the candidate used a consistent method of adherence monitoring, time/duration of exercise. This thesis has reported that time/duration continues to be the dominant measure reported in research and clinical guidelines (Kwakkel et al., 2004; Kaur, English & Hillier, 2012), hence the method of adherence monitoring used by the candidate aligns with current evidence. Given that some issues with reporting time as a measure have been described (Connell et al., 2014b), a further strength of this thesis is that the candidate used objective data collection methods (tablet computer and accelerometry) to support self-report findings.

## **8.7 Limitations**

A bias in research is defined as “the combination of various design, data, analysis, and presentation factors that tend to produce research findings when they should not be produced” (p. 697) (Ioannidis, 2005), and there are several biases specific to the research described in this thesis which may limit the replicability of findings. For example, except for Chapter 5, all studies were conducted with stroke survivors who had received their rehabilitation at a single site. This limits the generalisability of findings as this cohort of stroke survivors and delivery of interventions may not reflect the stroke population or delivery of stroke services in other states or countries (Teasell et al., 2009).

Furthermore, studies presented in Chapters 3 and 4 involved a small sample size (n=10) which limited the generalisability of findings (Pye, Taylor, Clay-Williams & Braithwaite, 2016). Additionally, the participants in Chapter 3 had agreed to an intensive ten-week exercise program (the INTENSE

trial) and hence could be considered highly motivated. This could be considered a form of selection bias (Tripepi, Jager, Dekker & Zoccali, 2010), as findings from this group of participants may not reflect the general stroke population. Similarly, in Chapter 4 participants had consented to an intensive four-week exercise program. It would be of benefit to examine the introduction of the concurrent visual feedback (tablet computer) in a group of stroke survivors considered to be less likely to adhere. In Chapters 3 and 4, a mixed-methods study with in-depth qualitative interviews would have provided a greater understanding of the feasibility of this approach to adherence monitoring, influence of the visual feedback aspect of the tablet computer, and exploration of factors that may have influenced adherence to the exercise programs. In Chapters 3 and 4 there were some issues with technology usability which impacted on data collection and completeness of the data set.

Chapter 6 described the implementation of an evidence-based approach and examined the outcomes of acceptability, adoption, and sustainability. The program demonstrated the approach was acceptable, readily adopted within existing resources, but in this study, there was no direct objective measurement of levels of adherence or exercise practice. There was also no control group. The follow-up interviews explored self-reported and carer reported adherence to exercise of the stroke survivor. In addition, an evaluation was not possible to make any definitive conclusions regarding the long-term benefits of attending the group from a carer or stroke survivor perspective as follow-up was only undertaken at 1-month post-discharge. There is potential for data collection bias (Smith & Noble, 2014) in this study as follow-up interviews were conducted with the stroke survivor and carer together; this may have impacted the responses given to questions such as reported carer burden. Furthermore, due to the male-dominated sample in this study (over 70%), there is a limitation in the generalisability of findings to a general stroke population.

Whilst all studies described adherence in terms of time spent exercising, there has been criticism of this approach (Connell et al., 2014b). A systematic review reported that stroke survivors are physically active for on average 60% of their physiotherapy sessions (Kwakkel et al., 2004), hence caution should be taken when reporting time spent in therapy sessions in research trials (Connell et al., 2014b).

A limitation of this thesis is a potential for population bias (Malone, Nicholl & Tracey, 2014), as an exploration of adherence across a range of cultural and economic settings was not conducted. This is an area for further research which would ensure increased generalizability of findings across the broader stroke population.

Chapter 7 presented the development of a guide for health professionals to use when prescribing home exercises for stroke survivors, however, the usability or usefulness of this infographic has not been established. The next stage of the process would be to implement and assess the usability of

this guide within the health setting.

## **8.8 Conclusion**

In this thesis the candidate described the lack of valid and reliable tools to monitor adherence in stroke rehabilitation and recommended that health professionals consider the use of additional objective methods, such as tablet computers, to supplement stroke survivor self-report. Furthermore, the candidate found key barriers to adherence to intensive exercise programs in stroke survivors, such as the amount of social support and level of physical impairment, and outlined how health professionals can use a behaviour change framework to address these barriers in therapy. This research has also established that health professionals can utilise simple forms of technology to provide extrinsic motivation in some stroke survivors. The work in this thesis has described how, through the development and implementation of an inpatient group, health services can include the family members or friends of the stroke survivor during the rehabilitation process to possibly support exercise adherence after discharge. Lastly, to enable health professionals to develop exercise programs that support adherence, this thesis has outlined the use of a behaviour change model and synthesised study findings to present a theory-informed infographic guide.



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## Appendix 1 Feasibility study; Ethics approval

### Ethics application approval

You are reminded that this letter constitutes ethical approval only. You must not commence this research project at any SA Health sites listed in the application until a Site Specific Assessment (SSA) form has been authorised by the Chief Executive or delegate of each site.

31 July 2015

Dear Mrs Levy

This is a formal correspondence from the Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC EC00188). This committee operates in accordance with the "National Statement on Ethical Conduct in Human Research (2007)." No hard copy correspondence will be issued.

**Application Number:** 246.15 - HREC/15/SAC/197

**Title:** Investigating the amount of upper limb exercise stroke patients do at home and examining factors that may influence adherence to a home exercise program

**Chief investigator:** Mrs Tamina Levy

**Public health sites approved:** Repatriation General Hospital

The Issue: The Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC) have reviewed and approved the above application. The approval extends to the following documents/changes:

- SA Health Low and Negligible Risk Application Form dated 26 May 2015
- SA Health Indemnity email dated 26 May 2015
- Head of Department - Professor Maria Crotty Support Letter dated 18 May 2015
- Literature Review
- Participant Information Sheet/Consent Form – Adult - Own Consent v3 dated 31 July 2015
- Social Support and Exercise Survey
- Multidimensional Scale of Perceived Social Support
- The Self-Efficacy for Exercise Scale

**Approval Period:** 31 July 2015 to 31 July 2018

**Please read the terms and conditions of ethical approval below, as researchers have a significant responsibility to comply with reporting requirements and the other stated conditions.**

**For example, the implications of not providing annual reports and requesting an extension for research prior to approval expiring could lead to the suspension of the research, and has further serious consequences.**

Please retain a copy of this approval for your records.

*Flinders  
Medical  
Centre  
The Flats G5  
– Rooms 3  
and 4  
Flinders  
Drive,  
Bedford  
Park SA  
5042*

*T: 08 8204 6453*

*F: 08 8204 4586*

*E: Research.ethi  
cs  
@health.sa.gov  
.au*

## TERMS AND CONDITIONS OF ETHICAL APPROVAL

Final ethical approval is granted subject to the researcher agreeing to meet the following terms and conditions.

**As part of the Institution's responsibilities in monitoring research and complying with audit requirements, it is essential that researchers adhere to the conditions below.**

**Researchers have a significant responsibility to comply with the *National Statement 5.5* in providing the SAC HREC with the required information and reporting as detailed below:**

1. **The approval only covers the science and ethics component of the application.** A SSA will need to be submitted and authorised before this research project can commence at any of the approved sites identified in the application.
2. **It is the policy of the SAC HREC not to provide signed hardcopy or signed electronic approval letters,** as our office is moving to electronic documentation. The SAC HREC office provides an unsigned electronic PDF version of the study approval letter to the Chief Investigator/Study Manager via email. These email approvals are generated via the email address [research.ethics@health.sa.gov.au](mailto:research.ethics@health.sa.gov.au) which can be linked back to the SAC HREC.
3. **If University personnel are involved in this project,** the Principal Investigator should notify the University before commencing their research to ensure compliance with University requirements including any insurance and indemnification requirements.
4. **Compliance** with the *National Statement on Ethical Conduct in Human Research (2007)* & the *Australian Code for the Responsible Conduct of Research (2007)*.
5. To **immediately report to SAC HREC** anything that may change the ethical or scientific integrity of the project.
6. **Report Significant Adverse events (SAE's)** as per SAE requirements available at our website.
7. **Submit an annual report on each anniversary of the date of final approval** and in the correct template from the SAC HREC website.
8. **Confidentiality** of research participants MUST be maintained at all times.
9. A copy of the **signed consent form** must be given to the participant unless the project is an audit.
10. Any **reports or publications derived from the research** should be submitted to the Committee at the completion of the project.
11. All requests for **access to medical records** at any SALHN site must be accompanied by this approval email.
12. To **regularly review the SAC HREC website** and comply with all submission requirements, as they change from time to time.
13. The researchers agree to use **electronic format** for all correspondence with this department.

Kind Regards

Anna Pantelidis  
Administration Officer, SAC HREC

On behalf of  
Professor David Gordon  
Chair, SAC HREC



## Appendix 2 Single-case series; Ethics approval



Government of South Australia

SA Health

Southern Adelaide Local Health Network

12 July 2018

Maggie Killington Rehabilitation and Aged Care Flinders University  
BEDFORD PARK SA 5042

Dear Ms Killington

OFR Number: 97.18

Study title: The feasibility of using a computer tablet to promote adherence to an upper limb home exercise program in stroke patients: a single case series

Chief Investigator: Maggie Killington

Ethics Approval Period: 05 June 2018 – 05 June 2021

The Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC EC00188) has reviewed and provided ethics approval for this amendment which meets the requirements of the National Statement on Ethical Conduct in Human Research (2007).

This amendment approval does not alter the current SAC HREC approval period.

Public health sites approved under this Ethics amendment application: Flinders Medical Centre The below documents have been reviewed and approved by the SAC HREC:

- Project amendment form - Remove kinematic assessment – dated 06 June 2018
- HREA dated 08 July 2018
- Project description v1.2 dated 06 June 2018
- Participant information sheet and consent form v2 dated 06 June 2018
- Technology questionnaire v1 dated 07 June 2018
- The system usability scale v1 dated 06 June 2018

Terms and Conditions Of Ethics Approval:

It is essential that researchers adhere to the conditions below and with the National Statement Chapter 5.5.

Final ethics approval is granted subject to the researcher agreeing to meet the following terms and conditions:

1. The approval covers the ethics component of the application. Please submit a copy of the approved amendment to the local RGO for acknowledgement
2. If University personnel are involved in this project, the Principal Investigator should notify

the University before commencing their research to ensure compliance with University requirements including any insurance and indemnification requirements.

3. Compliance with the National Statement on Ethical Conduct in Human Research (2007) & the Australian Code for the Responsible Conduct of Research (2007).
4. To immediately report to SAC HREC anything that may change the ethics or scientific integrity of Report Significant Adverse events (SAE's) as per SAE requirements available at our website.
5. Submit an annual report on each anniversary of the date of final approval and in the correct template from the SAC HREC website.
6. Confidentiality of research participants MUST be maintained at all times.
7. A copy of the signed consent form must be given to the participant unless the project is an audit.
8. Any reports or publications derived from the research should be submitted to the Committee at the completion of the project.
9. All requests for access to medical records at any SALHN site must be accompanied by this approval email.
10. To regularly review the SAC HREC website and comply with all submission requirements, as they change from time to time.
11. Once your research project has concluded, any new product/procedure/intervention cannot be conducted in the SALHN as standard practice without the approval of the SALHN New Medical Products and Standardisation Committee or the SALHN New Health Technology and Clinical Practice Innovation Committee (as applicable) Please refer to the relevant committee link on the SALHN intranet for further information.
12. Researchers are reminded that all advertisements/flyers need to be approved by the committee, and that no promotion of a study can commence until final ethics and executive approval has been obtained. In addition, all media contact should be coordinated through the FMC media unit.

For any queries about this matter, please contact the Executive Officer on (08) 8204 6453 or via email to [Health.SALHNOfficeforResearch@sa.gov.au](mailto:Health.SALHNOfficeforResearch@sa.gov.au).

A/Professor Bernadette Richards  
Chair, SAC HREC

## Appendix 3 Qualitative study; Ethics approval



21 August 2015

Professor Maria Crotty GPO Box 2100  
ADELAIDE SA 5001

Dear Professor Crotty  
Government of South Australia  
Southern Adelaide Health Service

HREC reference number: SSA reference number: Project title:

Ethics approval: Site:  
Subject:

HREC/15/RAH/222 (259.15) SSA/15/SAC/220  
The InTENSE trial: optimising upper limb recovery following stroke  
01 July 2015 - 01 July 2018  
Repatriation General Hospital Site Specific Assessment Review

Thank you for submitting an application for authorisation of this project. I am pleased to inform you that authorisation has been granted for this study to commence.

- RAH HREC approval letter dated 01 July 2015
- Ethics committee certificate of approval letter from The Alfred - no date
- Certificate of approval of amendments letter from The Alfred dated 27 April 2015
- Site Specific Assessment form
- CV for Professor Maria Crotty
- SA Health indemnity approval dated 02 June 2015
- RGH Participant information sheet and consent form v4 dated 03 June 2015

HREC reviewed documents listed on the approval letter dated 01 July 2015 from the RAH HREC are accepted as part of the site authorisation.

Should you have any queries about the consideration of your Site Specific Assessment form, please contact Timothy Jones on 8204 4507.

The SSA reference number should be quoted in any correspondence about this matter.

If University personnel are involved in this project, the Principal Investigator should notify the University before commencing their research to ensure compliance with University requirements including any insurance and indemnification requirements.

Yours sincerely

Timothy Jones  
Acting Research Governance Officer, Southern Adelaide Local Health Network

## Appendix 4 Carers Count study; Ethics approval

### Office for Research

Flinders Medical Centre  
Ward 6C, Room 6A219  
Flinders Drive, Bedford Park SA 5042  
Tel: (08) 8204 6453  
E: Health.SALHNOfficeforResearch@sa.gov.au



Government of South Australia

SA Health

Southern Adelaide Local Health Network

## Final Approval for Ethics Application

16 July 2019

Tamina Levy  
Rehabilitation and Palliative Division  
Flinders Medical Centre

Dear Ms Levy

**OFR Number:** 75.19

**HREC reference number:** HREC/19/SAC/83

**Project title:** A feasibility study to examine the effects of a carer-mediated exercise group on an inpatient stroke ward: the carer's count study

**Chief Investigator:** Tamina Levy

**Ethics Approval Period:** 16.07.2019 – 16.07.2021

The Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC) (EC00188) have reviewed and approved this application out of session, through the low and negligible risk pathway, and provided approval which meets the requirements of the *National Statement on Ethical Conduct in Human Research (2007, updated 2018)*.

You are reminded that this letter constitutes **Ethics** approval only. **Ethics approval is one aspect of the research governance process.**

You must not commence this research project at any SA Health sites listed in the application until a Site Specific Assessment (SSA), or Access Request for data or tissue form, has been approved by the Chief Executive or delegate of each site.

Public health sites approved under this application:

- Flinders Medical Centre

The below documents have been reviewed and approved:

Document	Version	Date
Cover letter	1	01.04.2019
HREA	AU/1/239A38	08.07.2019
Project description	1.1	05.04.2019
Participant information sheet and consent form - patients	2	08.05.2019
Participant information sheet and consent form - carers	2	08.05.2019
Participant information sheet and consent form - staff focus group	1	05.04.2019

Carer interview	2	09.05.2019
Carer: attendance record, pre-checklist, survey, logic model	1	05.04.2019
Focus group questions	1	05.04.2019
Intervention guide	1	05.04.2019
Patient interview	2	09.5.2019
Patient survey	1	05.04.2019
Staff survey	1	05.04.2019

### **TERMS AND CONDITIONS OF ETHICS AND GOVERNANCE APPROVAL**

The Principal Investigator must ensure this research complies with the National Statement on Ethical Conduct in Human Research (2018) & the Australian Code for the Responsible Conduct of Research (2007 updated 2018) by immediately reporting to the Office for Research (OFR) anything that may change the ethics or scientific integrity of the project. Final approval is granted subject to the researcher agreeing to meet the following terms and conditions:

1. Confidentiality of research participants MUST be maintained at all times.
2. If the research involves the recruitment of participants, a signed copy of the 'Consent Form' must be given to the participant. Any changes to the Participant Information Sheet/Consent Form must be approved by the lead HREC prior to being used.
3. No promotion of a study can commence until final ethics and SALHN executive approval has been obtained. All advertisements/flyers need to be approved by the committee and media contact should be coordinated through the FMC media unit.
4. Non-SA Health researchers viewing confidential SALHN data are required to complete and sign a SALHN Confidentiality Disclosure Deed
5. All approved requests for access to medical records at any SALHN site must be accompanied by this approval letter.
6. If your study involves a tertiary institution, contact the University to ensure compliance with University requirements prior to commencement of this study. This includes any insurance and indemnification.
7. The PI must adhere to Monitoring and Reporting requirements for both ethics and governance which are available on the SALHN Research Website.
8. The PI must immediately report to SAC HREC anything that may change the ethics or scientific integrity of the project
9. An annual report must be submitted to the SAC HREC and SALHN governance on each anniversary of the date of final approval. Please visit the Office for Research website for the current template.
10. Non-SA Health researchers coming onsite at SALHN must provide evidence of a recent (<3 years) screening check. It is the responsibility of the Principal Investigator to ensure any non-SA Health personnel who conducts or monitors research meets SA Health screening requirements as per the SA Health Criminal & Relevant History Screening Policy Directive before they access any SA Health site. The cost of any such screening is the responsibility of the individual accessing the site or their employer.
11. Any reports or publications derived from the research should be submitted to the Committee at the completion of the project.
12. Once the research project has concluded, any new product/procedure/intervention cannot be conducted in the SALHN as standard practice without the approval of the SALHN New Medical Products and Standardisation Committee or the SALHN New Health Technology and Clinical Practice Innovation Committee (as applicable). Please refer to the relevant committee link on the SALHN intranet for further information.
13. SALHN site-monitoring of authorised studies - this approval/authorisation is subject to participation in this monitoring process. You will be notified in advance if your site has been selected for an inspection.

Please visit the SALHN Research website regularly and comply with all submission requirements as they may change from time to time.

For any queries about this matter, please contact The Office for Research on (08) 8204 6453 or via email to [Health.SALHNOfficeforResearch@sa.gov.au](mailto:Health.SALHNOfficeforResearch@sa.gov.au)

Yours sincerely,

A handwritten signature in black ink, appearing to be 'Bill Heddle', written in a cursive style.

**Professor Bill Heddle**

Chair

Southern Adelaide Clinical Human Research Ethics Committee

# Appendix 5 Systematic review; Phase 1 search strategy

Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily, Ovid MEDLINE and Versions(R)  
 Search history sorted by search number ascending

#	Searches	Results	Type
1	Patient Compliance/ and (Exercise Therapy/ or Exercise Movement Techniques/)	1277	Advanced
2	((exercis* or activit* or physio*) adj8 (adher* or nonadher* or complian* or noncomplian* or concordan* or cooperat* or "co-operat*" or uncooperat* or "unco-operat*" or engag* or disengag* or attend* or uptake or participat* or maintenance)).tw,kw.	85071	Advanced
3	or/1-2	85767	Advanced
4	"surveys and questionnaires"/ or health care surveys/ or patient reported outcome measures/ or population surveillance/ or self report/	476018	Advanced
5	(survey* or questionnaire* or self report* or "self-report*").tw,kw.	926075	Advanced
6	(measur* or assess or assessment* or score* or evaluat* or analy* or tool* or track* or predict* or diary or diaries or observe or observing or observation or video* or checklist*).tw,kw.	10021227	Advanced
7	or/4-6	10341314	Advanced
8	cerebrovascular disorders/ or exp basal ganglia cerebrovascular disease/ or exp brain ischemia/ or exp carotid artery diseases/ or exp intracranial arterial diseases/ or exp "intracranial embolism and thrombosis"/ or exp intracranial hemorrhages/ or stroke/ or exp brain infarction/ or exp vertebral artery dissection/	314494	Advanced
9	(stroke or cerebrovasc* or brain vascul* or cerebral vascul* or cva* or apoplex*).tw,kw.	248576	Advanced
10	((brain* or cerebr* or cerebell* or vertebrobasilar or hemispher* or intracran* or intracerebral or infratentorial or supratentorial or MCA or anterior circulation or posterior circulation or basal ganglia) adj5 (ischemi* or ischaemi* or infarct* or thrombo* or emboli*)).tw,kw.	92812	Advanced
11	((brain* or cerebr* or cerebell* or intracerebral or intracran* or parenchymal or intraventricular or infratentorial or supratentorial or basal gangli*) adj5 (haemorrhage* or hemorrhage* or haematoma* or hematoma* or bleed*)).tw,kw.	49652	Advanced
12	(brain* adj3 injur*).tw,kw.	57803	Advanced
13	or/8-12	508317	Advanced
14	and/3,7,13	1648	Advanced

## Appendix 6 Systematic review; Phase 2 search strategy

Database(s): Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily, Ovid MEDLINE and Versions(R) 1946 to February 21, 2018

Search Strategy:

#	Searches	Results
1	"Surveys and Questionnaires"/	389602
2	(diar* or logbook* or "record of practice" or PASIPD or "Physical Activities Scale for Individuals with a physical disability" or journal* or survey* or questionnaire*).tw,kf.	1055355
3	or/1-2	1190939
4	exp Stroke/	111286
5	stroke.tw,kf.	201737
6	or/4-5	235248
7	exp exercise/ or Exercise therapy/ or exp Rehabilitation/	409518
8	(exercis* or physical* activit* or rehabilit*).tw,kf.	456950
9	or/7-8	704826
10	"reproducibility of results"/ or Psychometrics/	391778
11	(reproducibility or psychometric* or validity or reliability or test-retest or responsiveness).tw,kf.	406471
12	or/10-11	682111
13	and/3,6,9,12	376





## Appendix 8 Single-case series; Technology questionnaire

### TECHNOLOGY QUESTIONNAIRE

The following questionnaire is asking about how often you use everyday technology.

Please tick in the relevant column.

	More than once a day	More than once a week	More than once a month	Rarely, or more than once a year	Never
Search for information on the internet					
Use the TV remote control					
Withdraw money from the automatic teller machine					
Deal with recorded telephone messages					
Tape a TV program using a recording device					
Send and receive emails					
Use a mobile phone					
Operate a telephone answering service such as an answering machine or voicemail					
Use a microwave oven					

## Appendix 9 Qualitative study; Interview guide

### InTENSE TRIAL Qualitative Study Adherence Questions

Major constructs of the Processes of Change, Transtheoretical Model of Change, matched to interview questions:

Process	Description	Interview question
<b><i>Cognitive/thinking processes</i></b>		
Increasing knowledge	Increasing information about oneself and physical activity	Were you provided with enough information about what to do and how to perform the exercises?
Being aware of risks	Understanding the risks of inactivity and sedentary living	What did you think would happen if you didn't participate in the exercise program?
Caring about consequences to others	Recognising how inactivity might affect others, such as family and co-workers	What were your thoughts on how participating in the program might impact on your carer? What benefit do you think your carer gained from your participation in the trial?
Increasing healthy opportunities	Help to increase awareness of opportunities to be physical active	What benefits to your overall health did you notice from participation in the trial?
Understanding the benefits	Increasing awareness of the benefits of physical activity	Were you aware of the possible benefits of participating in the trial? What did you think were the benefits? Did this awareness motivate you to perform your exercises?
<b><i>Behavioural/doing strategies</i></b>		
Substituting alternatives	Seeking ways of being physically active when encountering barriers of time, etc	Overall, did you feel 60 minutes of exercise daily was achievable for you? Were there strategies you used to ensure you could manage this? Can you identify any barriers you faced in achieving this target of 60 minutes exercise?
Enlisting social support	Seeking support from others for your physical activity efforts	Did your carer/support person encourage you to participate in the program? Did they assist you with your exercises? What impact do you think this had on them? (ie burden)
Rewarding yourself	Praising and rewarding yourself, in a healthy way, for making successful efforts in physical activity	What feelings did you experience about your participation in the trial? (eg pride) How did you reward yourself for this commitment?
Committing yourself	Making plans and commitments for physical activity	What strategies did you use to ensure you were able to continue with the exercises for the full program (ie 12 weeks)? How did you manage to stay motivated to participate?
Reminding yourself	Establishing reminders and prompts for physical activity, such as diary time slots and making equipment easily available	Did you utilise any external cues to help you remember your exercises, such as alarms or calendars? How important do you feel these sorts of cues are in establishing good exercise habits?

Based on:

Marcus and Forsyth; *Motivating people to be physically Active*, 2<sup>nd</sup> Ed, 2018

Biddle and Mutrie; *Psychology of Physical Activity*, 2<sup>nd</sup> Ed, 2008

## Appendix 10 Carers Count study; search strategy

### CINAHL - EBSCO

#### Version 1 (Broad)

#	Query	Limiters/Expanders	Last Run Via	Results
S1	(MH "Stroke+") OR (MH "Stroke Patients")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	72,268
S2	TI ( stroke OR "cerebrovascular accident" OR CVI OR CVA ) OR AB ( stroke OR "cerebrovascular accident" OR CVI OR CVA )	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	94,835
S3	S1 OR S2	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	112,673
S4	(MH "Rehabilitation") OR (MH "Home Rehabilitation") OR (MH "Occupational Therapy") OR (MH "Physical Therapy") OR (MH "Hand Therapy") OR (MH "Constraint-Induced Therapy") OR (MH "Functional Training") OR (MH "Gait Training") OR (MH "Home Physical Therapy") OR (MH "Body-Weight-Supported Treadmill Training") OR (MH "Joint Mobilization") OR (MH "Hydrotherapy") OR (MH "Mirror Therapy") OR (MH "Manual Therapy") OR (MH "Therapeutic Exercise") OR (MH "Motion Therapy, Continuous Passive") OR (MH "Muscle Strengthening") OR (MH "Lower Extremity Exercises") OR (MH "Upper Extremity Exercises") OR (MH "Rehabilitation, Cognitive")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	115,975
S5	TI ( rehabilitation OR "physical therap*" OR physiotherap* OR "exercise therap*" ) OR AB ( rehabilitation OR "physical therap*" OR physiotherap* OR "exercise therap*" )	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	124,167
S6	S4 OR S5	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	202,546

S7	(MM "Caregiver Attitudes") OR (MM "Caregiver Burden") OR (MM "Caregivers") OR (MM "Caregiver Support")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	27,870
S8	TI ( carer* OR caregiver* )	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	23,306
S9	S7 OR S8	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	34,577
S10	S3 AND S6 AND S9	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	346

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Version 2 - Narrow

#	Query	Limiters/Expanders	Last Run Via	Results
S1	(MH "Stroke+") OR (MH "Stroke Patients")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	72,276
S2	TI ( stroke OR "cerebrovascular accident" OR CVI OR CVA ) OR AB ( stroke OR "cerebrovascular accident" OR CVI OR CVA )	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	94,865
S3	S1 OR S2	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	112,705

S4	(MH "Rehabilitation") OR (MH "Occupational Therapy") OR (MH "Physical Therapy") OR (MH "Hand Therapy") OR (MH "Constraint-Induced Therapy") OR (MH "Functional Training") OR (MH "Gait Training") OR (MH "Body-Weight-Supported Treadmill Training") OR (MH "Joint Mobilization") OR (MH "Hydrotherapy") OR (MH "Mirror Therapy") OR (MH "Manual Therapy") OR (MH "Therapeutic Exercise") OR (MH "Motion Therapy, Continuous Passive") OR (MH "Muscle Strengthening") OR (MH "Lower Extremity Exercises") OR (MH "Upper Extremity Exercises") OR (MH "Rehabilitation, Cognitive")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	114,904
S5	TI ( rehabilitation OR "physical therap*" OR physiotherap* OR "exercise therap*" ) OR AB ( rehabilitation OR "physical therap*" OR physiotherap* OR "exercise therap*" )	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	124,190
S6	S4 OR S5	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	202,073
S7	(MH "Caregiver Attitudes") OR (MH "Caregiver Burden") OR (MH "Caregivers") OR (MH "Caregiver Support")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	44,058
S8	TI ( carer* OR caregiver* )	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	23,313
S9	S7 OR S8	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	49,241
S10	(MH "Inpatients")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	82,028

S11	(MH "Rehabilitation Centers") OR (MH "Stroke Units") OR (MH "Hospital Units")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	15,786
S12	TI ( inpatient* OR hospitali* OR ward OR wards ) OR AB ( inpatient* OR hospitali* OR ward OR wards )	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	150,200
S13	S10 OR S11 OR S12	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	215,842
S14	S3 AND S6 AND S9 AND S13	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text	124

# A systematic review of measures of adherence to physical exercise recommendations in people with stroke

Clinical Rehabilitation  
1–11

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## Abstract

**Objective:** To review methods for measuring adherence to exercise or physical activity practice recommendations in the stroke population and evaluate measurement properties of identified tools.

**Data sources:** Two systematic searches were conducted in eight databases (MEDLINE, CINAHL, PsycINFO, Cochrane Library of Systematic Reviews, Sports Discus, PEDro, PubMed and EMBASE). Phase 1 was conducted to identify measures. Phase 2 was conducted to identify studies investigating properties of these measures.

**Review methods:** Phase 1 articles were selected if they were published in English, included participants with stroke, quantified adherence to exercise or physical activity recommendations, were patient or clinician reported, were defined and reproducible measures and included patients > 18 years old. In phase 2, articles were included if they explored psychometric properties of the identified tools. Included articles were screened based on title/abstract and full-text review by two independent reviewers.

**Results:** In phase 1, seven methods of adherence measurement were identified, including logbooks ( $n=16$ ), diaries ( $n=18$ ), 'record of practice' ( $n=3$ ), journals ( $n=1$ ), surveys ( $n=2$ ) and questionnaires ( $n=4$ ). One measurement tool was identified, the Physical Activity Scale for Individuals with Physical Disabilities ( $n=4$ ). In phase 2, no eligible studies were identified.

**Conclusion:** There is not a consistent measure of adherence that is currently utilized. Diaries and logbooks are the most frequently utilized tools.

## Keywords

Adherence, stroke, measurement, psychometric properties

Received: 6 June 2018; accepted: 17 October 2018

## Introduction

Evidence demonstrates that higher doses of therapy are associated with better outcomes after stroke.<sup>1–3</sup> However, providing high doses of therapy in practice is challenging and therapists face a number of barriers including limited resources and low tolerance among stroke survivors to participate in high-intensity therapy.<sup>4,5</sup> Therapists are encouraged to

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establish independent practice outside of supervised therapy time as a way of increasing therapy dose.<sup>3</sup>

The benefits of increasing therapy dose by prescribing independent practice, however, depend on adherence to the prescribed programme; studies suggest that adherence reduces over time.<sup>6</sup> Adherence has been defined as ‘the extent to which a person’s behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a healthcare provider’.<sup>7</sup> Adherence to exercise programmes has been shown to be especially challenging after stroke,<sup>8</sup> with between 30% and 50% of patients ceasing their exercise programmes within the first year.<sup>9</sup>

Measurement tools that quantify adherence to exercise programmes provide information for therapists about what the client is doing, in many cases, during times of the day when therapists are unable to observe the practice. Measurement of adherence can take various forms and there is no acknowledged gold standard.<sup>10</sup> Previous systematic reviews have assessed adherence to home-based rehabilitation,<sup>11</sup> self-reported measures of home-based rehabilitation,<sup>12</sup> patient or provider adherence questionnaires in physiotherapy<sup>10</sup> and measures assessing non-pharmacological self-management in musculoskeletal conditions.<sup>13</sup> These previous reviews have concluded that trials included largely self-developed questionnaires that lacked sufficient evidence of psychometric properties.<sup>10,12,13</sup> However, to date, no review has summarized methods of measurement of adherence to exercise and physical activity recommendations in stroke.

It is important to use a method of measurement of adherence that is valid in the specific population, that is, the tool measures what it is supposed to measure.<sup>14</sup> Given the important role adherence plays in determining the efficacy of an intervention, the adherence measurement methods chosen should be guided by the specific patient diagnosis group and by evidence of their measurement properties when tested within this group.

With limited understanding of the best methods of measuring adherence (and associated psychometric properties of these methods) for the

stroke population, the primary aim of this study was to identify adherence measurement methods used to quantify adherence to exercise and physical activity recommendations. The secondary aim was to report on the psychometric properties of the identified methods and synthesize findings to provide recommendations for both clinical and research use.

## Method

This review was conducted in two parts. An initial search was conducted to identify adherence measurement methods to exercise or physical activity in the stroke population. Following this, a second search was conducted to identify studies investigating the psychometric properties of the methods identified in phase 1. This review is reported in accordance with the PRISMA guidelines.<sup>15</sup>

### *Phase 1: identification of adherence measurement methods*

A search in eight electronic databases (MEDLINE, CINAHL, PsycINFO, Cochrane Library of Systematic Reviews, Sports Discus, PEDro, PubMed and EMBASE) was conducted in July 2017 and updated in September 2018 to identify adherence measurement methods. The search strategy for MEDLINE is included in Supplemental Appendix 1. An equivalent search strategy was individualized for all other databases and no limits were placed on publication dates.

Studies were included if they were (1) published in English, (2) included participants diagnosed with stroke (or greater than 80% of study population was diagnosed with stroke), (3) quantified adherence to exercise or physical activity recommendations, (4) were patient or clinician reported measures, (5) were defined and replicable measures and (6) were tested in patients >18 years old. Studies were included if they were conducted in any therapeutic setting including inpatient, outpatient and community settings. Studies using objective tools (which are not patient or clinician reported) such as accelerometers were excluded.

Conference abstracts which described eligible adherence measurement methods were included.

Once duplicates were removed, titles and abstracts of all identified studies were reviewed for inclusion by two independent reviewers and agreement achieved through discussion when needed. The same two reviewers screened the full-text articles for the inclusion and exclusion criteria. A third reviewer was available to resolve differences. Data extracted included the population that the tool had been used with, the setting the tool had been used in, the type of intervention it was measuring, whether it was patient or clinician administered and study and measurement-specific information.

### *Phase 2: properties of included adherence measurement methods*

To identify the psychometric properties of included adherence measurement methods, a search in eight electronic databases (MEDLINE, CINAHL, PsycINFO, Cochrane Library of Systematic Reviews, Sports Discus, PEDro, PubMed and EMBASE) was conducted in February 2018 and updated in September 2018. The search strategy for MEDLINE is included in Supplemental Appendix 2. An equivalent search strategy was individualized for all other databases and no limits were placed on publication dates.

Studies were included if they (1) were published in English, (2) included participants diagnosed with stroke (or greater than 80% of study population was diagnosed with stroke) and (3) reported research investigating at least one psychometric property for an adherence measurement method identified in phase 1. The primary psychometric property of interest was validity.

Once duplicates were removed, titles and abstracts of all identified studies were reviewed for inclusion by two independent reviewers and agreement was checked. The same two reviewers screened the full-text articles for the inclusion and exclusion criteria. A third reviewer was available to resolve differences.

Papers identified in phase 1 were grouped according to the type of adherence measurement

method used. For phase 2, we planned to assess measurement properties following the recommendations of the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN).<sup>16</sup>

## **Results**

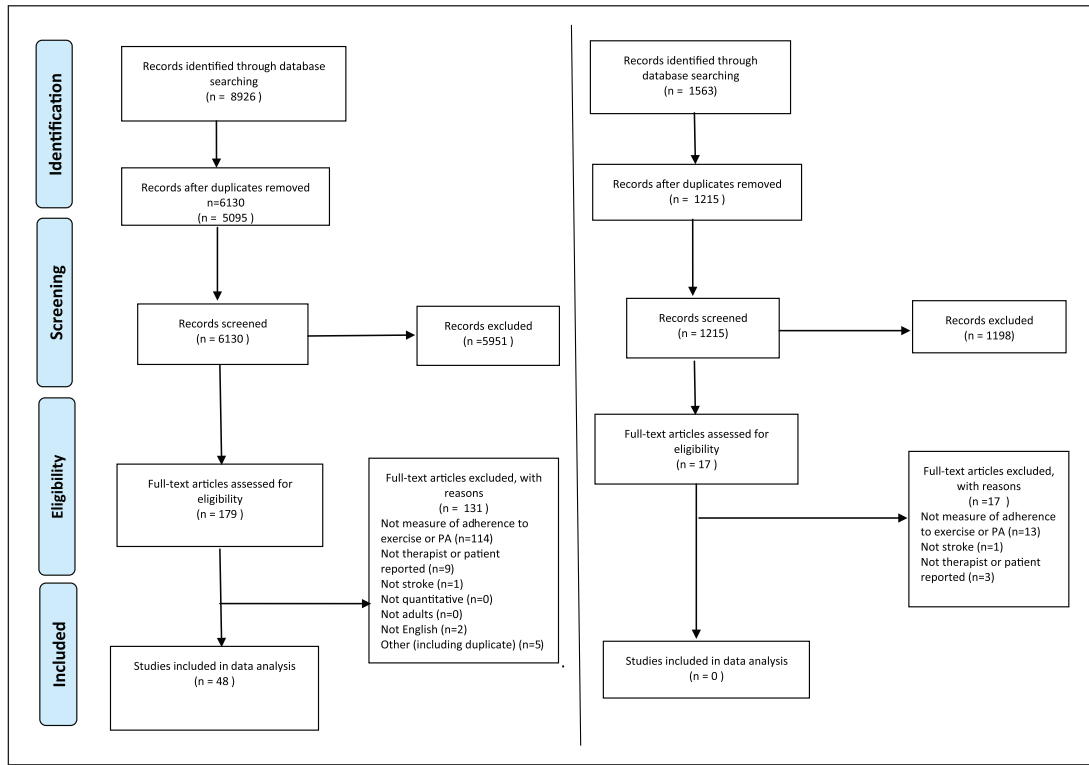
The review process for both searches is shown in the flowchart (Figure 1). Phase 1 identified a total of 48 articles for inclusion in our review, which included seven different adherence measurement methods (several studies evaluated multiple tools). Phase 2 failed to identify any articles which identified the psychometric properties of included adherence measurement methods for inclusion in our review.

### *Phase 1: identification of adherence measurement methods*

A total of 6130 citations were identified using the search strategy; of these, 179 articles were selected for full-text review and 48 studies were identified as being eligible for inclusion. These 48 articles contained seven separate adherence measurement methods. Table 1 provides a summary of adherence measurement methods and study design. We found that researchers used different terms for their adherence measurement methods and there is no widely accepted terminology; we describe the adherence measurement methods based on the terminology used by the researcher within the study description. Supplemental Table 1 presents the method and characteristics of the included adherence measurement methods.

Of the adherence measurement methods identified, diaries and logbooks were used most frequently. Studies seldom described the content within the diaries/logbooks. Some studies identified the parameters of exercise or activity that were recorded. The duration and frequency of exercise or physical activity were most frequently recorded in the diary or logbook.

Diaries were used in 18 of the identified studies. All home diaries were completed by the patient. Three of the identified studies utilized diaries as a component of the constraint-induced movement



**Figure 1.** Flowchart showing selection process for phases 1 and 2. Phase 1 - identification of adherence measurement methods and phase 2 - measurement properties of adherence measurement methods.

**Table 1.** Types of adherence measurement method and type of study in which the method was used.

Type of adherence measurement method	Number of studies identified using the method	Experimental studies (study reference)	Descriptive studies (study reference)
Diary	18	17–30	31–34
Logbook	16	35–45	46–50
Record of practice	3	51–53	
Journal	1		54
Survey	2		55, 56
Questionnaire	4		57–60
PASIPD	4		61–64

PASIPD: The Physical Activity Scale for Individuals with Physical Disabilities.

therapy (CIMT), where the focus was on recording the amount of activity performed with the affected upper limb.<sup>17,31,32</sup> Many of the included studies used diaries to record the duration or frequency of exercise or physical activity that was performed.

med.<sup>18–28,31</sup> The type of physical activity performed was included in the diary in seven studies.<sup>17,18,20,23,27,31,32</sup> The specific method of recording in the diaries was not described in six of the identified studies.<sup>21,28–30,33,34</sup>

Logbooks or daily activity logs were used as adherence measurement methods in 16 of the included studies. Four of the studies used a log to record time of functional activity and/or adherence to mitt use during CIMT.<sup>35,36,46,47</sup> A further study used a logbook to record type of activity performed during a goal-directed upper limb activity programme.<sup>37</sup> The most frequently recorded exercise or activity parameter was duration.<sup>35,36,38–40,46–50</sup> Other parameters recorded in the logbooks included weekly step activity,<sup>41</sup> intensity<sup>38</sup> and number of sets and repetitions of exercise.<sup>42,49,50</sup> Other studies did not provide any specific details regarding method of recording in the logbooks.<sup>43,44</sup>

Three of the included studies reported that subjects were asked to keep a ‘record of practice’ or recording sheet indicating how often they exercised.<sup>51–53</sup> In the study reported by Malagoni et al.,<sup>52</sup> participants were asked to fill out a daily training record indicating exercise completion and any adverse events. This record was then used by the authors to produce an adherence percentage (‘retention rate’), where the number of planned sessions relative to the recorded sessions was calculated. It was not clear whether this methodology was developed by the authors or based on previous research.

Hayward et al.<sup>54</sup> utilized a journal for recording adherence in their case study. Repetitions and a quality reflection were recorded.

This review identified a survey exploring exercise beliefs and adherence, originally developed by Miller.<sup>65</sup> The written exercise survey collected data including whether or not participants recalled being provided with a home exercise programme. For those that indicated a ‘yes’ response, data on adherence, non-adherence, reasons for non-adherence, perception of loss of function since discharge and exercise attitudes were collected.<sup>55</sup> This survey was developed after a literature review and was pilot tested and reviewed by experts in the field. The author acknowledged that a limitation of their study was a lack of information about the validity of the survey. An additional study included in this review used a phone survey to assess adherence; however, no details of the survey were available.<sup>56</sup>

Four papers included in this review used questionnaires as adherence measurement methods. Jurkiewicz et al.<sup>57</sup> developed a 16-item questionnaire comprising questions about the type and amount of exercise performed, factors that motivated patients to participate and reasons why they missed their workout. Touillet et al.<sup>58</sup> described using a semi-structured activity questionnaire, which explored type of activity as well as duration and frequency. In a study exploring longitudinal patterns of adherence to exercises in people with stroke, Yao et al.<sup>59</sup> utilized the Questionnaire of Exercise Adherence, a 14-item questionnaire consisting of three dimensions: adherence to exercise, effective supervision and advice seeking. An additional study included in this review developed a questionnaire that examined consistency between prescribed treatment and exercises completed.<sup>60</sup>

The Physical Activity Scale for Individuals with Physical Disabilities (PASIPD) was included in four papers identified in this review.<sup>61–64</sup> The PASIPD is a 13-item self-report tool that assesses physical activity in three domains: recreation, household and occupational activities.

## *Phase 2: psychometric properties of included adherence measurement methods*

The search for the second phase of this review, aimed at synthesizing the published psychometric properties of the adherence measurement methods, identified 1215 citations, and a total of 17 papers were sought in full text. Of these studies, none of the studies met all the inclusion criteria. Hence, analysis of the psychometric properties of the located adherence measurement methods was not possible.

## **Discussion**

This review identified that while there are adherence measurement methods used to assess adherence to exercise or physical activity recommendations after stroke, there are no published psychometric studies of these tools. Seven adherence measurement methods have been described in

the literature: diaries, logbooks, record of practice, journal, surveys, questionnaires and the PASIPD. There is no clear consensus on the optimal adherence measurement method to exercise or physical activity recommendations after stroke, since it remains plausible that existing approaches are not valid. The findings of this review are consistent with other reviews involving other populations, demonstrating that researchers tend to use tools that are developed and administered in an ad hoc manner, and existing measures have not been adequately psychometrically tested.<sup>10–13</sup>

Additional methods of monitoring were used in a number of other studies included in this review, including telephone monitoring and follow-up face-to-face meetings.<sup>17,22–28,40</sup> In addition, Gunnes et al.<sup>23</sup> combined participant-reported diaries with an adherence form completed by the physiotherapist on review of the diary. The adherence form was intended as a method of quality assurance and was completed at regular review appointments. The author combined the two measures and expressed this as a single value representing adherence. Given that use of a diary or logbook is commonly used, determining the validity and reliability of these approaches seems to be an important area of future research.

While no studies met the inclusion criteria for phase 2 of the review, we excluded one study involving a coded physical activity diary.<sup>66</sup> This study was not included as it described patterns of physical activity rather than adherence to a prescribed programme. These types of coded diaries are frequently used in stroke research activity trials; each day is divided into time intervals and codes are provided that represent specific activities. Patients are asked to choose the primary activity performed over the time interval. It is hypothesized that this sort of diary use may be easier for stroke patients to comply with as it minimizes writing, but there is as yet not research to support this suggestion. Therapists may consider this method of diary use when aiming to measure stroke patients' adherence to exercise programmes, but further research should be conducted prior to assuming that a diary of exercise represents actual exercise completed.

While participants were responsible for self-reporting in most studies, some studies also incorporated caregiver involvement into the recording process. Caregivers were required to either record the amount of exercise performed in the logbook or sign-off the completed exercises.<sup>38,45,48</sup> Caregiver support may increase the consistent use of adherence measurement methods; however, consideration must be given to the demands and burden placed on the caregiver. Again, however, there were no published studies to determine whether caregivers are more or less accurate in their reporting of completed exercise and the role of caregivers in physical activity and exercise studies warrants further research.

Our review did locate one tool; the PASIPD is a 13-item self-report tool that captures physical activity in three domain areas (recreation, household and occupational activities). While we could not synthesize findings from psychometric studies completed specifically in a stroke population, the PASIPD has published reliability and validity coefficients (test–retest reliability .77; criterion validity correlation .3) when used for measuring physical activity in individuals with disabilities (mixed population).<sup>61,67</sup> Thus, the PASIPD may be considered to be a tool for measuring physical activity in a population of people with disabilities. However, it was not designed to be a tool for measuring adherence, although it was used for this purpose in one study identified in this review.<sup>62</sup> To use the PASIPD as an adherence measurement method, Brown et al.<sup>62</sup> adapted the original assessment; however, it has not had psychometric evaluation for this purpose. Thus, further research to understand the validity and reliability of the PASIPD as an adherence measurement method is still required.

This systematic review was deliberately limited to identifying adherence measurement methods through methods of client or therapist report (and thus, we excluded approaches such as the use of accelerometers). We made this decision because there is already systematic review evidence for the role of accelerometry to monitor physical activity after stroke, concluding that accelerometers yield valid and reliable data about physical activity after stroke.<sup>68</sup> Despite this strong evidence, the uptake of

accelerometers by clinicians to monitor activity remains limited<sup>69</sup> and there is anecdotal evidence that independent use by stroke survivors is difficult. Furthermore, the use of accelerometers does not allow the therapist to monitor specific components of adherence such as counting repetitions. It is therefore important for clinicians to have inexpensive, readily available, quick and reliable adherence measurement methods that they or their patient could administer to measure adherence. This review has identified that currently such a method does not exist in the stroke literature.

The majority of studies identified in this systematic review recruited community-dwelling participants who were capable of participating in an unsupervised exercise programme. Of the studies incorporating cognitive and communication function into their inclusion and exclusion criteria, participants were excluded if they had issues that would prevent them following instructions relating to the intervention or method of assessment, including a lack of ability to follow two-step commands or mild cognitive deficits. A number of studies reported a mini-mental state examination (MMSE) cut-off score indicative of mild cognitive impairment (MMSE 18–23).<sup>17,18,22,23,27,30–32,52,61,70</sup> Thus, our findings also failed to identify adherence measurement methods that may be suited to a population with greater levels of disability.

As the adherence measurement methods identified in this review varied in terms of their format and detail, at this stage, it is not possible to recommend which is most likely to provide the most reliable and valid information in the stroke population. The most frequently used adherence measurement method identified in this review is the patient diary. The main limitation of this method is the possibility of inaccurate reporting with a bias towards over-reporting.<sup>71</sup> Exploration of some of the more advanced applications of diary use identified in this review, such as a coded diary and regular therapist review, warrants further investigation and validation.

Understanding adherence is a complex concept and there are a multitude of factors that may influence adherence in people with stroke.<sup>72</sup> First, the theories around behaviour change (such as the theory of planned behaviour) show that factors such as

attitude, norms and control influence intention (and subsequently behaviour).<sup>73</sup> Second, work shows that the process of establishing new habits (such as completing a self-directed programme) varies considerably among individuals and new activities often take weeks to become routine.<sup>74</sup>

The issue of bias was addressed in a small number of the included studies and must be considered in analysis. Studies that rely on patient self-report can be subject to many forms of bias including recall bias, optimism bias and social desirability response bias.<sup>75–78</sup> Recall bias has been identified as a limiting factor in survey-based studies<sup>65</sup> and self-report instruments such as diaries were reported to be vulnerable to patient's inaccuracies.<sup>23</sup>

The findings of this review echo those conducted in other fields. A systematic review of exercise adherence in the musculoskeletal field concluded that the measures identified were unacceptable for use and highlighted the importance of the development and evaluation of appropriate measures.<sup>79</sup> The development of a validated measure of adherence to exercise or physical activity in people with stroke should be a priority to provide researchers and clinicians with a greater understanding of this important concept.<sup>80</sup>

Limitations of this systematic review include possible bias as studies not published in English were not included. The grey literature was not searched in this systematic review which may be a further limitation. The greatest limitation, however, remains the lack of published psychometric studies testing whether or not the clinical tools used to monitor adherence to physical activity and exercise programmes for stroke survivors are sound.

### Clinical Messages

- There is a lack of a uniform method of measurement of adherence to exercise or physical activity recommendations in the stroke population.
- This study has identified diaries and logbooks as the most frequently used adherence measurement methods; however, there is a lack of standardization between tools.


## Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

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## Supplemental Material

Supplemental material for this article is available online.

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## **Appendix 12 Feasibility study; published paper**

### **Link to publication:**


<https://doi.org/10.1080/09593985.2019.1625092>

## RESEARCH NOTE

## Open Access



# Does the addition of concurrent visual feedback increase adherence to a home exercise program in people with stroke: a single-case series?

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## Abstract

**Objective:** Evidence is accumulating for the potential benefits of technology use in stroke rehabilitation. However, few studies have examined ways in which technology can be used to increase adherence to programs after discharge from rehabilitation. The aim of this study was to determine if the addition of concurrent visual feedback, via a tablet computer, increased adherence to an exercise program following stroke. Ten participants were provided with a self-administered exercise program and were asked to perform 60 min of the exercises daily. After a baseline phase (1 week), participants were given a tablet computer (2 weeks) and were asked to video record each exercise session. The tablet computer was removed during the fourth week of the program.

**Results:** Exercise duration, measured via wrist-worn accelerometry, was investigated over the 4 weeks using the two-standard deviation (2 SD) band method. A statistically significant effect was observed in four out of ten cases, demonstrated by two successive data points occurring outside the 2 SD band during the intervention phase, suggesting that adherence was increased in response to the tablet computer use. This preliminary study indicates that the use of visual feedback, via a tablet computer, may increase adherence to an exercise program in people with stroke.

*Trial registration* ACTRN: ACTRN12620000252910 (26 February 2020, Retrospectively registered)

**Keywords:** Stroke, Technology, Feedback, Exercise

## Introduction

The use of tablet devices to increase engagement in rehabilitation is increasing as services have greater access to technology [1]. Tablet computers, such as iPads<sup>®</sup>, are portable and inexpensive and many individuals own these devices [2].

Whilst there is an increasing number of applications installed on tablet computers to increase participation in therapy, there is a lack of research around use of tablet

computers as a means of video recording participation in therapy and providing real-time feedback. In a review of tablet use in stroke rehabilitation, Ameer and Ali described benefits in using a device with a camera within and outside of therapy; including allowing the therapist to record sessions and provide real-time feedback [3]. This finding is consistent with an exploratory study using video feedback of functional tasks after stroke, which found that participants who were provided with visual feedback during a task expressed greater satisfaction [4]. There is a lack of studies investigating the role real-time feedback, via tablet use, may play in promoting exercise adherence following stroke, and this should be further explored.

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Technology devices can also be utilised to monitor adherence. Adherence has been described as ‘the extent to which a person’s behaviour—taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a healthcare provider’ [5]. Researchers and clinicians require accurate methods to measure adherence. However, measuring adherence to exercise is challenging, and consensus regarding the gold standard is lacking [6, 7]. Accelerometers are wearable sensors, designed to measure movement in activity counts [8]. The advantage of accelerometers is that an objective measure can be gained. There is evidence that accelerometers produce reliable and valid metrics of upper limb use [9, 10] and the feasibility of using accelerometers to monitor exercise adherence should be explored.

The primary aim of this study was to determine if the addition of concurrent visual feedback, via a tablet computer, would increase adherence to an upper limb home exercise program in people with stroke.

A secondary aim was to assess the feasibility of use of accelerometers as a method of monitoring upper limb activity during a home exercise program in people with stroke.

## Main text

### Methods

Ethical approval for this study was granted by The Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC EC00188). Ten participants were recruited from the Flinders Medical Centre. Participants provided written informed consent. Inclusion criteria were diagnosis of stroke (> 3 months), completion of rehabilitation, and being able to pick up a small block with the stroke-affected hand. Patients were excluded if they were less than 18 years old, had a Mini-Mental State Examination score (MMSE) of less than 24 out of 30 [11], were non-English speaking, or had visual deficits preventing technology use. Baseline outcome measures were collected to provide an understanding of demographics. Measures were Fugl-Meyer Assessment (FMA) [12], Modified Rankine Score (0–6) [13], Motor Activity Log-14 (MAL-14) [14], Self-Efficacy for Exercise Scale [15], Box and Block Test (BBT) [16], line bisection test [17] and the Technology Use Questionnaire (developed by authors, see Additional file 1: Appendix S1). This study adheres to the CONSORT guidelines for clinical trials (Additional file 2).

A single-case series design was employed [18] with an A–B–A design. A single-case series design allows for detailed testing of the efficacy of an intervention on a chosen outcome. In single-case experiments, sequential measurements are recorded for each participant. After

an initial baseline period, an intervention is applied and the effect of this intervention relative to the baseline is investigated. Following the intervention phase, there is a follow-up phase with withdrawal of the intervention.

Participants were visited at home by the researcher. Following completion of baseline measures, the participants were instructed in the Graded Repetitive Arm Supplementary Program (GRASP) [19] and were asked to practice their program for a total of 60 min, daily for 4 weeks. The GRASP program, a self-directed arm and hand exercise program which has been shown to improve function after stroke, prescribes 1 h of daily exercises and a manual of exercises is provided [19]. Participants were provided with a recording sheet to record the time spent exercising during each session.

### Intervention (tablet computer use)

During the intervention phase (weeks 2 and 3), participants were provided with a tablet computer (Apple model A1474) and were asked to video record each session, using the MoviePro App, a videorecording app that was downloaded onto the tablet computer for a small fee paid by the researchers. The tablet computer was set up in front of the participant so that they were able to see themselves exercising and they were instructed to look at the screen as they exercised. Participants also recorded the start and finish times of each session on a recording sheet.

### Measurements

Participants were provided with two wrist-worn accelerometers (Actigraph) and were instructed to don these prior to their exercise session and to remove them at the completion of each session. The Actigraph, a lightweight accelerometer that resembles a wristwatch, measures movement of the upper limb through acceleration.

The outcome measure used to evaluate adherence in this study was active time when wearing the accelerometer. At the completion of the study the researcher downloaded recordings from the Actigraph devices. Data was analysed using the Actilife Software, and active time was calculated for each session.

To evaluate the feasibility of accelerometry use to measure adherence, The System Usability Scale (SUS), a 1 to 5 Likert scale that measures participants’ experience using technology was completed [20]. Additionally, the researcher kept a logbook, recording any issues that arose.

### Data analysis

Changes in amount of activity recorded on the accelerometers from the baseline phase to the “tablet intervention” phase provided an indication of whether adherence

to exercise increased in response to the tablet. Additionally, changes in accelerometer recorded activity following tablet removal in the follow-up phase provided extra information to inform interpretation of the data.

Following standards related to single-case series research where the participant acts as their own control, 5 measures were analysed in the baseline phase and the mean and standard deviation of measures were calculated to account for the level (mean score) and trend (slope) of the 5 measures prior to introduction of the tablet [21]. Active wear time data were then analysed using the two standard deviation (2 SD) band method which has been recommended for analysis of single-case series designs [18, 22, 23]. If two or more successive data points within the intervention phase fell outside the 2 SD band (i.e. outside the 95% confidence limits), changes from baseline to intervention were considered statistically significant. Rigour of the methodology was enhanced by replication of the design on 10 different occasions with 10 participants. This method of evaluation enables performance variability to be factored into the analysis [24].

**Results**

Table 1 presents the baseline demographics of participants.

**AIM 1: to determine if the addition of concurrent visual feedback, via a tablet computer, will increase adherence to an upper limb home exercise program in people with stroke**

Overall, a significant effect was observed in 4 out of the 10 cases (participants 1, 5, 7, 10), as demonstrated by 2 successive data points occurring outside the 2 SD band during the intervention phase, meaning that these participants performed a significantly greater amount of

exercise when they were using the tablet computer. These results are represented in Fig. 1.

Furthermore, one participant (participant 9) showed a statistically significant reduction in performance at follow-up when the tablet computer was removed (Fig. 2).

Nine participants reported that they enjoyed the tablet computer and found it beneficial for giving feedback and improving engagement. Participant 1 reported that he did not like the experience as he felt like he was being watched, however he still self-reported a perception that the tablet use improved his adherence.

When time since stroke was investigated, the two participants with the longest time since their strokes (participant 1 = 58 months; participant 7 = 110 months), both showed a statistically significant change. Furthermore, when level of motor ability was explored, 4 of the 6 non responders to the intervention (participants 2, 3, 8 and 9) had recorded a relatively high Box and Block Test score.

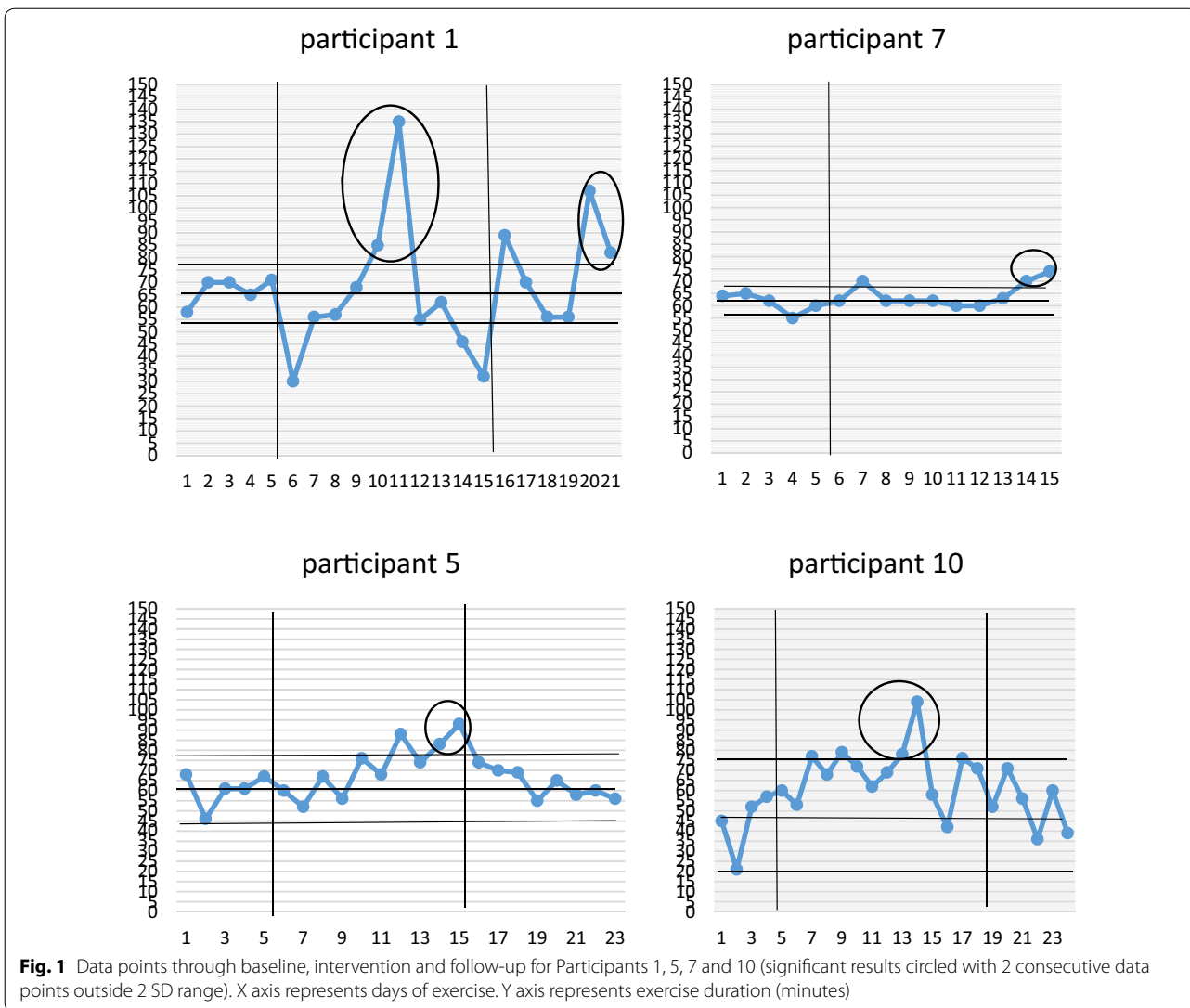
**AIM 2: to assess the feasibility of use of upper limb accelerometry as a method of monitoring upper limb activity**

The mean score for the System Usability Scale was 96.5 out of 100, indicating a high level of usability. There were several problems in terms of data collection. Issues that arose included missing data (participants 4, 9, 10); despite reportedly charging the devices, data were missing during the last three days of exercise in Participants 4 and 9. Two participants forgot to put devices on and/or off (participants 2 and 5), on one occasion for each participant. A further two participants forgot to charge the accelerometers (participants 1 and 7), and participant 7 had no recorded data after day 15. Two participants were unable to put the device on the non-affected wrist without assistance (participants 4 and 6).

**Table 1 Subject demographics at baseline**

Subject	Age	MMSE	FMA	MAL14	Self-efficacy	MRS	BBT (affected)	BBT (un affected)	Time since stroke (months)	Time since rehabilitation (months)
1	64	26	63	7.2	6.4	2	16	29	58	20
2	52	29	62	5.6	10.0	2	65	81	6	4
3	63	28	62	5.6	8.5	3	32	59	13	6
4	65	27	32	5.0	5.9	3	0	57	24	21
5	65	30	62	4.5	7.4	3	19	63	14	9
6	70	29	33	4.7	10.0	2	2	68	7	3
7	21	30	55	4.7	6.1	2	20	32	110	57
8	62	30	64	7.1	7.5	2	45	64	24	.5
9	56	30	65	7.9	9.7	2	48	54	3	1
10	63	30	35	5.1	7.3	3	36	60	5	4

MMSE Mini-Mental State Examination (0–30), FMA Fugl-Meyer Assessment (0–66), MAL14 Motor Activity Log-14 (0–10), Self-Efficacy Self-efficacy for Exercise Scale (0–10), MRS Modified Rankine Score (0–6), BBT Box and Block Test



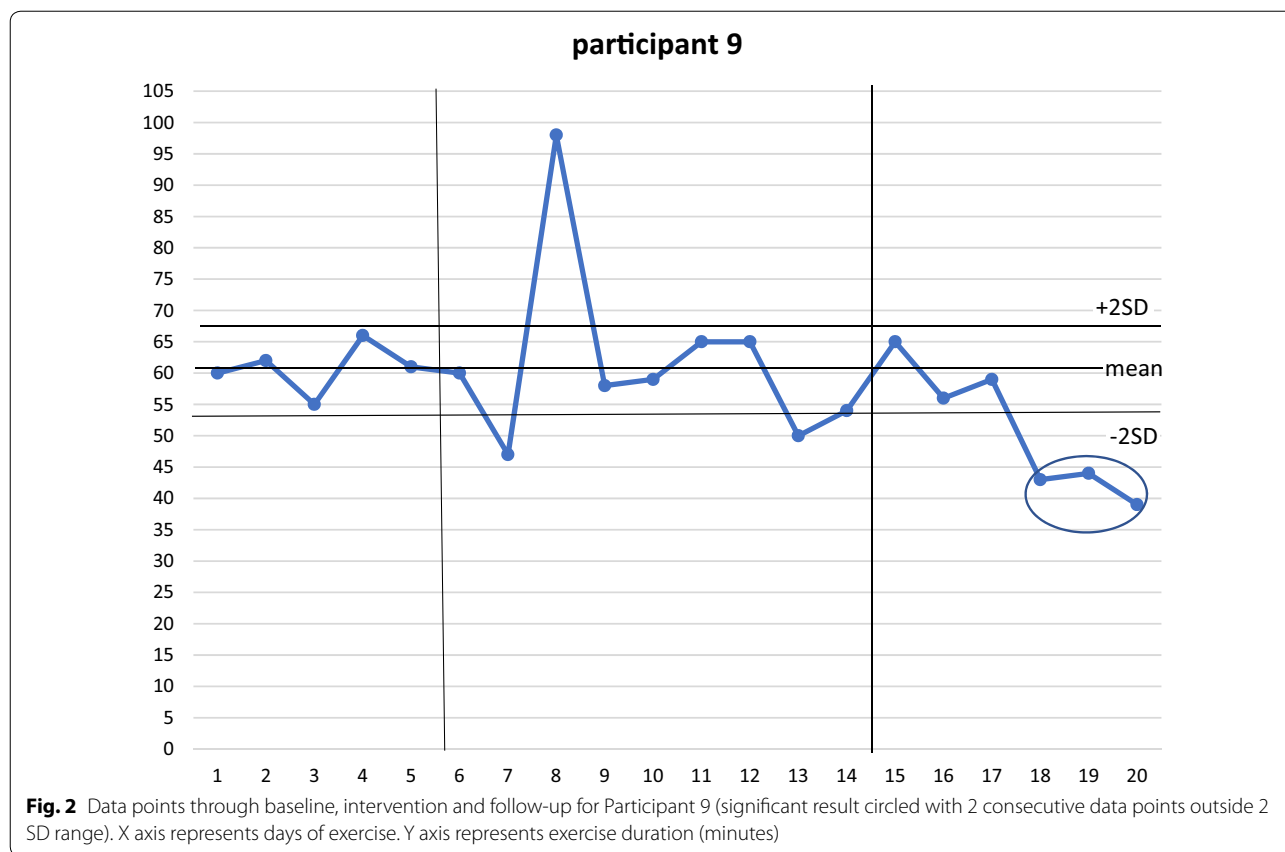
No issues arose with accelerometry utility or data collection in participants 3 and 8.

**Discussion**

This study demonstrated that using a tablet computer as a tool to promote adherence (via real-time feedback) to an upper limb home exercise program can be useful for some people with stroke. Clinicians should assess individual patient factors such as level of motivation, familiarity with technology, and level of motor impairment when considering this method of technology use. A significant improvement in the amount of exercise performed was observed in four of the 10 participants. Additionally, a further participant showed a statistically significant reduction in performance at follow-up when the tablet computer was removed.

Most participants reported positive feelings towards the approach. This is consistent with findings of Gilmore and Spaulding who reported greater satisfaction in participants who received video feedback during a functional task [4]. Furthermore, in a randomised controlled trial investigating adherence to exercise in people with stroke, Emmerson et al. [25] compared paper-based home exercises to home exercises filmed on a tablet. The authors stated that a potential benefit could be the feedback aspect of the video use and suggested that this may be evaluated further.

There were no technical issues reported with tablet computer use and all participants managed to operate the devices without any assistance or with minimal carer assistance. This aligns with qualitative data that reported



tablet computers are easy to use, acceptable and engaging [26].

A ceiling effect was observed in participants who were highly motivated; meaning there was less ‘room for improvement’, and hence no statistically significant effect occurred during the intervention. Testing the effect of the intervention on the adherence of a less motivated group of participants would be valuable. Four of the participants who did not show a significant change with the intervention were those who had recorded higher scores on the Box and Block Test. It may be that the visual feedback provided by the tablet computer is more sought out, utilised and beneficial when a patient has less motor control. The two participants in this study who presented at the longest time since stroke demonstrated a significant change with the intervention. It may be that this technology is most effective when patients are in the chronic phase of recovery, but this needs to be considered with caution.

The two participants in this study who had greater motor impairment required assistance to put the accelerometers onto their non-affected wrists. Some issues with utility arose, including participants forgetting to remove and charge the accelerometers. Interventions to promote reliability of accelerometry use should be considered

and may include scheduling applications and phone text reminders. This small study has demonstrated that there are issues that may reduce utility of home-based accelerometry use in people with stroke. The main advantage of using the accelerometers were that they provided accurate data on exercise time.

**Limitations**

The study sample was small and could be considered already motivated, having consented to a 4-week exercise program. A qualitative component would have enabled a greater exploration of participants’ experiences.

**Supplementary information**

Supplementary information accompanies this paper at <https://doi.org/10.1186/s13104-020-05202-2>.

**Additional file 1: Appendix S1.** Technology Use Questionnaire, developed by the authors.

**Additional file 2.** Consort checklist.

**Abbreviations**

GRASP: Graded Repetitive Arm Supplementary Program; SUS: System Usability Scale; 2 SD: two standard deviation band method.



**Acknowledgements**

We thank all the participants who gave their time for this study.

**Authors' contributions**

TL and MK conceived the design for the study. TL conducted the research, analysed and interpreted the data and was a major contributor in writing the manuscript. MK assisted in analysis of the data and was a major contributor in writing the manuscript. All authors read and approved the final manuscript.

**Funding**

This research was completed as part of TL's research higher degree studies. No external funding was received.

**Availability of data and materials**

The data that support the findings of this study are available on request from the corresponding author, TL. The data are not publicly available due to ethical restrictions (data may compromise the privacy of research participants).

**Ethics approval and consent to participate**

Participants gave written informed consent to participate in the study. Ethical approval for this study was granted by The Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC EC00188).

**Consent for publications**

Not applicable.

**Competing interests**

The authors declare that they have no competing interests.

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Received: 7 February 2020 Accepted: 22 July 2020

Published online: 29 July 2020

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