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**Translation of a lifestyle physical activity intervention  
into a regional rehabilitation service**

Thesis submitted by

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**Doctor of Philosophy**

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## Statement of contribution of others for publications

Thesis chapter/study	Publication on which based	Role of each author
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## Statement of contribution of others

Nature of Assistance	Contribution	Names, Titles and Affiliations of Co-Contributors
Intellectual support	Editorial assistance	Fiona Barnett, Melissa Crowe and Ruth Barker proofread the thesis.
	Supervision	A/Prof Fiona Barnett Dr Melissa Crowe A/Prof Ruth Barker Dr Kelly Clanchy Dr Sean Tweedy
	Research assistance	Tanya Ashton co- facilitated focus groups with CRnQ participants and Michelle Polley was note taker. I employed Professor Jenni Judd to conduct evaluation focus groups and interviews with CRnQ staff and Fiona Crowther to take notes during focus groups
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## Abstract

Individuals with neuromusculoskeletal (NMS) conditions are significantly less physically active compared to the general population and hence, are at increased risk of chronic disease. Additional barriers to physical activity (PA) for this population arise from the diverse range of physical, cognitive, linguistic and psychological impairments that they experience. The Adapted Physical Activity Program (APAP) is a lifestyle PA intervention that utilises evidence-based strategies to assist individuals with NMS conditions to increase their PA behaviour. APAP evolved at the School of Human Movement and Nutrition Sciences at the University of Queensland (UQ). APAP efficacy was demonstrated in a controlled clinical trial with individuals with brain impairment conducted by an Exercise Physiologist (EP) within the individual's home and community environment.

The purpose of this research project was to translate APAP from the metropolitan educational setting of UQ into a regional community rehabilitation service, Community Rehab nQ (CRnQ) in Townsville. The project comprised three phases. The aim of phase 1 was to establish factors that influence PA participation by gaining the perspective of individuals with NMS conditions. The aim of phase 2 was to plan and develop a protocol implementation and evaluation of APAP within the CRnQ setting. The aim of the third and final phase was to implement and evaluate APAP at CRnQ.

Phase 1 consisted of Study 1 (literature review) and Study 2 (focus groups and interviews). Study 1 revealed that factors that influence participation in PA for this population are complex, common to all, yet unique to the individual's context. Findings of Study 1 indicated that an individually tailored approach to PA interventions was required. Study 2 narrowed the focus to individuals with NMS conditions residing in regional North Queensland. Focus groups and interviews were conducted with participants who attended CRnQ. Factors



reported to influence PA were consistent with the findings of Study 1, however social support arising from attendance at regional health services was reported to be a major contributing factor to PA.

Phase 2 and 3 involved a mixed-method hybrid effectiveness-implementation Type 1 study design based on the (Reach, Effectiveness, Adoption, Implementation, Maintenance (RE-AIM) framework. In Phase 2, Study 3 (Part 1), a plan was developed throughout three overlapping and iterative stages: (i) Engagement and familiarisation with the APAP intervention and the implementation context of CRnQ (ii) Identification and familiarisation with the RE-AIM framework (iii) Tailoring the implementation of APAP to CRnQ's context guided by RE-AIM. This process identified that APAP was a complex intervention that was sufficiently flexible to be translated into a different setting. The process also identified that CRnQ was a suitable setting for translation of APAP on the basis that it provided services for the appropriate target audience and that it was sufficiently responsive to new ideas and opportunities to be able to adopt APAP. Key consistencies and differences between UQ and CRnQ were highlighted and corresponding strategies were developed to overcome associated challenges and enhance facilitators. Subsequently, an overall plan was devised for implementation and evaluation of APAP at CRnQ.

In Phase 2 of Study 3 (Part 2) a protocol for implementation and evaluation of APAP at CRnQ was developed. This involved integration of APAP into CRnQ processes, as well as inclusion of additional processes along the rehabilitation pathway. To **reach** the target audience the intake assessment was expanded to include additional PA questions and the clinical meeting included reminders to clinical staff to refer suitable participants to the program. To determine **effectiveness**, a range of therapist- administered and self- report measures were included in the CRnQ package of outcome measures to determine changes in PA levels, mediators of PA (e.g. social support), levels of fitness and participant satisfaction.

**Adoption** was fostered through discussion of participant progress during clinical meeting and inclusion of APAP in the emerging electronic health records. **Implementation** was driven through formal training of EPs prior to implementation, weekly feedback sessions between EPs during implementation and checklists to monitor APAP fidelity within the CRnQ context. **Maintenance** was promoted at the individual level through additional social support including a Facebook page and a buddy system and at the organisational level by embedding APAP in CRnQ electronic systems and processes.

Phase 3 involved implementation and evaluation of APAP at CRnQ. Study 4 consisted of a hybrid effectiveness-implementation type 1 trial based on the RE-AIM framework. APAP program **reach** over an eight-month period was 16% (n=23) with 88% completion with EPs working to full capacity. APAP was considered **effective** based on observed increased participant confidence, sense of well-being, independence in PA and successful integration into community. Based on quantitative outcome measures, significant increases were found in ‘friend’ and ‘family’ social support but not with perceived PA barriers and benefits. Increases were not significant for PA and fitness, possibly due to the use of outcome measures that were inappropriate for individuals who have complex conditions and a disproportionate amount of time spent on psychosocial issues versus PA. Time taken to conduct community sessions and between-session preparation were considered the greatest cost. An unanticipated outcome identified by EPs was a potential increase in workload for the family carer of an individual with a low level of function. APAP was considered to be **adopted** well as the clinical team perceived that it added value to CRnQ and that it positively influenced the way they practiced. During **implementation** the average number of sessions was the same as the UQ efficacy intervention but with an increased average intervention duration; mostly due to health setbacks. EPs reported a delayed uptake with training and understanding of the APAP due to its evolving nature and complexity. The program was

delivered with fidelity; however, EP Motivational Interviewing required further practice. APAP functioned satisfactorily as an individual program and concurrently with other CRnQ programs. APAP was delivered via Skype and telephone to those in rural and remote areas and the intervention was adapted for those with aphasia. **Maintenance** at the *individual level* was variable with factors exerting the greatest influence perceived to be social support and social media. **Maintenance** of APAP at the *organisational level* reduced upon withdrawal of the intervention champion and upon turnover of the clinical team. Suggestions made by the clinical team to improve implementation of APAP at CRnQ included the use of appropriate outcome measures, further integration of APAP into CRnQ processes and systems, allocation of EP resources and education of new clinical team members.

In conclusion, APAP was translated from the metropolitan university setting to a regional community rehabilitation setting. The individually-tailored, person-centred, flexible design of APAP enabled individuals with NMS conditions to participate in PA. Although APAP participant satisfaction was high and significant increases were demonstrated for ‘friend’ and ‘family’ social support, PA and fitness outcome measures chosen for this study did not demonstrate significant increases. APAP was considered a valuable addition to CRnQ by the clinical team and a positive influence on the way they practised, however they perceived the intervention to be too time consuming and complex. Feedback from the team suggests further integration of APAP into CRnQ with some intervention and delivery modification. More in-depth assessment of intervention fidelity and evaluation of contextual factors that influence adoption and implementation is required.

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## Declaration of Ethics

The research presented and reported in this thesis was conducted within the guidelines for research ethics outlined in the *National Statement on Ethics Conduct in Research Practice* (1997), the *James Cook University Policy on Experimentation Ethics, Standard Practices and Guidelines* (2001), and the *James Cook University Statement and Guidelines on Research Practice* (2001). The proposed research methodology received clearance from the James Cook University Experimentation Ethics Review Committee (approval # \_\_\_\_\_).

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Signature

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## Glossary

Administration team	Staff who provided administrative support to the management team, clinical team and CRnQ participants
APAP participants	Individual with NMS conditions who participated in the intervention study
Clinical team	Health professionals and students of each of those professions who worked with all individuals with NMS conditions at CRnQ, including clinical leader and rehabilitation assistants
CRnQ intervention implementers	Service director, clinical leader, education leader, health professionals and students of those professions, rehabilitation assistants, administrative staff
CRnQ participants	Individual who participated in other programs at CRnQ
Study period	Implementation period when data was collected for APAP participants
Family carer	Individual who was related to, and cares for individual with NMS condition (e.g. spouse, sister)
Full CRnQ team	Service director, clinical leader, education leader, health professionals and students of those professions, rehabilitation assistants, administrative staff
Management team	Service director, education leader, clinical leader
Paid carer	Individual who was paid to care for individual with NMS condition
UQ intervention developers	Exercise physiologists at UQ who developed the APAP intervention

## List of abbreviations

6MAC	Six minute arm crank
6MWT	Six minute walk test
ABI	Acquired brain injury
ACFC	ASPIRE coaching fidelity checklist
ADL	Activities of daily living
ANOVA	Analysis of variance
APAP	Adapted physical activity program
BI	Brain impairment
CBA	Cost benefit analysis
CCT	Controlled clinical trial
CEA	Cost effectiveness analysis
CFIR	Consolidated framework for implementation research
CP	Cerebral palsy
CRnQ	Community Rehab northern Queensland
CUA	Cost utility analysis
EP	Exercise physiologist
GP	General practitioner
HP	Health professional
ICF	International classification of functioning and disability
ICP	Integrated care pathway
IMPACT-S	ICF Measure of Participation and ACTivities questionnaire - Screener
JCU	James Cook University
KPI	Key performance indicators
LAPAQ	Longitudinal Aging Study Amsterdam (LASA) physical activity questionnaire

LL	Lower limb
MD	Muscular dystrophy
MET	Metabolic equivalent
MMC	Myelomeningocele
MND	Motor neurone disease
NC	Neuromusculoskeletal conditions
NMS	Neuromusculoskeletal
NQ	North Queensland
nQ	Northern Queensland
OT	Occupational therapist
PA	Physical activity
PADS-R	Physical activity disability survey - revised
PARIHS	Promoting action on research implementation in health services
PASIPD	Physical activity scale for individuals with a physical disability
PD	Parkinsons' disease
PHC	Primary health care
PT	Physiotherapist
QALY	Quality-adjusted life -year
QOL	Quality of life
RA	Rheumatoid arthritis
RCT	Randomised controlled trial
RE-AIM	Reach, effectiveness, adoption, implementation, maintenance
SB	Spina bifida
SCI	Spinal cord injury
SHMNS	School of Human Movement and Nutrition Sciences

SOC	Stage of change
SP	Speech pathologist
SPSS	Statistical package for the social sciences
TBI	Traumatic brain injury
TIDieR	Template for intervention description and replication
UQ	University of Queensland
USER	Utrecht scale for evaluation of rehabilitation

# Chapter 1

## Introduction

Physical activity (PA) participation rates for individuals with NMS conditions are exceptionally low (Dawes et al., 2006; Elsworth et al., 2009; Elsworth et al., 2011). People with disabilities are less active than the general population (Ravenek & Schneider, 2009) and in 2011/12 only 43% of Australian adults met the sufficiently active threshold (Australian Bureau of Statistics, 2013). Sufficient PA equates to  $\geq 150$  minutes per week (American College of Sports Medicine, 2010). In Australia, on average, people with a disability are 15% less likely to participate in sport and active recreation than the general population. Nearly 75% of those who currently participate would like to participate more (Australian Sports Commission, 2011). The most common barriers to participation in PA for people with NMS conditions are instability with walking balance; lack of confidence; lack of transport and/or costs and inaccessibility (Newitt, Barnett, & Crowe, 2016).

A NMS condition is any disease of the brain and spinal cord and the nerves that connect them (World Health Organization, 2006). Preparation of consistent estimates of incidence, prevalence, duration and mortality for neurological disorders requires a complex mathematical model as there are almost 500 sequelae to consider (Barendregt, van Oortmarssen, Vos, & Murray, 2003). In 2005, neurological disorders were estimated to constitute 6.3% of the global burden of disease and it is estimated that by 2030, this will increase to 6.8% (Mathers & Loncar, 2004). Cerebrovascular disease (e.g. stroke), and neuroinfections (e.g. meningitis) constitute 4.3% of the global burden of disease and, as a group, cause a much higher burden than digestive and respiratory diseases and malignant

cancers (World Health Organization, 2006). The prevalence of NMS conditions is increasing due to prolonged ageing and increased survival rates of children born with neurodevelopmental disorders (World Health Organization, 2006). Costs and the burden to health systems of NMS conditions are seen as one of the greatest threats to public health, with costs underestimated as they only take into account mortality rates and not disability rates (World Health Organization, 2006). Physical, cognitive, linguistic and psychological impairments result in symptoms that can be visible or invisible; temporary or long term; static or episodic or degenerating (World Health Organization, 2011). According to the International Classification of Functioning and disability (ICF) these impairments of bodily structures and function result in limitations to daily activities (e.g. walking, transferring from sit to stand), which then restricts participation in an individual's life areas (e.g. shopping, PA).

Physical activity is any bodily movement produced by skeletal muscles that results in energy expenditure (Caspersen, Powell, & Christenson, 1985). This broad definition means that PA can be categorised as activities of daily living (ADL), sport, recreational activities and exercise. Many of these activities involve social interaction. Physical activity is associated with good physical and psychological health (Lee et al., 2012). Regular PA manages mood and decreases the risk of lifestyle disease such as diabetes, hypertension and cardiovascular disease (Lee et al., 2012). People with NMS conditions who are regularly physically active experience the same benefits as the general population (Tweedy, 2007). Yet for individuals with physical disabilities, in many cases, movement is challenging, so in order to expend energy, health professionals need to consider all PA categories when prescribing exercise.

Formal evidence-based PA interventions for people with NMS conditions typically occur under ideal conditions (e.g. facility based, homogenous population, short term, expert intervention agents, willing participants), which does not address many of the significant real-life barriers to participation in PA. Several PA interventions for individuals with disabilities have included health promotion and behaviour-change frameworks that focused on self-motivated behaviour, capacity building and self-efficacy (Block, Vanner, Keys, Rimmer, & Skeels, 2010; Horner-Johnson, Drum, & Abdullah, 2011; Hsu, Buckworth, Focht, & O'Connell, 2013). These studies, however, were conducted in facilities that recruited participants by way of advertising, and eligibility was subject to inclusion and exclusion criteria. As a result, reach to the target population was limited, particularly given the access and transport issues common in this population. A recent controlled clinical trial tested the efficacy of the Adapted Physical Activity Program (APAP) (Clanchy, Tweedy, & Trost, 2016). Similarly, the intervention occurred under a highly specific set of circumstances, but a notable difference from the previous studies was the adoption of a community-based rehabilitation model of service to address common barriers experienced by individuals with disabilities (e.g. transport, costs, accessibility). Importantly, this combination of a lifestyle PA intervention and a community-based rehabilitation model of service enabled the promotion of PA in the environment where the person will adopt and maintain PA (Tweedy, 2007).

The APAP intervention was developed at the University of Queensland (UQ). It is a community-based, stage-matched lifestyle PA intervention that is individually tailored to address barriers experienced by people with NMS conditions. It consists of three steps: (1) pre-participation assessment; (2) individually-tailored stage-matched behaviour-change activities, exercise prescription and community access facilitation; and (3) relapse prevention strategies. The opportunity arose to test the intervention's generalisability/robustness in a

real-world setting when senior management of a new and evolving regional community rehabilitation service for people with NMS conditions who were familiar with APAP saw implementation in the community rehabilitation setting as an opportunity to improve the rehabilitation service.

Community Rehabilitation northern Queensland (CRnQ) is a community rehabilitation service for individuals with NMS conditions, located in regional Townsville, for the population of northern Queensland (nQ). CRnQ is a service that is accessible to all, irrespective of religion, culture or economic situation and flexible to address the unique needs of nQ people, particularly indigenous people. CRnQ decision makers considered PA a priority for its participants as was evidenced by the employment of EPs within the service. CRnQ's core principles of person-centredness, individual tailoring and goal focus aligned with those of APAP's, and the service had the resources required for delivery of the intervention. Translation of APAP to CRnQ offered the chance to demonstrate external validity by increasing the level of engagement with representative end users (Rabin, Brownson, Haire-Joshu, Kreuter, & Weaver, 2008).

Interventions involved in most behavioural and health promotion studies have not been translated into practice (Glasgow, Klesges, Dzewaltowski, Bull, & Estabrooks, 2004). This is because the characteristics that cause an intervention's success in efficacy research are fundamentally different from those in effectiveness research (Glasgow, Lichtenstein, & Marcus, 2003). Translation of interventions into community organisations, not only strengthens the research, but it is informed by the needs and priorities of the service and its practitioners (Stamatakis, 2012). Health professionals are expected to use the best evidence available to achieve the best participant outcomes possible (Krugman, 2003). Methodology in translation research has evolved to hybrid-design trials for clinical interventions to expedite knowledge creation and increase the usefulness and policy relevance of clinical



research (Glasgow et al., 2003). Effectiveness-implementation hybrid studies concurrently test the intervention's clinical effectiveness and implementation (Curran, Bauer, Mittman, Pyne, & Stetler, 2012). Researchers choose one of three hybrid study designs according to where the intervention is positioned on the efficacy-effectiveness-implementation spectrum. Hybrid trials should only be considered if an intervention has strong face validity that would support applicability to the new setting, population or delivery method in question (Curran et al., 2012). APAP has proved efficacious in a controlled clinical trial (CCT) conducted in a metropolitan educational setting. The next step was to test the intervention's feasibility and acceptability in a community rehabilitation setting and assess its impact on a more heterogeneous sample of individuals with NMS conditions. A hybrid effectiveness-implementation Type 1 design most closely matched the translational aims of this project. This study is aimed at testing the clinical intervention whilst gathering information on its delivery during the effectiveness study and/or its potential for implementation in a real-world setting (Curran et al., 2012)

On that basis, a three-phase study was undertaken to translate APAP, a lifestyle PA intervention, from UQ, an educational setting in Brisbane, Queensland, to CRnQ, a community rehabilitation service in Townsville, North Queensland. Phase 1 was a preliminary step toward translation and involved exploration of the factors that influence participation in PA from the perspective of individuals with NMS conditions. A review of the qualitative literature identified perceptions, attitudes, beliefs, barriers and facilitators to PA. As the literature identified factors relevant to individuals who lived in metropolitan areas, the focus of the exploration was narrowed to individuals with NMS conditions who live in regional North Queensland, the context for implementation of the intervention. Exploration was by way of focus groups and in-depth interviews with active participants of CRnQ.

The findings of phase 1 informed phase 2, the implementation methodology. Phase 2 involved the planning and subsequent development of a protocol for implementation and evaluation of APAP into CRnQ. Phase 2 consisted of two parts. Part 1 described the planning process, which assumed a collaborative community involvement design and the emergence of three overlapping elements: 1) familiarisation with the intervention in its original context and the context for delivery; 2) familiarisation with the RE-AIM (Reach, Effectiveness, Adoption, Implementation, Maintenance) framework; and 3) tailoring the implementation of APAP to CRnQ guided by the RE-AIM framework. Part 2 presented the protocol for the implementation and evaluation of APAP at CRnQ. The protocol outlined strategies to enhance facilitators and overcome barriers to implementation that were identified during the planning phase. The protocol also described the methodology for objectives 1 and 2 of the hybrid effectiveness-implementation type 1 study including evaluation aims, study participants, data collection procedures and data analysis.

Phase 3 reports on what transpired during implementation. Barriers and facilitators to protocol strategies were reported. Qualitative findings comprised implementation evaluation by the full CRnQ team by way of focus groups and interviews and APAP participant interviews evaluating program satisfaction. Quantitative outcome measures in terms of functional outcomes achieved by participants were also reported, but were not the focus of the study.

To the author's knowledge, this project is the first attempt to implement an individually-tailored, stage-matched behaviour-change PA lifestyle intervention for individuals with NMS conditions into a regional community rehabilitation service. In contrast to other lifestyle interventions for this population, the aim of this project was to address the common barriers to PA participation and include all individuals with NMS conditions regardless of the severity of their impairment and level of function. The outcomes of this thesis, therefore, will provide

EPs and other health professionals with methods to reach and deliver PA to this population. It will also provide intervention developers and intervention implementers with potential ideas and solutions for the successful implementation of APAP, a multifaceted behaviour-change intervention into a complex interprofessional health setting. This will have positive implications for the physiological and psychological health of individuals with NMS conditions.

## **1.1 Study aims**

The aim of this thesis was to translate APAP, a lifestyle PA intervention, from UQ, a metropolitan educational setting, to CRnQ, a regional community rehabilitation setting.

The objectives of this thesis were to:

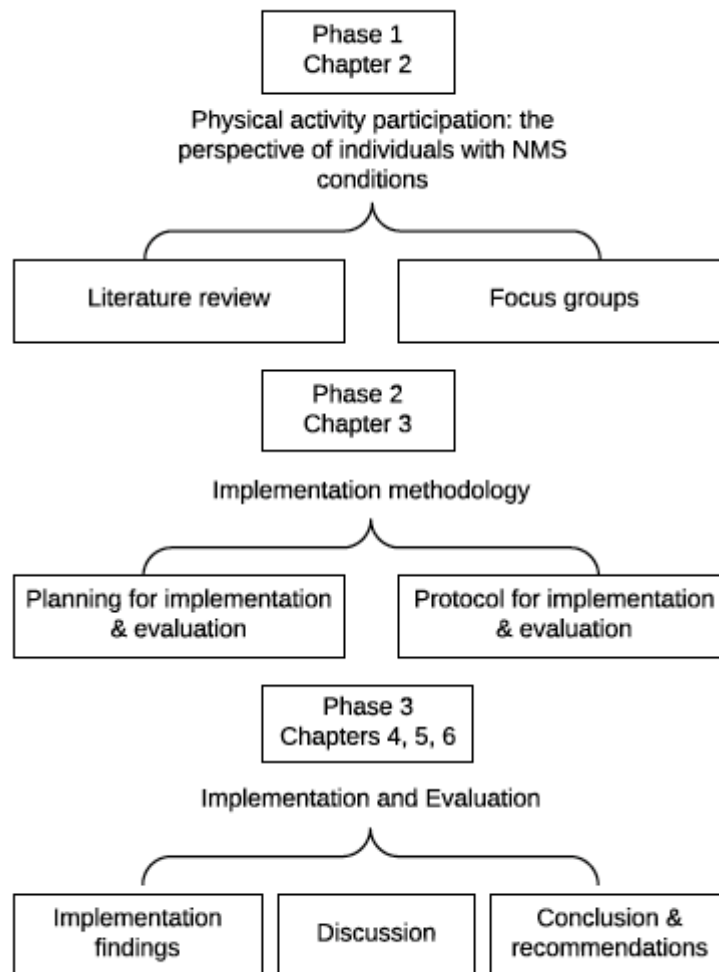
1. determine, from the perspective of individuals with NMS conditions, factors that influence participation in PA;
2. develop a plan, based on the RE-AIM framework for implementation of APAP into CRnQ based on the views of individuals with NMS conditions, information gathered from intervention developers and intervention implementers; and
3. evaluate, through a hybrid effectiveness-implementation Type 1 study design, the implementation of APAP at CRnQ.

Ethics approval for the studies included in this thesis was provided by the James Cook University Ethics Committee. ( Appendix 1).

## **1.2 Thesis overview**

The two studies presented in Phase 1 (Chapter 2) explore the factors that influence PA participation from the perspective of individuals with NMS conditions. The first study

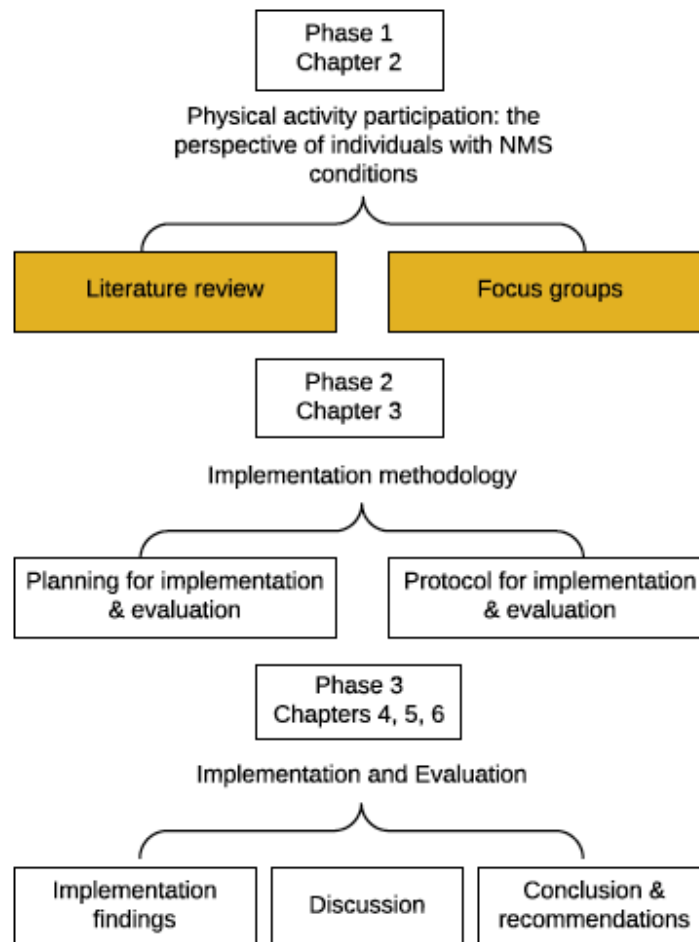
consists of a qualitative review of the literature to gain the global perspective. The second study narrows the focus to the site for implementation, gaining the perspective of individuals with NMS conditions from regional North Queensland on PA by way of focus groups and interviews. Phase 2 (Chapter 3) outlines the methodological processes and outcomes involved in the development of a protocol for implementation and evaluation of APAP at CRnQ. Phase 3 (Chapters 4, 5, 6) presents the implementation findings including barriers and facilitators to implementation and discusses key factors that emerged from the translation. The thesis is drawn to a close with future directions with regard to clinical practice and future research.



# Chapter 2

## Factors that influence participation in physical activity

The purpose of this chapter was to explore factors that influence participation in PA from the perspective of individuals with NMS conditions. Firstly, a review of the qualitative literature was conducted to discover what is known globally. The review has been published (Newitt et al., 2016). Secondly, investigation, by way of focus groups and interviews, occurred in the region of North Queensland, the context for implementation of APAP. This study has been submitted for publication.



# **Understanding factors that influence participation in physical activity among people with neuromusculoskeletal conditions: a review of qualitative studies**

## **2.1. Introduction**

Understanding factors that influence PA participation in the general population is complex as knowledge, expectations, attitudes, beliefs and barriers vary greatly from one individual to another. In the context of disability, the determinants to PA participation are amplified (Hughes, 2006).

To establish effective PA programs for people with a NMS condition, health professionals must firstly understand the factors that influence engagement in PA (Heath & Fentem, 1997). Factors that influence adherence to PA fall into the three general categories: cognitive, motivational and resource-based. In other words, individuals must know, want and be able to participate in PA (Shumaker, Ockene, & Riekert, 2008). Several intervention studies for individuals with disabilities have implemented a holistic approach employing health promotion and behaviour-change frameworks such as Social Cognitive Theory, Self-determination Theory and the Salutogenic Model (Block et al., 2010; Horner-Johnson et al., 2011; Hsu et al., 2013). These approaches focus on self-motivated behavior, capacity building and self-efficacy. It appears though, that many studies demonstrate limitations in the resource-based area. The interventions are facility based, and evidence indicates that individuals with NMS conditions cite lack of transportation and/or costs as a significant barrier to participation in PA (Driver, Ede, Dodd, Stevens, & Warren, 2012). As a consequence, participants are not representative of the target population. Individuals who are

not attending facility-based interventions may disclose reasons or exhibit circumstances for non-participation in PA that are immune to strategies used in any of the intervention studies.

It is, therefore, the purpose of this literature review to explore factors that influence participation in PA for this population. In order to obtain a comprehensive understanding of these factors, a qualitative inquiry was chosen as this research method will provide rich descriptive data that will not only reveal what influences participation, but why (Liamputtong, 2009). The review was limited to qualitative research methods outside the context of a PA intervention. Moving away from a structured setting will open the findings to include individuals who are not likely to participate in a program allowing for wide-ranging experiences and issues (Kayes, McPherson, Taylor, Schluter, & Kolt, 2011). The inquiry extended no further than the last decade. This is because society has evolved to a certain extent with regard to the material environment and accessibility (Levins, Redenbach, & Dyck, 2004).

The WHO's ICF framework guided the categorisation of factors that influence participation in PA (Figure 2.1) (World Health Organization, 2001). The Australian Institute of Health and Welfare ([AIHW], 2003a) notes the ICF framework provides for the conceptualisation, classification and measurement of disability. It defines functioning and disability as multi-dimensional concepts relating to the body function and structures of people; the activities people do and the life areas in which they participate, and the factors in their environment which affect these experiences. It describes human functioning as a continuum, not just at the extremes ([AIHW], 2003a). It also recognises that personal factors such as self-esteem and motivation influence an individual's participation in society (World Health Organization, 2011). The reason the ICF framework was employed as a guide in this review was to ensure

that major factors of interest with regard to disability were not omitted; a vital step for health professionals who are developing effective approaches to PA interventions for individuals with NMS conditions.

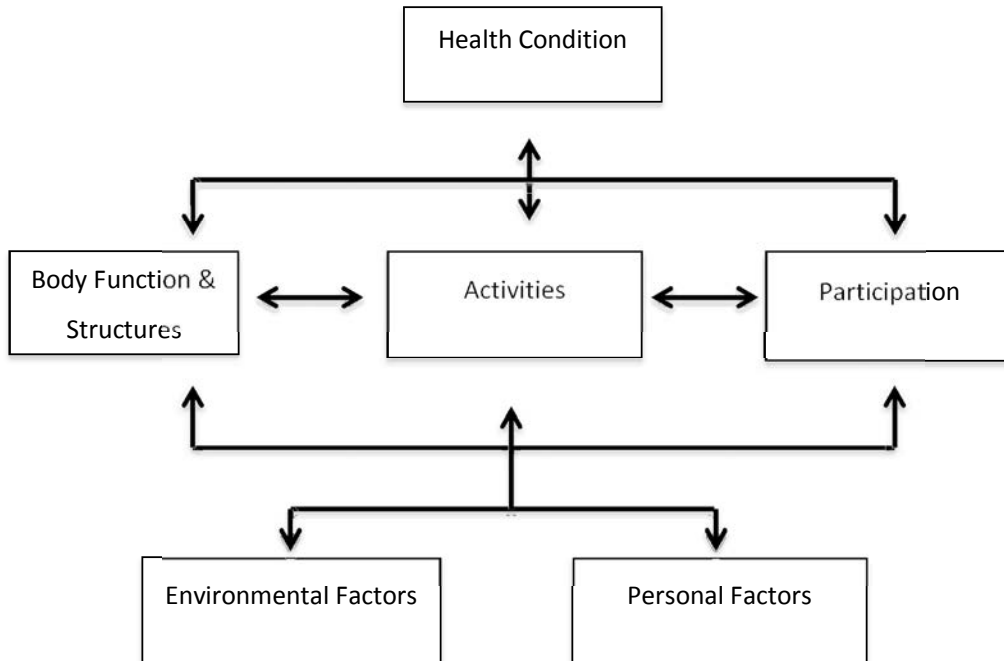


Figure 2.1 ICF framework (World Health Organization, 2001)

## 2.2. Methods

### 2.2.1 Search strategy

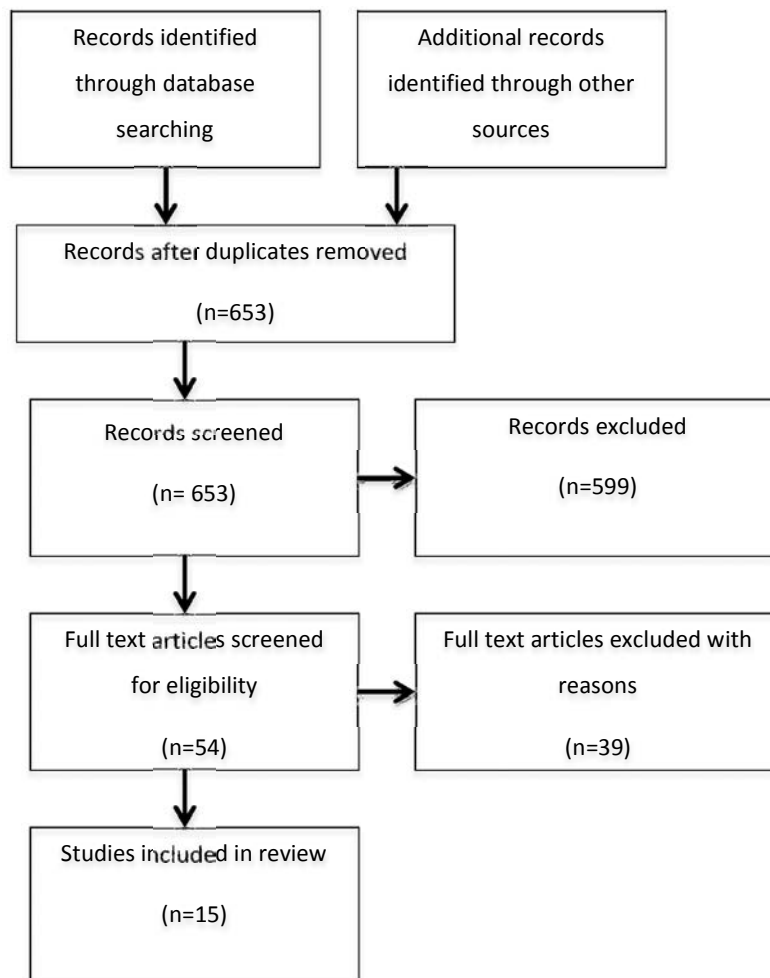
A literature search was performed using Medline, Cinahl, Scopus, Informit, Sportdiscus and The Cochrane Library. Three lines of key words were included in the search strategy with appropriate truncations:

1. Exercise, sport, athletics, recreation, social participation, social adjustment, PA, training, fitness, social support, life style
2. Disabled, disability evaluation, disabled persons, disabled athletes, disability, cerebral palsy, multiple sclerosis, spinal cord injury, brain injury, head injury, Parkinson's disease, stroke, cerebral vascular accident



### 3. Barriers, facilitators, determinants, correlates, influence

Papers were also identified from references of papers included in the review. The summary flowchart summarises the assessment and exclusion of articles (Figure 2.2.) The title and abstract of all 653 citations were scanned by the first author to determine their suitability. If any uncertainty concerning inclusion arose, two authors read the article in full.



**Figure 2.2 Flowchart of study selection process**

The following inclusion criteria were placed on all studies:

1. Published in English in a peer-reviewed journal.
2. Reported from 2003 to 2013.
3. Investigating factors that influence participation in PA from the perspective of individuals ( $\geq 18$  years) with a neuromusculoskeletal condition.
4. Qualitative research methods outside the context of an activity intervention.
5. Quality.

Two authors independently linked the factors that influence participation in PA outline in each citation to the constructs in the ICF framework. In the case of inconsistencies, consensus was obtained by consulting a third person. Studies were analysed for methodological quality according to the guidelines developed by the McMaster University Occupational Therapy Evidence-Based Practice Research Group (Letts et al., 2007). When considering the reliability and validity of studies, rigour is used as a way of evaluating qualitative research (Liamputtong, 2009). Trustworthiness is the principal concept when considering rigour, and the four components of trustworthiness are credibility, transferability, dependability and confirmability (Letts et al., 2007). To illustrate the methodological rigour and trustworthiness of each study included in the review, the guidelines were modified by awarding a numerical score for criteria met under this quality assessment tool where each criteria was awarded one point and studies were scored out of 23 (Barras, 2005). The criteria and scoring are outlined in Table 2.1.

**Table 2.1 Qualitative criterion scoring system**

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Qualitative criteria

Total quality score out of 23

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1. Study purpose was stated clearly
2. Relevant background literature was reviewed
3. Study design was appropriate to study question
4. Theoretical perspective for study was identified
5. Study methods were congruent with study purpose
6. Selection process was described in detail
7. Selection occurred until data redundancy was reached
8. A clear site description was provided
9. A clear participant description was provided
10. Role of researcher was clearly described
11. Any assumptions and biases of researcher described
12. Procedural rigour used in data collection methods
13. Analysis of data was inductive
14. Findings were reflective of data
15. Decision trail was developed during analysis
16. Data analysis process was clearly described
17. A meaningful picture of phenomenon under study emerged
18. Methods used to ensure credibility were described
19. Methods used to ensure transferability were described
20. Methods used to ensure dependability were described
21. Methods used to ensure confirmability were described
22. Conclusions were appropriate to study findings
23. Findings contributed to future research and practice

(Barras, 2005)

## 2.3. Results

In total, 54 articles relevant for this study were sourced and, through exclusion criteria, 15 were included in the review. The main reasons for excluding articles were: (1) Studies covered all disabilities, not just NMS conditions; (2) The inquiry was linked to a PA intervention and; (3) The data collected was via quantitative surveys. Of the 15 studies included, three employed a focus group method and 12 conducted interviews. The quality of the studies ranged from a score of nine to 22. The most frequent shortcomings were achievement of data redundancy; a clear description of the role of the researcher; a description of any assumption and biases of the researcher and emergence of a meaningful picture of phenomenon under study.

Most of the studies in the review interviewed participants who resided in an urban setting with the majority emerging in the United States (4), followed by United Kingdom (3) and two each in the Netherlands, New Zealand, Sweden and Canada. Overall, the studies represented a total of 196 participants with NMS conditions of which 57% were male and 43% female ranging in age from 19-82 years. Overall representation of diagnosis was spinal cord injury (SCI; n=89), multiple sclerosis (MS; n=44), cerebral palsy (CP; n=26), Parkinson's disease (PD; n=13), traumatic brain injury (TBI; n=17), stroke (n=13), motor neurone disease (MND; n=6), muscular dystrophy (MD; n=5), myelomeningocele (MMC; n=4), acquired brain injury (ABI; n=2) and rheumatoid arthritis (RA; n=2) (Table 2.2).

**Table 2.2 Study characteristics**

First author/year	Method	Setting	Conditions	M	F	Age (M) (yrs)	Time since injury (yrs)	Level of function	Quality score /23
Borkoles (2008)	Semi-structured interview	UK	MS	3	4	47.1	16.3 SD 9.1	4-6 on Kurtzke EDSS	11
Buffart (2009)	Focus group	Netherlands	MMC, CP, ABI, RA	12	4	22.4	Childhood onset	50% w/c dependent	10
Damush (2007)	Focus group	US	Stroke	8	5	59	<1	Slight or moderate level	18
Dlugonski (2012)	Semi-structured interview	US	MS	0	11	42.9	Not stated	Low-level, median PDDS score 1	20
Elsworth (2009)	Focus group	UK	MD, MS, MND, PD	24		54	Not stated	All levels	9
Kayes (2011)	Semi-structured interview	NZ	MS	3	7	44	3-17	Low-high	22
Kehn (2009)	Semi-structured phone interview	US	SCI	16	10	52 46	1	Complete & Incomplete; C & T level	9
Kerstin (2006)	Semi-structured interview	Sweden	SCI	12	4	36	2-41	8 tetraplegics, 8 paraplegics	10
Levins (2004)	Semi-structured interview	Canada	SCI	5	3	42	>1	Paraplegic T1 to low thoracic levels	19
Ravenek (2009)	Semi-structured interview	Canada	PD	4	3	52.1	3.5 SD 2.1	Stage II of Hoehn & Yahr scale	20
Sandstrom (2009)	Semi-structured interview	Sweden	CP	12	10	47	Childhood onset	Level II-IV GMFC	18
Self (2013)	Semi-structured group interview	US	TBI	12	5	28	1mth-1yr	14 independently mobile, 1 w/c, 1 walker, high cognitive function	18
Smith (2011)	Semi-structured interview	NZ	MS	0	9	28-70 (range)	1-30	Secondary progressive, relapsing/remitting, not known	20
Stephens (2012)	Semi-structured interview	UK	SCI	6	1	38	4-33	4 tetraplegic, 3 paraplegic	19
Vissers (2008)	Semi-structured interview	Netherlands	SCI	24	8	45	8.6 SD 8.6	Complete, incomplete, unknown	11

**Table 2.3. Summary of data categorised using ICF framework**

Body function & structures, activities, participation		Environmental		Personal	
Demotivator	Motivator	Barrier	Facilitator	Demotivator	Motivator
Stiffness	Health improvements	Lack of accessibility	Social support eg. exercise buddy, group exercise, family, friends, health professionals, caregivers, people in similar situation	Self-consciousness	Positive attitude
Pain,	Increased strength	Costs	Appropriate gym equipment	Negative social appraisal	Increased motivation
Fatigue	Increased fitness	Lack of transport	Having a peer role model	Social comparison with able-bodied exercisers or with former able self	Fulfillment
Injury eg. upper body overuse	Weight control	Health professionals/fitness staff/leisure staff lack of knowledge/incompetency	Being a peer role model	Self-judgmental	Physical challenge
Depression	Improved appearance	Holding 'able-bodied' individuals up on golf course	Transportation eg. pushing w/c to shops	Anxiety & worry for safety around extent of impairments	Enjoyment
Health eg. Asthma	Prevent physical deterioration/slow progression of disease	Dependence on others	Social aspect eg. team sports	Feeling uncomfortable or ashamed	Rewarding
Cognition	Pain management	Lack of 'rest' places	Weather	Lack of motivation	Achieving goals
Muscle weakness	Improved mood/mental health	Slippery surfaces	Dog	Feeling good	Habit
Heaviness in legs	Lessen risk of complications	Societal attitudes eg. discrimination, stereotyping & stigmatization,	Fill empty schedule	Lack of time	Clear the mind
Thermoregulation	Learning to read your body	Lack of social support	GP recommendation	Other priorities	Motivation
Relapse experience	Lower cholesterol	Weather	Building social support networks	Too much effort	Feeling normal
UTIs	Increased energy	Lack of information eg. facilities, activities		No perceived health benefits	Accomplishment
Emotional distress	Avoid regression after rehab	Poorly maintained equipment		Fear of injury & another stroke	Creating flexible routine
Bladder & bowel problems	Improved fatigue,	Timing of medications		Fear & worry in a new environment	Prioritising & scheduling PA
Pressure sores	Improved physical sensation,	Pool temperature		Embarrassment	Self-efficacy
Spasms	Improved relaxation	Lack of personal assistance		Lack of confidence	Optimism
Reduced stability	Improved mental clarity	Lack of special equipment		Feelings of inertia	Diagnosis of MS as a motivator
Reduced walking balance	Prevention of pressure sores	Unpleasant childhood experiences with PT		Anger	Focus on positive aspects of mobility
Lack of mobility	Maintaining/improving function eg. IADLs & ADLs	Discouragement from PT		Frustration	Redefine self after the loss of able-bodied identity
Modified sport not comparable	Learning new physical strategies	Lack of modified leisure activities & sport		Emotions with symptom change eg. Loss of job, transition to walking aids	
Unable to push to physical limits eg. no "runners high"	Incidental learning	Lack of time eg. work, school, family commitments		Lack of routine	
	Gaining new w/c skills	Assistive devices eg. halo braces			
	Home exercise programs	Lack of understanding from family & friends			
		Lack of appropriate medical advice			
		Patronising views of others			
		Lack of public awareness			

UTI=urinary tract infection; IADL=instrumental activities of daily living; ADL=activities of daily living; PT=physiotherapist; GP=general practitioner

For the purpose of this review, when listing factors relating to the environment, terminology will reflect the ICF definitions. Environmental factors will be described as “barriers” or “facilitators”. In the case of personal factors and the three areas of functioning; body functions and structures, activity and participation, reasons for and against participation in PA will be described as “motivators” and “demotivators” (Fekete & Rauch, 2012).

### **2.3.1. Areas of Human Functioning**

#### *Body function and structures*

##### *Demotivators*

Thirteen of the 15 studies identified the role of impaired body function and structures as demotivators to PA participation with only three studies addressing demotivators in detail (Elsworth et al., 2009; C. Smith, Olson, Hale, Baxter, & Schneiders, 2011; Vissers et al., 2008). Fluctuating symptoms and fatigue were mentioned in all of the progressive conditions. Other common impairments included muscle weakness, pain, stiffness, bladder and bowler problems, depression, thermoregulation and fear of injury.

Eleven of the 15 studies identified demotivators for participation in PA in the activity and participation area of functioning. Seven of these studies listed balance and stability. Other factors listed were lack of mobility, transfers, communication difficulties, inability to perform activities of daily living (ADL) and self-care, limitations to maximum exertion, lack of social connectedness, dissatisfaction with modified sport and loss of sport skills.

##### *Motivators*

Ten of the 15 studies identified motivators to participation in PA in body function and structures. The most common motivator was maintenance of function and weight control

followed by prevention of secondary conditions such as high cholesterol and urinary tract infections (UTI). The most common motivator to participation in PA in the activity and participation area of functioning was maintaining independence and this was identified in eight of the 15 studies. Other common motivators included improved function with ADLs and instrumental ADLs, and creating a flexible routine.

### **2.3.2. Environmental Factors**

#### *Barriers*

All of the studies in the review listed environmental barriers to participation in PA. Accessibility was listed in 81% of the studies and problems encountered include inaccessible buildings and pools, long distances to travel to accessible facilities, no rest places near equipment or rails to hold onto. Individuals frequently reported a lack of information on PA for individuals with a NMS condition, for example, where to exercise, how to exercise and the physical and medical consequences of exercise. Other common themes included lack of finances; lack of transport; lack of health professional and fitness trainer knowledge, and negative societal attitudes.

#### *Facilitators*

All of the studies in the review identified environmental facilitators. The most common environmental facilitator of participation in PA is social support and this factor was mentioned in every study. Most individuals reported that support from family, friends, co-workers and an exercise buddy facilitated participation in PA. Some reported social contact, like-minded peers, team support, assistance and encouragement from health professionals in rehabilitation and inclusive exercise groups as facilitators. Other environmental facilitators included safe exercise equipment, safe environment and safety devices, physician



recommendation, prioritising and scheduling PA, caregiver patience, the diagnosis of a condition as a trigger for commencing or increasing PA, and having a dog.

### **2.3.3. Personal Factors**

#### *Demotivators*

All of the studies identified personal demotivators to participation in PA. A lack of motivation was most commonly reported and participants described feelings of self-consciousness, embarrassment, anxiety, frustration, anger, vulnerability, sadness, hopelessness and feeling uncomfortable in a new environment. Individuals also described that coming to terms with a loss of their able identity and making a social comparison to able-bodied exercisers or their former able-self as demotivators to participation in PA.

#### *Motivators*

Fourteen of the 15 studies identified personal motivators to participation in PA and these included goal setting and achieving, enjoyment, feeling good, feeling 'normal', motivation and optimism. Participants described PA as a form of escapism, an emotional outlet and playing a pivotal role in redefining self. Some individuals stated that a wellness philosophy and a 'move it or lose it' belief acted as motivators. Improved appearance, feelings of accomplishment and learning to accept assistance were also listed as motivators.

## **2.4. Discussion**

The factors that influence participation in PA for individuals with NMS conditions have been collated from 15 qualitative studies and categorised under the guidance of the ICF framework. The greatest number of factors recorded in the review fall under the contextual factors category; environmental and personal, with fewer numbers of demotivators and

motivators reported in the three areas of functioning. Only three of the 15 studies in the review reported functional limitations in detail (Elsworth et al., 2009; C. Smith et al., 2011; Vissers et al., 2008); surprising considering the number of impairments that people with NMS conditions experience.

It has been stated in the literature that in many instances the environment is the barrier to participation, not an individual's health condition (Rimmer, 1999). The fact that people are disabled by environmental factors is confirmed in the World Health Report, however, the report also recognises that their bodies contribute to their disability (World Health Organization, 2011). The most common environmental barriers that appear in this review of the literature are accessibility, costs, lack of transport and a lack of health professional knowledge. The most common environmental facilitator is social support.

### **2.4.1. Environmental Factors**

#### *Accessibility*

Some studies acknowledge that there is still considerable work to be done in the area of accessibility with most organisations addressing provision for individuals with disabilities as policy add-on rather than forming an integral part of sports development strategies (French & Hainsworth, 2001; Kirchner, Gerber, & Smith, 2008). If an individual did choose to participate in PA outdoors, they are often faced with inaccessible sidewalks with inappropriate width, damage to pavement and cars blocking access, lack of curb cuts and puddles or poor drainage among many others (Kirchner et al., 2008). The WHO sees disability as a human rights issue (World Health Organization, 2011). Three of the general principles listed in article 3 of the United Nations (UN) Conventions on the Rights of Persons with Disabilities (CRPD) are accessibility; full and effective participation and inclusion in

society; and non-discrimination (World Health Organization, 2011). The CRPD entered into legislation for Australia in 2008 with an understanding that States in Australia are obligated to take all appropriate measures to eliminate discrimination against persons with disabilities.

### *Costs*

Across the world, working-age persons with disabilities experience much higher unemployment rates than people without disabilities (World Health Organization, 2011). In a study surveying 83 adults with stroke, 65 per cent of participants received an income of less than \$15,000 US with 77 per cent receiving disability benefits (Rimmer, Wang, & Smith, 2008). In addition to this, some individuals require expensive medications for their condition and adaptive equipment for everyday function (Block et al., 2010). The highest ranked barrier to participation in PA for 61 per cent of participants was cost of the program. When funds are limited, the fulfillment of basic needs becomes the priority and individuals are less likely to spend money on PA and leisure (Maslow, 1943). Results from another study interviewing stroke survivors revealed a group perception that PA had to be planned, structured and purposeful (Damush, Plue, Bakas, Schmid, & Williams, 2007). This may highlight a need for further education and information about what constitutes PA and how to find opportunities to be active with existing resources.

### *Transport*

Cost barriers can be related to transport barriers as participants may be unable to afford bus, train or cab fares, although reasons may include limited physical ability to access public transport (Rimmer et al., 2008). Planning, organisation and patience have been described in one study as essential when arranging transport for people with disabilities (Rolfe, Yoshida, Renwick, & Bailey, 2009). Participants in this study travelled long distances to participate in

exercise due to a lack of nearby accessible facilities. Forty-five minutes of PA can take up to two and a-half hours of a person's day. Some state that a spontaneous decision to exercise is not an option as accessible transit services require bookings 24 hours prior to an activity. The article further suggests that energy spent organising transport and travelling would be better used engaging in exercise. Interestingly, few participants in this study reported transportation as a major barrier. Shake-It-Up is a health promotion program offered in the US that provides education information and skills training for individuals with neurological conditions (Block et al., 2010). As part of skills training, participants learned to make their own way to the program by either providing their own transport, using public transportation or arranging carpools. The LIFE project system also includes access and transport as part of the five key components in the PA support system (Elsworth et al., 2011). Both programs acknowledge that transport is a major barrier and take steps to address the barrier; however, in the first study participants volunteered to participate, and in the second, transport expenses were covered by the study. A true measure of effectiveness of the skills training will be with the target population who choose not to participate and have no avenues for transport. It may reveal that facility-based PA is not the answer.

### *Health Professional Knowledge*

Throughout most of the studies participants cite a lack of confidence in the fitness staff and health professionals with regard to knowledge of the effects of a health condition on the exercise response (Elsworth et al., 2009; Levins et al., 2004; Ravenek & Schneider, 2009; Sandström, Samuelsson, & Öberg, 2009; Stephens, Neil, & Smith, 2012). This opinion is echoed in other studies that report difficulties promoting self-management of health among people with disabilities due to a lack of appropriately trained health professionals (Rimmer & Rowland, 2008). The WHO, in a recent investigation into public health challenges with regard to neurological disorders, highlighted wide gaps in different aspects of NMS condition care globally, specifically, a lack of public and professional education and awareness of the conditions, lack of resources for appropriate patient care and training of health professionals, and a lack of research into appropriate service delivery models (World Health Organization, 2006). An increase in survival and life expectancy rates of people with NMS conditions, an earlier functional age-related decline and an ageing population have all contributed to an increase in the prevalence and severity of NMS conditions over the last decade (Krause & Broderick, 2005). In Australia an increased demand for specialised community rehabilitation services has not been met resulting in a shortage of clinicians with specialised skills to supervise university allied health students in the NMS field (Barker, 2010).

### *Social Support*

Social support is a consistent determinate of PA in quantitative and qualitative studies among population with and without health conditions (Kosma, Ellis, & Bauer, 2012). Support can come from many sources, and in the case of this review, participants list health professionals, exercise buddies, family, friends, peers, role models, fitness instructors and caregivers as providers of social support. Through investigations with individuals with PD, three different

types of support were identified: instrumental, informational and emotional with support provided by family, friends, work colleagues, health care professionals and social support groups (Ravenek & Schneider, 2009). This study also revealed an interaction between the role of social support and perceived control of the disease. Participants felt that participation in PA gave them control over their condition by making them stronger and slowing progression of the disease. Other successful interventions demonstrating sustained increases in PA amongst individuals with NMS conditions have implemented social support by way of video coaching, Internet-delivered support, fitness instructors and health professionals while still maintaining a low-cost system (Dlugonski, Motl, Mohr, & Sandroff, 2012; Elsworth et al., 2011).

## **2.4.2. Personal Factors**

### *Motivation and Emotional Responses*

When reviewing the personal demotivators, listed repeatedly was a lack of motivation and many emotional responses such as self-consciousness, feeling uncomfortable, ashamed, embarrassed, fear of injury, anger and frustration. When exploring the reasons for a lack of motivation, two studies neglect to state for what reason (Damush et al., 2007; Elsworth et al., 2009) and others state too much effort, or a limited return for amount of effort required (Buffart, Westendorp, van den Berg-Emons, Stam, & Roebroek, 2009; Kayes et al., 2011; Kehn & Kroll, 2009). Individuals report that during PA they experience an exacerbation of previous symptoms; others state that it takes a week to gain benefits and only a day to lose them, returning back to where they started (Kayes et al., 2011). When an activity that requires a great deal of effort to perform is not yielding the expected outcomes, it follows that individuals will lose motivation (Bandura, 1986). It should also be noted that a lack of motivation for an individual with a brain injury could be attributed to injury to the areas of

the brain that control motivation (J. H. Powell, al-Adawi, Morgan, & Greenwood, 1996). For those individuals with progressive conditions who experience fluctuating symptoms, it can seem like PA is having no positive impact and, as stated by Kayes (2011), this can be linked to emotional responses such as frustration and anger. Other emotional responses listed in this review such as self-consciousness, feeling uncomfortable, ashamed and embarrassed are related to being physically active in unfamiliar environments around able-bodied people. Typically, it was the discomfort of being watched by others whilst performing activities, especially walking (Borkoles, Nicholls, Bell, Butterly, & Polman, 2008). Impaired walking balance is the most common activity limitation in this review for individuals with NMS conditions and is linked to fear of falling and injury. For able-body older adults, one of the most relevant behaviour-related risk factors for falls is a fear of falling (Boelens, Hekman, & Verkerke, 2013). Factors that identify older adults with a fear of falls include, using a walking aid, unable to rise from a chair of knee height, difficulty in using public transport, poorer physical health, self-reported balance problems and a higher body mass index (BMI) (Kumar, Carpenter, Morris, Iliffe, & Kendrick, 2014). All of these factors are specifically relevant to individuals with NMS conditions. Individuals who experience a fear of falling are more likely to restrict their participation in activities that they value and gain satisfaction from resulting in social isolation. All of the examples listed above demonstrate a strong link between personal factors and level of function.

The ICF model is ideal for demonstrating the complex interaction between the components. Figure 2.3 is an example of how factors that influence participation in PA for an individual with MS from one of the studies reviewed (Kayes et al., 2011) fit into the ICF model. This example highlights the dynamic interaction between the three areas of functioning and the personal and environmental factors. The model demonstrates that personal factors such as

frustration, fear and worry are linked to the degenerating nature of the condition. It also shows that motivators in the three areas of function such as weight loss and learning new wheelchair skills contribute to motivating personal factors such as challenge, reward and enjoyment. Health Professionals who take the time to qualitatively explore an individual's personal factors may develop a better understanding of an individual's barriers and facilitators to PA participation and work with them to find solutions to overcome barriers and capitalise on facilitators.

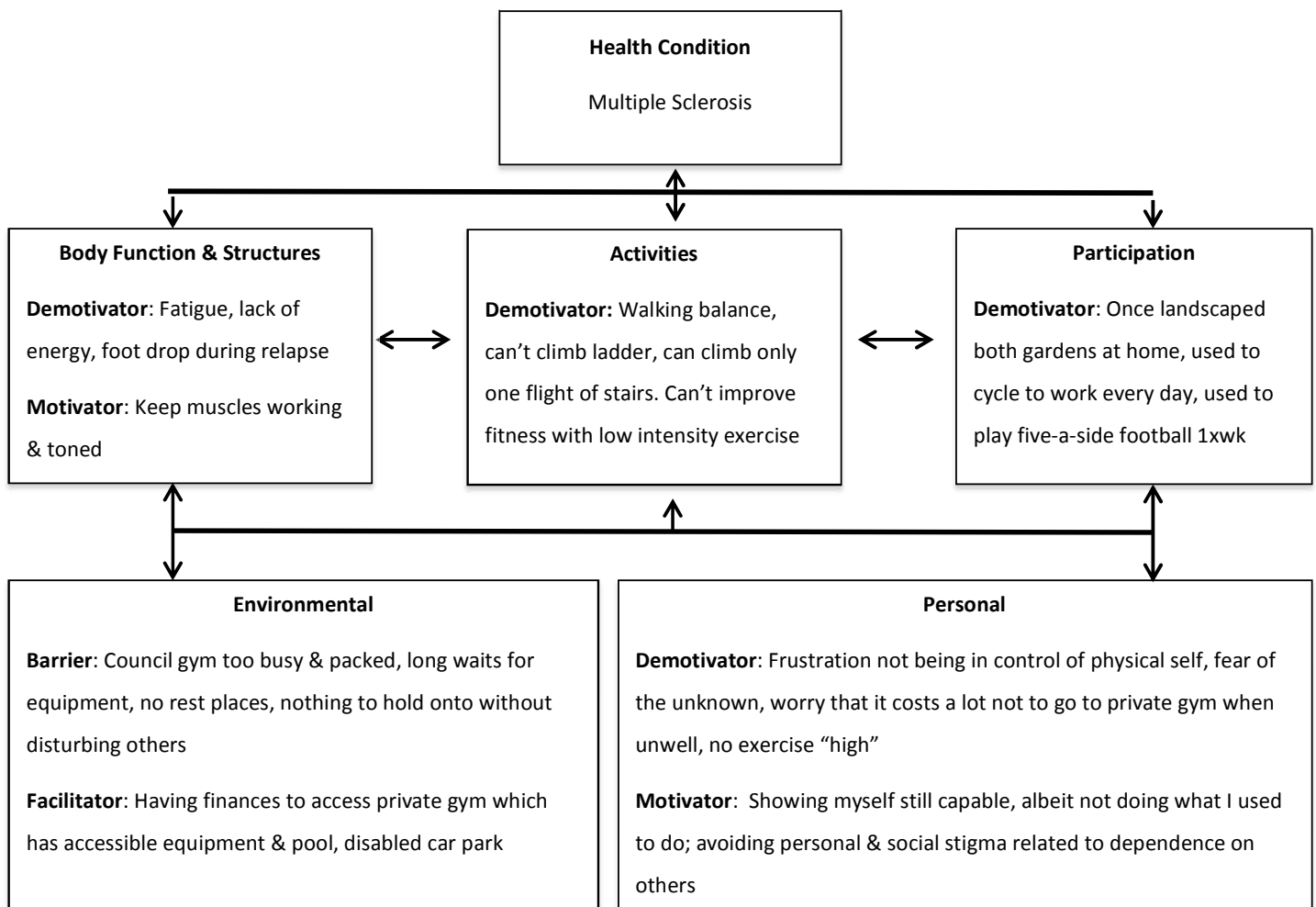


Figure 2.3 ICF framework for an individual with MS



### *Benefits of PA*

Most individuals in the studies in the review agreed that PA was beneficial regardless of whether they participated or not, and this is corroborated by the numerous facilitators and motivators recorded in Table 2.2. Many reported feelings of enjoyment, fulfillment, accomplishment, improved well-being, self-efficacy and optimism, assisting with weight control and feeling good. Most agreed that PA contributed to the maintenance of independence and function and was an emotional outlet for frustration and anger. These benefits are not dissimilar to those given by individuals without health conditions. This is a foreseeable finding as the benefits of consistent PA do not discriminate against any population whether young, old, able or disabled (Moore, 2009). More condition-specific PA benefits reported were that participants felt “normal” and saw sport as an avenue for escapism from the everyday limitations and boundaries imposed on them by their health condition. In some instances, PA was seen as a way to redefine self after losing their able-body identity. (Stephens et al., 2012).

### *Individuality*

Regardless of the known benefits of PA, the data presented in this review demonstrates that factors that influence participation in PA among people with NMS conditions are indeed complex due to the varying nature of conditions and symptoms and the characteristics, attitudes and beliefs of each individual. Even though many of the factors listed in the studies in this review are the same, the way in which they influence participation in PA is unique to the individual. This is demonstrated in Kayes’ study (Kayes et al., 2011) where the diagnosis of MS acted as a demotivator for some, however, triggered an increase in PA for others. Further, the study describes the decision to participate in PA as being fluid and requiring constant re-evaluation due to the fluctuating nature of symptoms. Another study exploring

SCI and PA reported that the benefits of participating in PA can change for a person over the course of a condition from socialisation, gaining knowledge and incidental learning during the adjustment process, to the benefits of health and wellbeing following acceptance of an injury (Stephens et al., 2012). Preferences with regard to the timing of interventions post-injury enforce the notion of an individually tailored approach. Some individuals choose not to participate in PA immediately post-injury as their priority is the process of restarting and rediscovering a new life and a new situation (Levins et al., 2004) while others expressed a need for increased exposure to PA in acute rehabilitation saying it aided in the re-establishment of a new lifestyle (Stephens et al., 2012). For individuals experiencing stroke symptoms, developing a rigid routine to fill an empty schedule facilitated participation in PA (Damush et al., 2007), whilst, for individuals with MS, creating a flexible routine was essential to accommodate fluctuating symptoms (Dlugonski, Joyce, & Motl, 2012).

With regard to attitudes and beliefs about PA, it was interesting to note that only six of the 15 studies in the current review discuss the influence of pre-condition PA on post. Only four of the six studies specifically investigated participant participation pre-condition. Some individuals reported that their previous PA experience assisted them to feel more in control, spontaneous and autonomous in their approach to current PA participation (Borkoles et al., 2008). These individuals were extremely active before the diagnosis of MS and mourn the loss of their former exercise identity. They report missing the ability to run, cycle to work, play football and physically pushing themselves to the limit, however, despite these negative evaluations, they were determined to remain active. Another study reported that pre-injury participation in exercise was not a strong indicator for post-injury as some participants who were active pre-injury did not continue post-injury and vice versa (Kehn & Kroll, 2009). This result is corroborated with another study where 79% of non-active post-injury

participants were active pre-injury (Lund, Michelet, Kjekken, Wyller, & Sveen, 2012). Alternatively, some individuals state that memories of how strong they felt and remembering “flying up hills” prior to their injury acted as a motivator to their current PA (Kerstin, Gabriele, & Richard, 2006). There are instances where participants with childhood-onset health conditions describe unpleasant physiotherapy experiences in early life as deterrents to PA in later life (Sandström et al., 2009) and others who were insufficiently active pre-injury are of the opinion that it is more important to be physically active post-injury to maintain health and increase energy (Self, Driver, Stevens, & Warren, 2013).

What is evident from reading the literature is that individuals with NMS conditions who are determined to be physically active can generally find a way to overcome barriers. Some of the strategies implemented include cycling a stationary bike with fans to overcome thermoregulation deficits in the heat; walking on a treadmill instead of outside when stability is worse; putting support systems in place to increase motivation (Dlugonski, Joyce, et al., 2012). Some participants will exercise to videos at home to overcome accessibility issues and others go to great lengths to plan and organise transport, persisting with participation regardless of travel delays and cancellations (Rolfe et al., 2009). One individual with PD who is determined to stay self-sufficient uses humour as a coping mechanism, and is quoted as saying: “I dust myself off and fall again!” (Pretzer-Aboff, Galik, & Resnick, 2009). Many studies have found that people who are inactive report more barriers than physically active individuals (Dlugonski, Joyce, et al., 2012; Driver, Ede, et al., 2012; Kehn & Kroll, 2009).

### *Individually Tailored PA*

When encouraging individuals with a NMS condition to participate in PA, individually tailored strategies are essential, and this is no different to the approach used with able-bodied individuals. However, when we refer to the World Report on Disability (World Health Organization, 2011), it states that disability is not a matter of yes or no, it is more or less. To investigate what is more or less for a person with regard to PA requires in-depth exploration. It is essential to identify the problems encountered in all three areas of functioning along with the context in which they take place, as stated in the ICF framework (World Health Organization, 2001), because these factors will influence the sort of intervention that is likely to successfully increase physically active behaviour in a given individual.

### **2.4.3. Multidisciplinary Approach**

Of particular note in all of the health promotion programs mentioned in the literature review, was the necessity to incorporate a number of allied health professionals including exercise physiologists, occupational therapists, psychologists, physiotherapists and health specialists. It appears that an integral strategy of successful programs, when promoting sustainable PA in people with special needs, is to draw upon appropriate expertise when needed (Stephens et al., 2012).

### *Limitations*

Although a small sample of individuals was included in the review, there was sufficient representation of NMS conditions, however only six of the 15 studies reported data saturation. The majority of participants in this review had a diagnosis of SCI, where the majority of cases are traumatically acquired by young males (Norton, 2010), and MS, a progressive condition that typically presents in females between 20 and 50 years (Milo &

Kahana, 2010). Despite the prevalence of participants with these conditions, the studies in this review manage to gain the perspective of individuals with congenital conditions, conditions that are progressive and non-progressive; conditions acquired both early and late in life and with individuals with varying levels of function, a wide age range and equal representation of gender. More demographic and background information such as age, education level, socioeconomic status, employment status, family/friend support and PA history would have been beneficial as all of these factors can significantly influence individuals capacity to participate in activities (Dlugonski, Joyce, et al., 2012). As far as the authors can tell, all of the studies included in the review took place in an urban setting. Future studies should explore factors that influence participation in PA in regional and remote settings.

## **2.5. Conclusions**

The results of this literature review indicate that factors that influence participation in PA are complex and, although similar amongst participants, can act as a barrier or facilitator to participation depending on the individual's characteristics, attitudes and beliefs. The studies in this review examine factors in every domain of the ICF and the results highlight that the interaction between the person with a health condition and their contextual factors is indeed dynamic. It is for this reason that health professionals should be guided by the ICF framework when conducting individual assessments. This will ensure the collection of all major factors of interest, including the acquisition of intensely personal information required to develop a truly individually tailored approach to participation in PA. Thorough assessment and management of barriers may require the expertise of other allied health professionals. The majority of individuals, regardless of whether they participate or not, believe that PA is

beneficial to their health and wellbeing, a factor that health professionals must capitalise on to promote long-term participation in PA.

## **Factors that influence participation in physical activity: the perspective of individuals with neuromusculoskeletal conditions in a regional area**

This study was deemed necessary for two reasons. Firstly, results from the literature review indicated the factors that influence PA participation were predominantly acquired from the perspective of individuals with NMS conditions who live in urban areas. Secondly, APAP was to be implemented into a regional community rehabilitation setting and it is important to know and understand the context for implementation. Development of a protocol for implementation is dependent upon all factors related to the local context and setting.

## **2.6. Introduction**

Physical activity (PA) is associated with improved physical and psychological health (Dishman, 2004). Regular participation in PA decreases the risk of lifestyle disease such as diabetes, cardiovascular disease and some cancers (Lee et al., 2012). Despite the growing body of evidence endorsing the benefits of PA, 67% of Australians were found to be either sedentary or insufficiently physically active (i.e. <150 minutes per week) in 2011-12 (Australian Bureau of Statistics, 2013). The most common barriers to PA participation that have been reported include motivation, time, disinterest and cost (Andajani-Sutjahjo, Ball, Warren, Inglis, & Crawford, 2004; Burton, Walsh, & Brown, 2008). Individuals with physical disabilities, particularly those with NMS conditions, face additional barriers to PA participation compared to the general population (Rimmer, Riley, Wang, Rauworth, & Jurkowski, 2004). These barriers include factors related to physical, cognitive, linguistic and psychological impairment (Mulligan, Hale, Whitehead, & Baxter, 2012) and the subsequent activity limitations and participation restrictions that arise and factors that relocated to the individual's environmental and personal context, as described in the ICF framework (World Health Organization, 2001). The ICF framework, which has advanced the understanding and measurement of disability, demonstrates the dynamic interaction between disability and function and the environmental and personal context in which they occur. Health professionals who have an understanding of this interaction are well placed to design better PA interventions to meet the needs of individuals with NMS conditions.

A recent literature review explored factors that influence participation in PA for individuals with NMS conditions categorising results into components of the ICF (Newitt et al., 2016). The most common functional barriers to PA were fluctuating symptoms and fatigue, and poor walking balance. The most common personal factors were a lack of motivation and feelings



of self-consciousness, embarrassment, anxiety and frustration. The most common environmental factors were accessibility, a lack of information on where and how to exercise, costs and transport. The review demonstrated that even though people report similar barriers and facilitators to participation in PA, it is their contextual factors that make these barriers unique to the individual. For example, the diagnosis of a progressive condition can motivate one individual to commence PA, whilst another is deterred (Kayes et al., 2011). Additionally, for some individuals with spinal cord injury, PA was viewed as a coping mechanism for life-changing events whilst others required time to adjust before becoming physically active (Kerstin et al., 2006). Interestingly, all of the studies included in the literature review were conducted in metropolitan settings with subjects predominantly living in urban areas.

Physical activity is significantly lower among adults living in rural areas compared to those in urban areas (Trost, Owen, Bauman, Sallis, & Brown, 2002). Individuals who live in regional, rural and remote areas, comparatively, have poorer health than their metropolitan counterparts (Aged & Community Services Australia & National Rural Health Alliance, 2005). This is, in part, due to reduced accessibility to health and community support services (National Rural Health Alliance, 2009). Accessibility, social and environmental factors are determinants of PA and knowledge of determinants is essential when designing and delivering lifestyle PA interventions for individuals with NMS conditions (Trost et al., 2002). It is, therefore, the aim of this study to gain the perspective of people with NMS conditions who live in northern Queensland with regard to factors that influence participation in PA.

## **2.7. Methods**

A qualitative research design was chosen for this study on the basis that qualitative inquiry would provide rich descriptive data that would not only reveal what influences participation

but also why (Liamputtong, 2009). Two focus groups (n=9) and four in-depth interviews (n=4) were used to gather data over a three-month period. The data were collected, compared to the literature and analysed using pre-existing themes. These themes were the elements of the ICF (World Health Organization, 2001). Axial coding occurred with the development of a coding paradigm that asked the following questions about each theme: 1) What conditions give rise to the category; 2) What is its context; 3) What are the interactional strategies by which it is handled; 4) What are the consequences of those strategies (Green, 2009). Focus groups were chosen on the basis that interaction between focus group participants, by way of sharing common experiences, disagreeing and challenging each other, is thought to produce data and insights that may be less accessible with other methods (Morgan, 1997). In-depth interviews were chosen to enable the researcher to delve deeper into the lived experience of participants, capturing their thoughts, perceptions and feelings; responses that might otherwise be influenced by a group (Liamputtong, 2009). The number of focus groups and in-depth interviews conducted was determined by saturation of data, the point where there were no new constructs emerging. Participant data was also collected from the electronic record system at CRnQ. Ethical approval for this study was obtained from the James Cook University Ethics Committee in Townsville (H5272). Written informed consent was obtained from those who agreed to participate.

### **2.7.1. Participants**

Participants recruited for the study were eligible to participate if they had been diagnosed with a NMS condition, were >18 years of age; able to communicate with the researcher and were participants of CRnQ, Townsville, Australia. CRnQ is a service that is offered at no cost to people with NMS conditions who live in regional, rural and remote northern Queensland. CRnQ is accessible to all, irrespective of religion, culture or economic situation

and flexible to address the unique needs of nQ people, particularly Indigenous people and people from remote areas that together have the poorest health and the poorest access to health service. To obtain maximum variation, participants at CRnQ were purposively selected according to demographics (e.g. Indigenous, non-Indigenous, regional, rural, remote location) types of NMS conditions (e.g. congenital, acquired, progressive) and known moderators and mediators of PA (Rimmer et al., 2004) (e.g. social support, transport, socioeconomic status, employment). Allied health professionals (AHPs) from CRnQ nominated suitable CRnQ participants for the focus groups accordingly. The researcher then contacted the CRnQ participant and invited them to attend a focus group at one of two nominated times at CRnQ. Transport was provided if required. All participants were either past or present participants of CRnQ, therefore were familiar and comfortable with their surroundings. Most of the participants had met previously as they had accessed the same regional health services throughout the life of their condition.

### **2.7.2. Focus group data collection procedures**

A semi-structured interview process was utilised for both the focus group and individual interviews. Two facilitators and a note taker were present during both focus groups. The first author (RN) was the primary facilitator initiating most of the discussions. The role of the second author (TA) was to assist with facilitation by identifying emerging themes and encouraging further discussion and clarification. The note taker's role was to record both verbal and non-verbal responses. Focus group questions (Table 2.4) were based on previous literature and included topics that were considered relevant to factors that influence participation in PA (Elsworth et al., 2009; Newitt et al., 2016; Rae-Grant et al., 2011). Questions related to PA definitions, PA history and perceived benefits, and barriers/facilitators to participation in PA. Questions had been piloted previously during two

face-to-face interviews and were refined, via an iterative analysis process in later interviews and focus groups in order to explore evolving issues (Liamputtong, 2009). The questions were open-ended with prompts used when necessary. During introductions, the facilitator outlined the focus group procedure, the role of each of the researchers and a number of ground rules to ensure a smooth discussion. (e.g. No right or wrong answers, expect differing points of view). Focus groups lasted from 60-90 minutes and were audio-taped once consent was received from each focus group participant.

**Table 2.4 Focus group and individual interview questions**

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1. What is physical activity to you?

2. What are your experiences of physical activity throughout life?

Probes included: Did you grow up in a family who were always active? Were there changes to your activity throughout your life? Did you do physical activity before your health condition?

3. What is it that stops you from participating in physical activity?

Probes included: Are there any aspects of your health condition that stop you from participating in physical activity?

4. What is it that helps you participate in physical activity?

Probes included: What is it that motivates you to be physical activity?

5. What do you expect to get from doing physical activity?

Probes included: Do you expect benefits? Do you expect to feel worse sometimes?

---

### **2.7.3. Individual interview data collection procedures**

Individual interviews took place in a quiet environment either in the participants' home or in the interview rooms at CRnQ. Transport was provided if required. The same procedure was used for individual interviews as was used for the focus group interviews. Data obtained from the two pilot interviews that informed the focus group process was deemed comprehensive and rich by the first author, therefore, were analysed and included as part of the study along with two additional interviews.

### **2.7.4. CRNQ electronic record system data collection procedures**

Data about the participants' PA and transport status and balance capacity were sourced from the CRnQ by the principal investigator.

### **2.7.5. Data Analysis**

Initial analyses were conducted by the lead author (RN), firstly, by transcribing the data verbatim, followed by reading and re-reading. Data was initially coded into elements of the ICF framework. Transcripts were initially read through in entirety and then multiple times conducting a line-by-line analysis. Constant comparison was applied to identify connections and relationships between the data and to explore the properties, context, interactional strategies (purposefully employed and factors beyond control) and consequences of each ICF element. Data for each element was further categorised into facilitators and barriers. A number of strategies were used to ensure overall rigour (Letts et al., 2007). To ensure credibility, data were collected using two methods, interviews and focus groups, over a

prolonged period from a range of participants. Member checking was conducted by summarising each of the participant's transcriptions and returning to them for review of content accuracy. Additionally, data were coded by two other researchers (investigator triangulation) who had a background in PA research. Results and descriptions of the data were compared with those of the first author. Disagreements between coders occurred but were dealt with on a case-by-case basis and did not affect significant pieces of data.

## **2.8. Results**

Participant characteristics are outlined in Table 2.5. Age range for participants was 27-79 years. Overall representation of diagnosis was stroke (n=4), multiple sclerosis (MS; n=3). It was observed by the researchers that participants in northern Queensland access the same health services and became acquainted with each other and the health professionals (HP) at these services.

Factors that influence participation in PA for this group of individuals with NMS conditions who live in regional North Queensland are described in the following section and illustrated in Table 2.6.

**Table 2.5 Participant characteristics**

	Gender	Condition	Ethnicity	Type of condition	Assistive device**	Living Alone	Own Transport	Single Income	Employed	Pension	Currently Physically active	PA history
1	Male	Polymyelitis	Caucasian	Progressive	SPS	No	Yes	No	No	Yes	Yes	Exercise & sport whole life
2	Female	Spina bifida	Caucasian	Congenital	WC	No	No	Yes	No	Yes	Sometimes	Exercise & Sport whole life
3	Male	BI	Caucasian	Acquired	Nil	No	Yes	No	Yes	No	Yes	Exercise & sport whole life
4	Female	Stroke	Aboriginal	Acquired	SPS	No	No	No	No	Yes	No	Sport in school
5	Male	Stroke	Caucasian	Acquired	SPS AFO	No	Yes	No	No	Yes	No	Sport in school
6	Female	BI	Caucasian	Acquired	Forearm crutch WC	Yes	Yes	Yes	Yes	Yes	Yes	Exercise & Sport whole life
7	Male	PD	Caucasian	Progressive	4WW	No	Yes	No	No	Yes	No	Exercise, sport, dancing sporadically
8	Female	Stroke	Caucasian	Acquired	WC	Yes	No	Yes	No	Yes	No	Sport in school
9	Male	MS	Caucasian	Progressive	4WW	No	Yes	No	No	Yes	No	Incidental throughout life
10	Male	Stroke	Caucasian	Acquired	Nil	No	No	No	No	Yes	Yes	Exercise & sport whole life
11	Female	MS	Caucasian	Progressive	SPS 4WW WC	Yes	Yes	Yes	No	Yes	No	Recreational activity until diagnosis
12	Female	MS	Caucasian	Progressive	SPS AFO 4WW WC	No	Yes	Yes	No	No	Sometimes	Incidental, exercise, recreational until diagnosis
13	Male	Spina bifida	Caucasian	Congenital	Underarm crutches	Yes	Yes	Yes	Yes	No	Sometimes	Recreational as child, exercise sporadically

BI: Brain injury; MS: Multiple Sclerosis; PD; Parkinson's Disease; SPS: single point stick; WC: wheelchair; AFO: ankle-foot orthosis; 4WW: four-wheel walker



**Table 2.6. Factors that influence participation in PA categorised into ICF components**

Body function & structure	Activities	Participation	Environmental factors	Personal factors
<p>Facilitators</p> <ul style="list-style-type: none"> <li>• Maintain function</li> <li>• Improved strength</li> <li>• Weight management</li> <li>• Improve fitness</li> </ul> <p>Barriers</p> <ul style="list-style-type: none"> <li>• Health setbacks</li> <li>• Fatigue</li> <li>• Impaired thermoregulation</li> <li>• Reduced vision</li> <li>• Seizures/Epilepsy</li> <li>• Reduced cognitive function</li> <li>• Tiredness</li> <li>• Impaired motor control</li> <li>• Muscle weakness</li> <li>• Depression</li> <li>• Back pain</li> <li>• Lack of energy</li> </ul>	<p><b>Limitations</b></p> <ul style="list-style-type: none"> <li>• Walking</li> <li>• Walking/standing balance</li> <li>• Getting up and down off ground</li> <li>• Driving</li> <li>• Cooking</li> <li>• Setting the table</li> <li>• Falling</li> </ul>	<ul style="list-style-type: none"> <li>• Life areas used to do</li> <li>• Adapted life areas</li> <li>• New life areas</li> <li>• Life areas want to do</li> </ul>	<p><b>Social support facilitators</b></p> <ul style="list-style-type: none"> <li>• Out amongst other people</li> <li>• Encouragement from HPs</li> <li>• Expert HPs</li> <li>• Social interaction</li> <li>• Support groups (brain injury group)</li> <li>• Community Rehab &amp; HPs</li> <li>• Local facility staff</li> <li>• Members of public - helpful</li> <li>• Word of mouth (PA links in the community)</li> <li>• Piggy back from work colleague</li> <li>• Peer models</li> <li>• Having somebody around you</li> <li>• Sporting Wheelies</li> <li>• Enjoying scenery</li> </ul> <p><b>Social support barriers</b></p> <ul style="list-style-type: none"> <li>• Members of public – over-helpful</li> <li>• Friends – over-helpful</li> <li>• Family – over-protective</li> <li>• Rehab sessions finish up and no support</li> </ul> <p><b>Accessibility facilitators</b></p> <ul style="list-style-type: none"> <li>• Safe environment (gym)</li> <li>• Safe equipment (tricycle)</li> <li>• Climate (controlled)</li> </ul> <p><b>Accessibility barriers</b></p> <ul style="list-style-type: none"> <li>• Unstable ground/outside</li> <li>• Escalators</li> <li>• Wet surfaces</li> <li>• Crowds of people</li> <li>• Rain</li> <li>• No lift in work building</li> <li>• Inaccessible shops/restaurants</li> <li>• No driver's licence</li> <li>• Climate (heat, rain)</li> </ul>	<p><b>Trait facilitators</b></p> <ul style="list-style-type: none"> <li>• Perseverance</li> <li>• Determination</li> <li>• Self-consciousness about appearance</li> <li>• Embarrassment</li> </ul> <p><b>Trait barriers</b></p> <ul style="list-style-type: none"> <li>• Lack of motivation</li> <li>• Lack of confidence</li> <li>• Intrinsically lazy</li> <li>• Too proud to ask for help</li> </ul> <p><b>Psychological, cognitive, emotional</b></p> <p><b>Facilitators</b></p> <ul style="list-style-type: none"> <li>• Self-efficacy</li> <li>• Maintain independence</li> <li>• Activity meaningful</li> <li>• I'm going to age well</li> <li>• PA part of daily routine</li> <li>• Sense of achievement</li> <li>• Music and dancing</li> </ul> <p><b>Barriers</b></p> <ul style="list-style-type: none"> <li>• Low self-efficacy</li> <li>• Repetitive exercise is boring</li> <li>• PA feels like penance</li> <li>• All good feelings from exercise went away with health condition (endorphins, love of outdoors)</li> <li>• Time consuming</li> <li>• Not interested in exercise for exercise sake</li> <li>• Don't like exercising in groups</li> </ul>

### **2.8.1. Body function and structures**

Participants felt that participation in PA was essential to maintain function and to slow the progression of their health condition. Some state they were physically active because they want to live longer and age well.

*If I don't keep doing it [PA], I'm not going to be able to walk. So it's a case of do it or lose it. (Male, polymyelitis)*

All participants stated that their impairment (e.g. epilepsy, thermoregulation, fatigue) was a barrier to participation in PA. One participant said that reduced vision, seizures and tiredness as a result of his stroke had prevented return to work. Those with fluctuating symptoms experienced good and bad PA days. Feelings of depression occurred from health setbacks and not being able to achieve what they would like to achieve.

*When I've had a setback, I feel like I've lost 50 per cent of my independence...and then I get cranky at people...I hate the world, I hate me. (Female, stroke).*

Strategies to manage impairments included exercising in a controlled environment (e.g. air-conditioning), walking to cope with depression, swimming to relieve back pain, and the cessation of contact sports. Participants reported feeling mentally and physically stronger after PA with increased PA confidence and tolerance to PA. Alternately, putting in extra effort at the gym (e.g. increasing walk on treadmill by one minute) or a busy day at work could result in exhaustion or insufficient energy for the remainder of the day for some participants.

## 2.8.2. Activities

Of the participants whose primary means of locomotion was walking, 91% experienced poor walking balance. Most participants experienced regular falls at home and in public, which they reported as “confidence shaking” and a deterrent to PA.

*...because you just don't know what you're going to hit. You don't know how hard your head's going to hit the floor or wall or whatever's there...But it doesn't matter which way you fall or how you fall, it shakes up your confidence...and it's hard to get straight back up and start exercising again. (Male, PD)*

Having impaired balance, participants found that they began to automatically anticipate and plan tasks. Some participants said they can no longer walk on the beach or in the bush and found walking amongst people challenging. Some moved about in a wheelchair for safety when in public. Conversely, others attended rehabilitation to learn to run again and improve balance. Strategies employed by some participants to manage activity limitations included asking for assistance from family, friends, colleagues or members of the public. Alternately, some participants stated they were too proud to ask for help.

*...for a grumpy old bugger like me who's too proud...I won't ask for help until I fall over and somebody comes and picks me up. (Male, polomyelitis)*

Participants also reported limitations related to upper-limb activities such as cooking and setting the table, getting up and down off the ground. Four participants could no longer drive due to their health condition.

*I haven't been able to get around unless I've got my husband or one of my daughters driving me around. It's really hard. (Female, stroke).*

Well-meaning, over-protective family and members of the public were thought by some to inhibit activities (e.g. cooking, pushing own wheelchair, riding the escalator), whilst other participants took the time to educate others about their disability.

*I get my groceries every Saturday and the trolley guy comes out and gets my wheelchair. I asked him once 'cause I had a sore back, so he runs over and grabs it out. (Female, pontine cavernoma cerebral haemorrhage,)*

### **2.8.3. Participation**

Participants described participation as life areas they used to do and no longer can, such as preparing meals for the family, employment, rock climbing and hockey.

*You don't really see how dangerous it is until you sit on the sidelines for a season...people coming off with black eyes...I don't know if I can return to play hockey. (Male, oligodendroglioma, anaplastic epilepsy).*

Participation was also described by some as adapted or new life areas including wheelchair dancing, coaching and swimming.

*I'd get up on the dance floor in my wheelchair and I have a dance...I mean, people look at you strange...I enjoy myself." (Female, stroke)*

Lastly, two participants expressed sadness when referring to life areas they would like to do but never will (e.g. collecting things on the beach with grandchildren and fussing over daughter's wedding).

*I look down there at low tide and I know what's there, but I know that if I didn't have MS and I could get around, I would be down there looking at what's there, thinking*

*about taking my grandchildren down there...but I can't do that now and that makes me sad actually. (Female, MS).*

Strategies adopted by participants to continue participation included learning to swim; taking on a coaching role instead of playing a contact sport; attending the gym instead of outdoor activity and acquiring the assistance of health professionals to re/learn skills. Some participants chose to cease participation due to safety, inability and insurmountable barriers. As a result, participants felt sad, frustrated and annoyed and lost. Reasons stated for pursuit of activities included determination, confidence and importance of the activity to the participant.

*Something drives me to want to do it...and so whatever it takes, it doesn't matter...I'll try anything...I'll get there by some means. If it means being slung over someone's shoulder, I would do that, but if I have to find my way, then I would try my best to do it. If the carrot was big enough at the end...because then I'm not thinking, 'oh, can I do that?'* (Female, MS).

#### **2.8.4. Environmental Factors**

Social support was the most common facilitator to PA according to participants and the factor that they felt most strongly about. Support was by way of HPs, members of the public, support groups, friends, family, peer models, sporting organisations and word of mouth about PA information. Participants felt safe with others around; they could ask for assistance; they received encouragement, were inspired by peers and learned skills.

*I find it more motivating for me to come here and do the exercises than doing the same things at home, 'cause I don't drive myself nearly as hard as I should. (Male, stroke)*

*There's people in the building who actually know me...they hold the door open until I can actually get in. (Male, 57, spina bifida)*

Conversely, some participants found others a hindrance when offering assistance and reported that friends and well-meaning over-protective family members, on occasion, prevented incidental activity.

*I wanted to have a go at going up the escalator. My husband said: 'No, no, no...use the lift'. (Female, stroke).*

For participants, social support enabled participation in life areas, social interaction, friendships and acquaintances and increased confidence.

Accessibility issues described by participants in this study included not having transport, unstable surfaces, lack of space, presence of stairs, long distances and moving obstacles. Alternately good accessibility meant a safe environment (e.g. gym) and safe equipment (e.g. tricycle). For individuals with mobility issues, unstable surfaces and moving people were described as trip hazards. Early retirement was forced upon one participant as there was no lift access to her office. Participants who were no longer able to drive found it difficult to participate:

*Yeah, I think that I would do more [PA] if I had the transport." (Female, SB).*

Air-conditioned gyms, adapted equipment and cooler temperatures enabled PA participation for some participants, especially those with impaired thermoregulation (n=5).

*On a good day when temperature is cool, all targets are achieved. I felt good and walked to the car, put my four-wheel walker in, and didn't require a sleep when I got home...Unfortunately, I'm going to expect myself to exceed those targets again. Some days I'm going to fail miserably, but I hope it doesn't set me back too far. (Male, MS)*

## 2.8.5. Personal Factors

Participants made reference to personal factors which influenced PA including personality traits and PA attitudes and beliefs. For example, participants spoke about perseverance, and pride; views that exercise was boring; that it felt like penance, was time consuming and not a priority. Alternately, some saw PA as a way to maintain independence and an important part of their day. Participants who had participated in sport their entire life considered it a way of life. Participants reported feelings of self-consciousness and embarrassment when exercising in public. A recurring theme throughout the interviews was participants' lack of confidence to participate in PA, and then the resulting increase in confidence once they had participated with the help of a HP.

*My thing is I started swimming last week, but I used to be a swimmer and it was really good to get back into the water again after so many years of being out...just made me feel really good, you know, good to be doing something. And it brings your confidence up too 'cause I lacked confidence after so many, you know, things went wrong for me. It kind of built me up that way. ....And, really, people that were there weren't interested in what, you know, I was doing...getting in with the special pool wheelchair or things like that. That was my main thing...but it was all good, and, yeah, I was able to enjoy myself, which was even better. (Female, Spina Bifida)*

*Yeah, confidence is really irreplaceable, so, you know, if you don't have confidence, you don't really – yeah, you can't do anything... As soon as I was on my bike again, you know, five minutes on the bike and you just – did the world of confidence. (Male, oligodendroglioma)*

Most participants preferred to be physically active with others and some preferred PA on their own. Strategies adopted by participants to be physically active included setting

challenges/goals and routines, keeping a diary of activities, anticipating and planning for obstacles and performing meaningful activities. As a result of participating in PA, participants felt their day was complete and described a sense of achievement from making the effort, or doing something they thought they could not do or had not done in a long time. Additionally, all participants were motivated by progress and results, with others receiving inspiration from their peers.

*But I've walked into the gym, you look around and there's lots of people a lot worse off than you and you think, here's people working hard to get back; I'm going to work hard too.* (Male, polomyelitis)

Conversely, participants were sometimes frustrated and disappointed with a lack of, or slow progress and the absence of good feelings they used to experience with PA (e.g. endorphins).

*I used to love being able to push past the limit, just going for a run and seeing how far I'd go.* (Male, oligodendroglioma)

*Sometimes it makes me jealous. Because when I feel good, it's not necessarily at the same times as other people do.* (Male, MS)

## **2.9. Discussion**

This qualitative study explored factors that influence participation in PA from the perspective of individuals with a NMS condition who live in a regional area. The results indicated that, with regard to all elements of the ICF, factors influencing participation in PA were similar for this group of individuals living in regional areas to those reported in the literature. Furthermore, even though factors were common for all, participation in PA was governed by the individual's environmental and personal factors.



Although most individuals know what constitutes PA and are aware of the benefits of PA if performed regularly, for many and varied reasons, most experience a lack of motivation to be physically active (Buffart et al., 2010; Stephens et al., 2012). To be motivated means ‘to be moved’ to do something (Ryan & Deci, 2000). Motivation based on the reasons for doing something can be distinguished as intrinsic or extrinsic. Intrinsic motivation occurs when an individual is inherently interested or gains enjoyment from an activity. Extrinsic motivation refers to doing something because it leads to a discrete outcome (Ryan & Deci, 2000). Exercise professionals endeavour to understand what intrinsically motivates an individual to be physically active. If intrinsic motivation is present with regard to a particular activity, an individual is more likely to engage and persist in that behavior (Dacey, Baltzell, & Zaichkowsky, 2008). When participants in this study were asked about their lived experiences in relation to PA, many reminisced about the joy and satisfaction they received from activities in the past, for example, pushing to the limit when running, enjoying the wildlife when bushwalking, and a love of dancing. These activities appeared to be meaningful to them, a source of intrinsic motivation; however, due to their health condition and associated barriers, they relied on extrinsic motivation. An extrinsic factor common to all in this study was social support.

Social support is believed to be a strong mediator for PA motivation (Damush et al., 2007). There are four different types of social support: instrumental, informational, emotional and appraisal (Marcus & Forsyth, 2003). Instrumental social support involves giving a person something tangible in order to be physically active, for example, a lift to the gym. Informational support is providing relevant information about PA, for example, the provision of information about pools that are accessible in the local area. An example of emotional support would be to call and check on a person’s PA progress, and examples of support by appraisal would be to provide feedback and encouragement. Due to impairments in

communication, mental and movement-related function, individuals with NMS conditions experience limitations and restrictions in their community, social and civic life. Consequently, they become isolated and interpersonal interactions and relationships are impacted (World Health Organization, 2001). Participants living in the regional area of northern Queensland accessed the same health services and became acquainted with each other and with health professionals. Health professionals typically have community connections and these relationships become a potential opportunity for social support and an opportunity for the health professionals to establish and facilitate this social support where possible. Social support, in all its forms, was identified as a major facilitator to participation in PA by all participants in this study. Social support, therefore, should be a key consideration when developing PA interventions for individuals with NMS conditions.

Another recurrent factor in this study was a lack of confidence to participate in activities. Confidence in one's ability to successfully perform a particular behaviour is referred to as self-efficacy (Marcus & Forsyth, 2003). For individuals with NMS conditions, particularly those with physical impairment, PA self-efficacy levels can be low (Driver, 2006). Self-efficacy has been shown to be related to PA behavior (J. F. Sallis et al., 1989). There are two types of PA self-efficacy: task self-efficacy, which is described as situation-specific self-confidence (Lox, 2003), and self-regulatory efficacy, which is self-confidence that an individual can perform a task in the face of barriers (Bandura, 1997). The participants in the current study who displayed self-regulatory efficacy had been physically active throughout their lives and continued to be so. This supports Bandura's Self-efficacy Theory (Bandura, 1997) that past performance has the greatest influence on self-efficacy followed by vicarious experience, social persuasion and physiological state. When applying self-efficacy theory to PA and individuals with brain injury however, it is thought that physiological state may have a greater influence on self-efficacy due to movement and mobility problems, pain,

awkwardness and spasticity (Driver, 2006). In the current study, participants repeatedly mentioned low self-efficacy due to symptoms of their NMS condition. Participants also gave examples of both positive and negative vicarious experiences. One individual described a situation where others, who had a lower level of function, had inspired him at the gym. Another participant who experienced health setbacks reported feelings of jealousy when seeing others improve during rehabilitation. In the literature, individuals with PD report that, in a group session, the presence of older members in the group was a depressing reminder of what lay ahead (Ravenek & Schneider, 2009). The author stated that variation of disease progression of group members needs to be a consideration when determining suitability of groups. This may not always be possible in regional settings where populations are smaller. Participants in the current study also reported examples of positive social persuasion from health professionals and other members of an exercise group, however some can be subjected to negative social persuasion from well-meaning over-protective family members who place restrictions on incidental PA for safety reasons. These restrictions are not unfounded as accessibility was the most common environmental barrier for participants in this study.

Stable surfaces, safe equipment and a controlled climate were considered to be accessible facilities by participants in this study. When referring to facilities, this means anywhere where the participant can get out and about to move, for example, gyms, shopping centres, swimming pools and parks. Some individuals in this study prefer integration with the rest of the community and some liked to do activities with their peers. Regardless of preference, there was a need for accessible facilities with competent staff at all times of day. Participants in the current study reported that these were lacking in their regional area. This is not exclusive to regional areas as the results of this study are consistent with previous research findings identifying inaccessibility and a deficiency of qualified staff as barriers to

participation in PA in urban settings (Damush et al., 2007; French & Hainsworth, 2001; Kehn & Kroll, 2009; Sandström et al., 2009).

Most of the participants in this study indicated that they valued the outcomes of PA rather than enjoy it. They identified numerous barriers to participation in PA, which to some, are insurmountable and others, a temporary challenge. For this particular group of people with NMS conditions, there were no definite patterns with regard to their areas of functioning, contextual factors and participation in PA. This is consistent with the ICF framework which describes a dynamic interaction or complex relationship between an individual's areas of functioning and contextual factors (World Health Organization, 2011). Ultimately, it is the individual's context (e.g. environmental and personal conditions) that makes the commonly reported factors unique to them. The results from this study emphasised the importance of basing PA pre-participation assessment on the ICF framework and tailoring PA to the individual and to the context in which they live.

It is important to note that the findings reported herein were unique to the specific and contextual situations of the participants in this study and may not be transferrable to others with NMS conditions. Participants with communication impairment were not represented in this study, a group who represent a significant proportion of individuals with NMS conditions. Remote areas in northern Queensland were not represented in the study, an isolated context that can result in additional barriers to participation. Qualitative studies present the opportunity to examine reasons and motives behind people's behaviours. The method adopted in this study, however, did not enable identification of how many participants perceived a certain barrier or facilitator or whether there were differences between males or females or other subgroups. Conclusions, therefore, cannot be drawn about which factors have the largest impact.

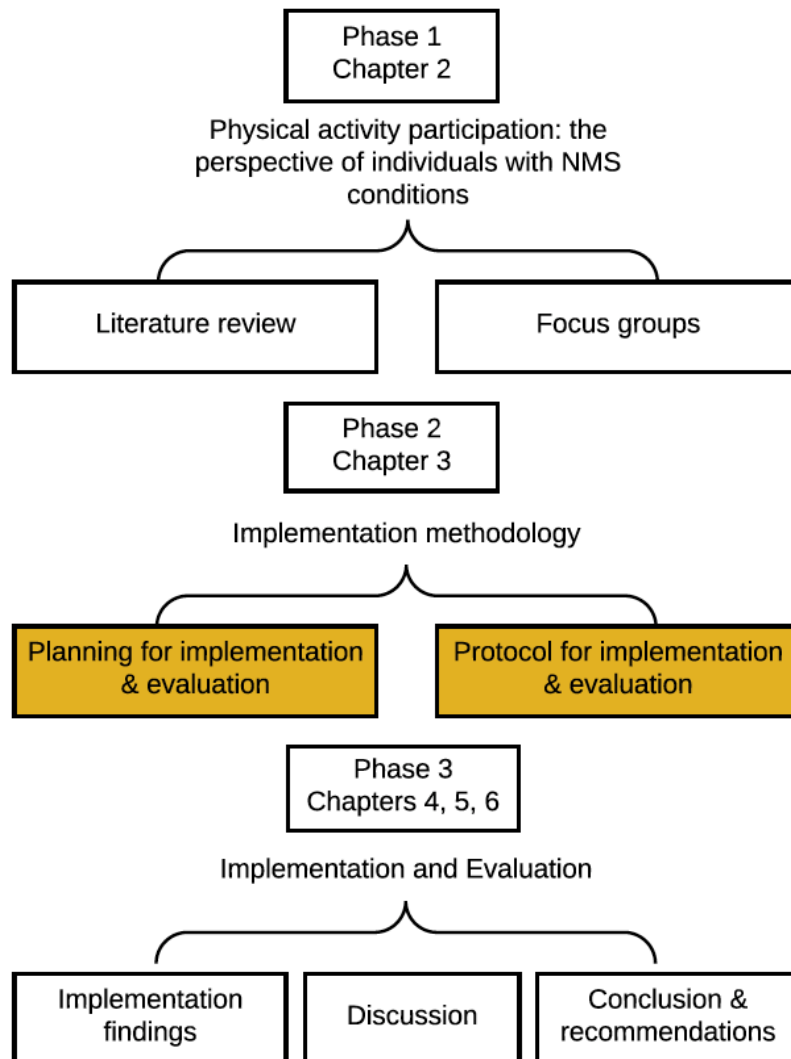
## **2.10. Conclusion**

Participants with NMS conditions in the area of regional North Queensland reported similar PA participation factors to those in the literature. It is the individual's context that makes the commonly reported factors unique to them. In this regional area, there was increased opportunity for social support. Participants identified a need for social support to overcome low PA self-efficacy and low motivation. Pre-participation assessment based on the ICF framework may assist exercise professionals to understand these factors and develop individually-tailored PA interventions.

# Chapter 3

## Implementation methodology

The purpose of this chapter is to describe the methodology for planning and development of a protocol for implementation and evaluation of APAP with CRnQ in Townsville. During this next phase of translation, consideration was given to barriers and facilitators that would influence implementation and evaluation of APAP at CRnQ.



## Introduction

Translation of evidence-based programs into real-world settings is considered to be a more complex endeavour than the program itself (Rohrbach, Grana, Sussman, & Valente, 2006). The integration of research with practice involves a multi-level approach that requires teamwork, time and sustainable community relations (Colditz, Emmons, Vishwanath, & Kerner, 2008). For these reasons, advances in the field of translation research over the past 10 years have included the development of conceptual frameworks, trans-disciplinary approaches and implementation strategy terms and definitions to guide translation (B. J. Powell et al., 2015; Sussman, Valente, Rohrbach, Skara, & Ann Pentz, 2006).

The aim of this project is to translate APAP from UQ to CRnQ in order to: 1) test the feasibility and acceptability of the intervention in a real-world setting (e.g. potential barriers and facilitators to 'real-world' implementation, problems associated with delivery, and potential intervention modifications required to maximise implementation); and 2) to assess the intervention's impact on participant outcomes. A hybrid effectiveness-implementation type 1 design most closely matched the aims of the project. In addition, APAP fits the recommended conditions for use of Hybrid 1 designs in that it has: 1) strong face validity that would support applicability to the new setting, population and delivery method in question; 2) a strong base of data from an associated population that supports applicability to the new setting and delivery method in question; and 3) minimal direct and indirect risk associated with the intervention. (Curran et al., 2012). This chapter describes the methodology for translation in two parts. Part 1 describes the methodical planning involved in the development of a protocol. Part 2 outlines the protocol for implementation and evaluation.

## **Chapter 3 - Part 1**

### **Planning for implementation and evaluation**

#### **3.1. Design**

Planning for implementation of APAP at CRnQ involved a collaborative community involvement design whereby researchers, community and other stakeholders worked together on the project that was designed, initiated and managed by the researchers (Brownson, Colditz, & Proctor, 2012). This design can result in higher recruitment rates and lower attrition, as well as fewer cultural and linguistic barriers. As a result, accuracy of data reporting, and the appropriateness and effectiveness of interventions is increased (Brownson et al., 2012). Three overlapping implementation planning processes emerged as a result of a pragmatic iterative approach: (i) Engagement and familiarisation with the APAP intervention and the implementation context of CRnQ (ii) Identification and familiarisation with the RE-AIM framework (iii) Tailoring the implementation and evaluation of APAP to CRnQ's context guided by the RE-AIM framework.

For the purpose of this translation project, 'context' refers to the intervention and its underlying theories; the organisation and its resources, policies and procedures; the characteristics of the implementers and their perceptions and understanding of the organisation and the intervention (Pawson, Greenhalgh, Harvey, & Walshe, 2005). 'Setting' includes the environmental characteristics in which implementation occurs (Damschroder et al., 2009).



## 3.2. Participants

Characteristics of participants involved in the planning process are described in Table 3.1. Participants included UQ intervention developers (n=3), CRnQ intervention implementers (n=16), community stakeholders (n=1), and individuals with NMS conditions (n=3). An EP at CRnQ was selected prior to the formal planning process and awarded a PhD scholarship to undertake the translation of APAP from UQ to CRnQ. Selection of the EP (author) was based on the nature of the program to be translated (PA intervention), their position as an EP at CRnQ (full time prior to PhD; 0.2 full-time equivalent (FTE) during scholarship), four years' experience in clinical practice, and their understanding of the CRnQ context. The EP acted as knowledge broker for the translation of APAP from UQ to CRnQ. The knowledge broker's role in the planning process was to obtain a thorough understanding of the intervention and the UQ context, facilitate the interaction between the UQ intervention developers and CRnQ intervention implementers and provide assistance with the organisational problem-solving processes. Having conducted research Phase 1, 2 and 4 studies (J.F. Sallis, Owen, & Fotheringham, 2000) with individuals with NMS conditions (Clanchy, Tweedy, & Boyd, 2011; Clanchy, Tweedy, Boyd, & Trost, 2011; Clanchy et al., 2016; Tweedy, 2005, 2007; Tweedy & Trost, 2005) intervention developers at UQ were recognised for their expertise in PA lifestyle interventions for individuals with NMS conditions and for development of the APAP intervention. The role of the UQ intervention developers was to interact with the knowledge broker to understand the CRnQ context and provide education and advice about the intervention to the intervention implementers. CRnQ intervention implementers were included on the basis of their employment at the service. Clinical, administrative and management staff members were recognised for the complementary and critical roles they would play in implementation. The role of intervention

implementers was to inform intervention developers about the CRnQ context, recruit program participants, deliver the intervention and provide feedback on implementation of the intervention.

Community stakeholders were recognised for their links in the community with the target population. As part of planning, the stroke support group, which included many individuals who had experienced stroke, hosted an APAP informational session to assist in the promotion of the intervention. It was anticipated that their contribution to the planning process would result in higher recruitment rates, fewer cultural and linguistic barriers and greater community 'buy-in' and trust. The individuals with NMS conditions involved in the planning process were purposively selected based on interest, need and ability to provide objective feedback. As part of the process of translation, their role included participation in the pilot intervention (n=2) to allow the knowledge broker to practice delivery of APAP and to gain feedback. The other community stakeholder (n=1) who had been diagnosed with a NMS condition attended an APAP planning workshop to provide feedback and suggestions with regard to the intervention components.

**Table 3.1. Characteristics of participants involved in planning process**

<b>Professional backgrounds/Title</b>	<b>N</b>	<b>Position</b>	<b>Role in development of plan for implementation</b>	
<b>UQ</b>				
Exercise Physiologists	2	Researchers & Intervention developers	Presented APAP intervention/worked case study at workshop	
	1	Professor of physical activity & health	RE-AIM adviser	
<b>CRnQ</b>				
Physiotherapist	16	Clinical Leader & researcher	Clinical decision maker/present CRnQ context at workshop	
Occupational therapist		Service Director	Service delivery decision maker	
Pharmacist		Education Leader	Host workshop/ student practicum & professional development	
Exercise Physiologist		Knowledge broker & PhD student	Present focus group findings at workshop	
Exercise Physiologists		Clinical Team & Intervention implementers		Present CRnQ case studies
Physiotherapists				
Occupational Therapists				
Speech Therapist				
Social worker				
Psychologist				
Nurse				
Dietitian				
<b>Community stakeholders</b>				
Male, Cerebral Palsy	2	CRnQ participants	Pilot intervention	
Female, Cerebral Palsy	1	CRnQ participant/Dietitian/Sport scientist	Attended APAP planning workshop	
Female, sequelae of intracerebral haemorrhage				
Group	1	Stroke support	Host information session about APAP	

UQ=University of Queensland; CRnQ=Community Rehabilitation northern Queensland

### **3.3. Planning processes**

Implementation and evaluation are dynamic processes with many interacting variables. Accordingly, a pragmatic iterative approach was taken to planning of the APAP translation from UQ to CRnQ. Three overlapping processes occurred which enabled the identification of variables that were pertinent to the development of a protocol for implementation and evaluation of APAP at CRnQ. These processes were: (i) Engagement and familiarisation with the APAP intervention and the context of CRnQ (ii) Identification and familiarisation with the RE-AIM framework (iii) Tailoring the implementation and evaluation of APAP to CRnQ's context guided by the RE-AIM framework.

#### **3.3.1. Engagement and familiarisation with APAP and the CRnQ context for implementation**

Engagement and familiarisation with APAP and the context for implementation took place over a period of approximately 14 months. As the UQ intervention developers and the CRnQ intervention implementers were located in different cities, meetings occurred by telephone, Skype and, occasionally, face-to-face. Initial communication and correspondence was between the UQ intervention developers and the CRnQ knowledge broker and focused on intervention familiarisation, including discussions about APAP case studies. Discussions progressed to advice with delivery of APAP, both during the pilot and the research period. APAP had been evolving at the completion of the UQ efficacy study (Clanchy et al., 2016) and protocols for a business model were under development. As a result, preparation by UQ and uptake by CRnQ of implementation resources was a gradual process. Familiarisation with APAP underpinnings by the CRnQ knowledge broker occurred as a result of recommendations by the UQ intervention developers to read the literature on behaviour

change and attend a Motivational Interviewing workshop (W.R. Miller & Rollnick, 2012). To further enhance engagement and familiarisation, an APAP planning workshop was conducted. The one-day workshop took place at CRnQ and was attended by UQ intervention developers, CRnQ intervention implementers and one community stakeholder who was an individual with a NMS condition and a health professional. The purpose of the workshop was to introduce APAP to the full CRnQ team and to facilitate UQ intervention developers and CRnQ intervention implementers understanding of APAP's original context and their understanding of CRnQ as the new context for APAP implementation. The workshop content included presentations and discussion groups to exchange information such as the results of the preliminary CRnQ focus groups and the UQ APAP efficacy study; provide case studies from both settings and to provide an introduction to the RE-AIM framework by the UQ intervention developers. The outcomes of the workshop were pulled together in a final planning meeting between the core group of researchers from UQ and CRnQ.

### ***Intervention***

APAP is PA lifestyle intervention (Clanchy et al., 2016). It consists of three steps: (1) Pre-participation assessment tailored to the components of the ICF model (World Health Organization, 2011) (2) Individually-tailored stage-matched behaviour change activities, exercise prescription and community access facilitation; and (3) Relapse prevention strategies. The pathway through the intervention for individuals with NMS conditions is determined by their motivational readiness, information gained during the pre-participation assessment and the outcomes of sessions conducted. Appendix 2 includes a full description of the APAP intervention as per the efficacy study using the Template for Intervention Description and Replication (TIDieR) checklist (Hoffmann et al., 2014). APAP was designed to promote health by assisting individuals to change their PA lifestyle, an approach that was new to the EPs at CRnQ. Whilst the individual's health condition is an important

consideration, the components of this program concentrate on exploring what is meaningful to the person and incorporating a PA routine to suit. EPs work with the participant in their community to overcome barriers to the adoption and maintenance of this PA or to a return to PA. This may involve modifying activities, exploring potential where participants are unsure of their ability and facilitating social support and community access. To compliment this unique approach, a menu of individually-tailored behaviour-change activities, including Motivational Interviewing, are matched to the individual's stage of motivational readiness in order to educate, increase motivation and self-efficacy and prevent physical inactivity relapses.

### *APAP Contexts and settings*

#### *University of Queensland*

APAP was developed at the School of Human Movement and Nutrition Sciences (SHMNS) at UQ, which is an educational facility in Brisbane, Australia. In the area of chronic and complex health conditions, SHMNS offers one student-assisted health service, namely APAP. The APAP intervention was offered as an evidence-based PA promotion service for people living in the Brisbane area. For the purpose of an APAP efficacy study, the service was offered to individuals with brain impairment (BI) including stroke, TBI and CP who lived within a 150km radius of the university. Participants were recruited through gatekeeper referral agencies including community-based service providers for people with BI and outpatient rehabilitation services in Brisbane. The service was offered at no charge and the program was delivered by one EP in the participant's home and community. The program adopted the community-based rehabilitation theory-driven model of service delivery (with community being described as the person's physical surrounds that they typically inhabit or could easily access) (Tweedy, 2007).

## *CRnQ*

CRnQ is a publicly funded community rehabilitation service offered at no charge for individuals from Townsville and nQ with NMS and ageing conditions. CRnQ provides service for individuals who live in regional, rural and remote northern Queensland that include predominantly face-to-face, some telerehabilitation and relatively limited outreach services. The organisation has an evidence-based culture, which includes adequate resources for research activities, support and encouragement for inquiry, and an expectation that the team engage in research activities. CRnQ is funded at an organisational level, initially, by the Federal Government and later by the Queensland State Government and administered by a not-for-profit primary care organisation. Services are predominantly delivered at the facility with visits to the participant's home and community as necessary. CRnQ offers a wide range of rehabilitation services in prevention, early intervention, post-discharge and long-term support. Referrals to CRnQ occur by way of healthcare practitioners including general practitioners (GP), or self-referral by the participant. The team strives to deliver evidence-based services using a person-centred, goal-driven, student-assisted and interprofessional model of service delivery. The clinical team includes physiotherapists, occupational therapists, speech pathologists, exercise physiologists, a social worker, a psychologist, rehabilitation nurses, a dietitian and rehab assistants (including one Indigenous rehab assistant), as well as students of those professions. Thirty-eight per cent of the professional clinical staff are recent graduates. With the assistance of students, the role of each health professional includes Lead Clinician of intervention programs (e.g. Balance and Mobility Circuit, Communication Group), Case Coordinator for several participants and Student Supervisor for students of their profession. Key performance indicators for CRnQ include a range of outcome measures including self-rating of participant goals as well as functional

outcome measures at the impairment, activity and participation level of function. To retain recurrent funding for the service, the key performance indicator for CRnQ is occasions of service. An occasion of service is defined as any examination, consultation, treatment or other service provided to a patient (Australian Institute of Health and Welfare, 2003b). CRnQ must achieve a target number of occasions of service annually in order to retain funding for the service. Each health professional is required to contribute to that target through the programs offered at CRnQ.

### *Summary of findings from process of engagement and familiarisation*

Two key factors emerged from the first planning process involving engagement and familiarisation with APAP and CRnQ. The first key factor was that APAP is a complex intervention. The second was that, even though the principles between the two services aligned, the contexts were very different. Table 3.2 lists the key differences between UQ (efficacy study) and CRnQ. Noteworthy is the differing program participant pathways, which are illustrated in more detail in Table 3.3. The participant pathway through APAP at UQ is a stand-alone pathway that can be flexible and determined from session to session. At CRnQ, each program is integrated with other programs according to standard procedures. Hence, the participant pathway is part of an integrated care pathway (ICP) for program participants. For the purpose of this study an ICP refers to structured multidisciplinary care plans that detail essential steps in the care of participants with a specific clinical problem (Campbell, Hotchkiss, Bradshaw, & Porteous, 1998). Consideration of these key differences was paramount to tailoring the implementation of APAP to CRnQ.



**Table 3.2. Key differences between the UQ efficacy study and CRnQ contexts and settings**

	<b>CRnQ</b>	<b>UQ efficacy study</b>
<b>Service area</b>	Regional, rural & remote	Metropolitan
<b>Service delivery</b>	Facility, home & community	Home & community
<b>Human resources</b>	3 EPs + clinical team + students	1 EP
<b>Services offered</b>	14 programs; 4 led by EPs, 2 EP involvement	1 program
<b>Health conditions</b>	45 neurological conditions	BI from TBI, Stroke & CP
<b>Age</b>	Range 19-82 years	Mean age 38.1 ± 11.9 years
<b>Inclusion criteria</b>	Able to participate	Able to walk (with/out aids) Cognitive ability for behavior-change activities
<b>Exclusion criteria</b>	None	LL surgery in past 6 months or scheduled during intervention LL botox in past 3 months or scheduled during intervention Serious, regular or uncontrolled substance abuse Documented violent or aggressive behaviour or suicidal ideation
<b>KPI</b>	Occasions of service	None
<b>Participant pathway</b>	Integrated care	Dependent upon stage of exercise behaviour and outcomes of each session

EP= exercise physiologist, BI= brain injury, KPI= key performance indicators, LL = lower limb, PA = physical activity

**Table 3.3. Program participant pathway for CRnQ service and UQ efficacy study**

Participant pathway through CRnQ	Participant pathway through UQ ( <i>efficacy study</i> )
Referral to service <ul style="list-style-type: none"> <li>- phone call, letter of referral</li> </ul>	Referral to research study: Participants recruited through gatekeeper referral agencies, including community-based service providers for people with BI, and outpatient rehabilitation services in Brisbane. Referral agencies were provided with an overview of the intervention and the inclusion and exclusion criteria and asked to identify participants who met the criteria. Participant details passed to research personnel.
Telephone screen by relevant health professional with participant &/or referrer <ul style="list-style-type: none"> <li>- Contact details, demographics, diagnosis</li> <li>- Reason for referral</li> <li>- Inclusion/exclusion criteria for specific programs</li> </ul>	Preliminary phone screening to determine suitability for the research study. (Inclusion and exclusion criteria)
Allocation to an appropriate five-week intervention program/s <ul style="list-style-type: none"> <li>- Program information sent to participant (contents of the program, requirements for participation, dates and times)</li> <li>- Request to GP for review to ensure participant is medically fit for program allocated</li> </ul>	Baseline data collection
Team meeting for allocation of responsibilities <ul style="list-style-type: none"> <li>- Disciplines to be involved identified and schedule drawn up</li> <li>- Case coordinator allocated based on most relevant service for goals</li> <li>- Arrangements made for transport &amp; /or accommodation</li> </ul>	Stratification and allocation to intervention or control group.
Five week program commences <ul style="list-style-type: none"> <li>- Full assessment of participant with goals established and outcome measures completed that are relevant to goal</li> <li>- Participation in program</li> <li>- Case conference – recommendations for future follow-up</li> </ul>	12- week program commences
Program completed <ul style="list-style-type: none"> <li>- Full assessment and completion of post-program outcome measures</li> <li>- Participant interview to establish achievement of goals and plan for follow-up program</li> </ul>	Post intervention data collection Follow up period commenced 3 months with no researcher contact.
Recommendations confirmed <ul style="list-style-type: none"> <li>- Continue with another five-week program</li> <li>- Continue with alternative five-week program</li> <li>- Return for follow-up program in three months</li> <li>- Return for review in 12 months</li> </ul>	Last data collection period.
Return for follow-up program as recommended	

### **3.3.2. Identification and familiarisation with the RE-AIM framework**

RE-AIM was a translational framework chosen to guide implementation and evaluation based on recommendations by the UQ researchers. As the CRnQ knowledge broker and intervention implementers were new to the field of implementation science, the next step was familiarisation with RE-AIM. The beginning of the process of familiarisation with the RE-AIM framework occurred through a presentation by the UQ implementers, followed by exploration of the RE-AIM website (Estabrooks et al., 2011; Glasgow, Vogt, & Boles, 1999) and literature (Altpeter, Gwyther, Kennedy, Patterson, & Durrence, 2013; Caperchione et al., 2015; Van Acker, De Bourdeaudhuij, De Cocker, Klesges, & Cardon, 2011). RE-AIM is a multi-stage, multi-level framework designed to facilitate the planning, conduct and evaluation of studies having the goal of translating research into practice (Glasgow et al., 1999). The five stages of RE-AIM are Reach, Effectiveness, Adoption, Implementation and Maintenance and the dimensions are assessed at an individual, organisational and community level. RE-AIM was identified as appropriate for translation of APAP from UQ to CRnQ as it comprised tools that assist in planning, evaluation and reporting of applied interventions. RE-AIM is the most cited translational framework in the field of chronic disease management (Milat & Li, 2017) and has been utilised to assess the fit and external relevance of PA interventions in real-world settings (Caperchione et al., 2015). RE-AIM, therefore, guided the final planning process, which was tailoring the implementation and evaluation of APAP to CRnQ's context.

### **3.3.3. Tailoring the implementation and evaluation of APAP to CRnQ's context**

Tailoring the implementation and evaluation of APAP to CRnQ involved consideration of the aims of the project, consideration of factors related to the five RE-AIM domains, and consideration of the key differences between APAP's original context and the new context for implementation. Potential barriers and facilitators to implementation were identified through collaboration with all stakeholders and exploration of the translation literature. A comprehensive description of these methods is set out below under the RE-AIM domains.

#### **3.3.3.1. Reach**

Reach is the absolute number, proportion and representativeness of individuals who are willing to participate in a given intervention (Glasgow et al., 1999). To enable the assessment of APAP, the study sample needs to be indicative of a real-world setting. Hence, the sample needed to include adults of all ages with varying levels of impairment, activity limitations and participation restrictions who were not sufficiently physically active to accrue health benefits. At CRnQ exposure to this population is optimal as the service forms part of the continuum of care in northern Queensland for individuals with NMS conditions. It was anticipated that a significant barrier to achievement of a sufficient sample size and representativeness in a limited research period would be staff resources. Strategies to overcome barriers and enhance facilitators included discussions with executive-level staff, the clinical lead at CRnQ, and statisticians at James Cook University (JCU). Consideration was given to allocation of key implementation staff and utilisation of CRnQ promotional material to attract potential participants.

To evaluate reach, consideration was given to how the number, proportion and representativeness of participants eligible for APAP compared to the number who participated in APAP could be measured and how the data would be collected.

### **3.3.3.2. Effectiveness**

Effectiveness is the impact of an intervention on important outcomes, including potential negative effects, quality of life and economic outcomes (Glasgow et al., 1999). The aim of APAP is to increase the adoption and maintenance of PA. Important outcomes in this study, therefore, were related to PA adherence, as well as any unanticipated positive or negative outcomes experienced by program participants, and any costs associated with delivery of APAP (e.g. personnel, time, intervention materials).

With regard to increases in adoption and maintenance of PA, qualitative and quantitative methods of data collection were considered and were reflective of the complexity of the APAP intervention and outcomes measured used in the efficacy study at UQ (Clanchy et al., 2016). Anticipated challenges associated with the selection of appropriate measures included the wide range of impairments and varying levels of function for the program participants at CRnQ, time restrictions and other service demands for key implementers.

Strategies to address the challenge of identifying appropriate outcomes measures and constructs for the current study were undertaken by the knowledge broker. This involved a search of the literature, consultation with CRnQ decision makers, intervention developers at UQ and statisticians at JCU. Consideration was given to outcome measures used in the efficacy study at UQ. The primary outcome measure was daily activity counts and minutes of moderate-to-vigorous-intensity PA measured with an accelerometer. The study reported significant increases from baseline to post-intervention, but changes from baseline to follow-

up were non-significant. Secondary outcome measures included the self-efficacy, social support and the decisional balance scales. Significant changes were reported only for the decisional balance from baseline to post-intervention with the author concluding that changes to the primary outcome measure were mediated by variables not measure in the study. Intervention developers at UQ suggested that effectiveness measures were secondary to the primary aim of testing the acceptability and feasibility of implementation of APAP at CRnQ.

The literature identified the difficulties involved in measuring physical outcomes for individuals with NMS conditions, specifically, those with a low level of function and those participating in multifaceted PA interventions (Driver, 2007; Van Den Berg-Emons et al., 2011; Van Nimwegen et al., 2013; Warm's, 2006). Physical activity scales suitable for individuals with disabilities were explored and it was established that there was a lack of valid and reliable self-report PA instruments for people with NMS conditions including the Longitudinal Aging Study Amsterdam Physical Activity Questionnaire (LAPAQ) (Stel et al., 2004), the Physical Activity and Disability Survey Revised (PADS-R) (Kayes, Schluter, McPherson, Taylor, & Kolt, 2009) and the Physical Activity Scale for Individuals with a Physical Disability (PASIPD) (Van Den Berg-Emons et al., 2011; Washburn, Zhu, McAuley, Frogley, & Figoni, 2002).

Accelerometers were considered, although it was recognised that all participants in the current study may not be able to walk and that they were time consuming, relatively expensive and not practical in a community rehabilitation setting. The 6MWT was considered as an alternate to accelerometers as it has been validated among individuals with disabilities. Secondly, even though there was no association demonstrated between APAP secondary outcome measures and increases in PA in the CCT, social support and decisional balance will be considered as these PA mediators are a focus of APAP strategies. Health measures (i.e. blood pressure and weight) were considered as they demonstrate the effects of increases in

PA on APAP participants. Alternatively, outcomes were not the focus of the study and the aim was to increase the adoption and maintenance of PA.

With regard to outcome constructs, as the focus of APAP was participation in the community to increase PA, participation questionnaires were explored including the Utrecht Scale for Evaluation of Rehabilitation – Participation (USER–Participation) (Post et al., 2012), the ICF Measure of Participation and ACTivities questionnaire - Screener (IMPACT-S) (Post et al., 2008) and community enfranchisement (Heinemann et al., 2013). It was thought that increases in community participation may demonstrate an improvement in quality of life, however this was not included in the definition of effectiveness in the current study.

Statisticians at JCU were approached with regard to sample size and it was identified that sample size calculations were not relevant for such a heterogeneous population.

Consultation with CRnQ decision makers identified that APAP delivery costs were related to the clinical team’s number of face-to-face contacts with APAP participants.

### **3.3.3.3. Adoption**

Adoption is the absolute number, proportion and representativeness of settings and intervention agents who are willing to initiate a program (Glasgow et al., 1999). In this study, adoption was considered at the individual level, namely, the willingness of the team at CRnQ to integrate APAP into their service. The clinical leader at CRnQ had identified a need for APAP in a regional community rehabilitation context and this was considered a key facilitator to adoption of the intervention. Also favourable to adoption was the fact that CRnQ was new and evolving with a team who were accustomed to change. At its establishment stage, promotion of the organisation’s services was a priority. Based on the knowledge broker’s experience at CRnQ, anticipated barriers included other service demands faced by

the interprofessional team and their goal-based principles (e.g. decisions regarding participant allocation to programs based on goals). Adoption strategies would need to reflect organisational culture and team engagement. The knowledge broker explored the literature on management and leadership processes (Kotter, 1997) and implementing change in health settings (Schmidt, 2009).

As the full CRnQ team were the target for strategies to increase adoption, they were considered the most relevant candidates to evaluate the adoption component.

#### **3.3.3.4. Implementation**

Implementation, at the setting level, refers to the intervention agents' fidelity to the various elements of an intervention's protocol (Glasgow et al., 1999). In this study, implementation included both training methods and delivery of the APAP intervention with fidelity. Key considerations for implementation included methods to assess fidelity and delivery consistency, challenges of other service demands for EPs, and pre-participation risk assessment measures for APAP participants. With an interprofessional model of service delivery in place at CRnQ, time and scheduling were deemed the greatest barriers to implementation. Integrated care plans meant that scheduling for individual and group sessions and appointments for the clinical team and students were booked weeks in advance. It was anticipated that these barriers would impact EP and EP student availability for training and delivery of APAP, an intervention with a pathway that was determined, to an extent, by the outcomes of each session. To overcome barriers, the knowledge broker had discussions with decision makers about time allocation for student training and utilisation of the CRnQ student portal to introduce EP students to APAP pre-placement. Consideration was given to delivery of certain components of APAP by other clinical team professions (e.g. behaviour change). After receiving APAP protocols from the UQ intervention developers, as well as



scheduled training sessions, consideration was given to the piloting/practicing of intervention behaviour-change strategies with existing program participants. A key facilitator to implementation in the CRnQ context was that clinical team were familiar with the ICF framework and its application to assessment of function and contextual factors, goal setting and treatment; factors consistent with the APAP intervention.

Consideration was given to qualitative methods such as interviews to evaluate EPs and EP student satisfaction with training and delivery confidence and the RE-AIM planning tool suggested a fidelity checklist to record the extent to which EPs deliver APAP as intended in the protocols.

### **3.3.3.5. Maintenance**

Maintenance is the extent to which a program becomes part of the routine organisational practices (Glasgow et al., 1999). Maintenance at CRnQ, at the individual level, is the continued adoption of PA long-term for participants. Maintenance at the organisational level is entrenchment of APAP at CRnQ with increased throughput. To a large extent, maintenance of APAP at CRnQ would be dependent upon the success of strategies adopted in the reach, effectiveness, adoption and implementation domains of RE-AIM. Strategies needed to be monitored throughout implementation, but consideration was given to mid-way assessment.

## **Conclusion**

Through a collaborative planning process, information was gained about the intervention, the settings and their contexts and the RE-AIM framework. A protocol was developed to implement and evaluate APAP with a view to testing the feasibility and acceptability of the intervention's implementation approach at CRnQ and its impact on participant outcomes. The protocol is described in part 2.

## **Chapter 3 - Part 2**

### **Protocol for Implementation and evaluation**

A protocol for implementation and evaluation of APAP at CRnQ was developed and is described in this section. Evaluation strategies outlined in the protocol were designed to identify 1) potential barriers and facilitators to ‘real-world’ implementation of APAP; 2) problems associated with delivery of APAP and how they translate, or not, to real-world implementation; and 3) potential intervention modifications required to maximise implementation (Curran et al., 2012). A hybrid effectiveness-implementation Type 1 study design tests a clinical intervention while gathering information on its delivery during the effectiveness study and/or on its potential for implementation in a real-world setting (Curran et al., 2012). The conditions in this study align with those recommended for hybrid Type 1 studies for the following reasons: APAP is based on the community-based rehabilitation model of service and hence, potentially generalisable to CRnQ; APAP is an efficacious theoretically-based intervention with clear outcomes; the intervention was designed to be delivered by EPs who have experience in behaviour-change strategies and exercise prescription for people with NMS conditions, and has sufficient risk assessment procedures in place; APAP’s efficacy was tested among individuals whose conditions are closely associated with those at CRnQ and will be cost effective for participants at CRnQ.

The protocol consists of two parts: 1) implementation strategies for each RE-AIM domain; and 2) methods for data collection and analysis. The protocol was written in the future tense because its contents represent what was proposed. Deviations from the protocol were expected as translation of APAP from UQ to CRnQ was considered to be a first step in a series of plan-do-study-act iterative cycles (Peters, 2013). Findings presented in chapter 4

will describe, therefore, how events actually transpired during implementation of APAP at CRnQ.

### **3.4. Implementation strategies**

The APAP intervention is based on a community rehabilitation model of service delivery. Intervention developers anticipated seamless integration into a community rehabilitation service (Clanchy et al., 2016). CRnQ, as the community rehabilitation service intended for implementation, was declared a receptive context with a team who were familiar with, and open to change. Planning processes undertaken in this study identified anticipated differences between APAP's original context and the new context for implementation. Strategies in this protocol were designed to address anticipated differences between contexts, but to an extent, implementation would be unpredictable. Overall, strategies were designed to enhance reach, effectiveness, adoption, implementation and maintenance and are presented under each of those domains. Table 3.4 outlines the implementation and evaluation research questions and outcome measures associated with each element of RE-AIM. Table 3.5 outlines the psychometric properties of the outcome measures.

**Table 3.4 Implementation and Evaluation research questions and outcome measures**

Component	Level	Question	Measure	How to assess?
<b>Reach</b>	<b>Individual</b>	Are the target audience participating in the program?	<ul style="list-style-type: none"> <li>Of current participants at CRnQ:</li> <li>Characteristics (condition, age, BMI, gender, marital status, employment status, primary means of locomotion, driving status)</li> </ul>	<ul style="list-style-type: none"> <li>CRnQ health record system</li> <li>APAP participant questionnaires</li> </ul>
		<ul style="list-style-type: none"> <li>In what numbers?</li> <li>What percentage of participants who are offered APAP are declining?</li> <li>What are the reasons they are declining?</li> <li>What are the characteristics of the participants who are declining?</li> <li>What percentage program completion &amp; attrition?</li> </ul>	<ul style="list-style-type: none"> <li>% approached for APAP (how, when, by whom)</li> <li>% accepted APAP</li> <li>% declined APAP (why, who)</li> <li>% completed APAP</li> </ul>	<ul style="list-style-type: none"> <li>CRnQ clinical team interviews</li> <li>Clinical meetings</li> </ul>
<b>Effectiveness</b>	<b>Individual</b>	Are APAP participants increasing participation in PA?	Amount of PA	<b>Primary measure</b> PASIPD
		<ul style="list-style-type: none"> <li>Are APAP participants increasing their PA social support?</li> <li>Are participants overcoming perceived PA barriers &amp; do they see the benefits of PA?</li> <li>Are APAP participants changing their PA behaviour?</li> <li>Are participants increasing their CR fitness?</li> <li>Were there any unanticipated outcomes, positive or negative, that the APAP participants encountered?</li> <li>Are APAP participants satisfied with the program</li> </ul>	<ul style="list-style-type: none"> <li>Changes in PA social support (family &amp; friend)</li> <li>Changes in amount of barriers &amp; knowledge of benefits</li> <li>Changes in PA motivational readiness</li> <li>Changes in 6MWT &amp; 6MAC distances</li> <li>Changes in behaviour, attitudes, coping of participants</li> <li>Good/negative points of program; expectations; enjoyment; goal achievement</li> </ul>	<b>Secondary measures</b> <ul style="list-style-type: none"> <li>Social support questionnaire</li> <li>Decisional balance questionnaire</li> <li>PA SOC questionnaire</li> <li>6MWT</li> <li>6MAC</li> <li>CRnQ clinical team interviews</li> <li>APAP participant interviews</li> </ul>
<b>Effectiveness</b>	<b>Organisational</b>	How much did it cost CRnQ to deliver APAP?	<ul style="list-style-type: none"> <li>Costs in terms of face-to-face contact time with APAP participants</li> <li>Vehicle use</li> </ul>	<ul style="list-style-type: none"> <li>Occasions of Service extracted from CRnQ health system record</li> <li>Logbooks</li> </ul>
<b>Adoption</b>	<b>Organisational</b>	Are the CRnQ team confident that APAP can be a part of the service?	APAP's value at CRnQ; APAP fits with CRnQ standard procedures	Whole CRnQ team interviews
<b>Implementation</b>	<b>Organisational</b>	<ul style="list-style-type: none"> <li>Was the training for APAP sufficient to deliver the intervention with fidelity?</li> <li>Was APAP delivered with fidelity?</li> </ul>	<ul style="list-style-type: none"> <li>Questions about recommended changes to training format or content; confidence with conducting the intervention</li> <li>Number of sessions &amp; phone calls in the time frame;</li> <li>Questions about recommended changes to program tools &amp; resources</li> </ul>	<ul style="list-style-type: none"> <li>EP &amp; EP student interviews</li> <li>Fidelity checklist</li> <li>Audit of clinical notes content</li> <li>Whole CRnQ team interviews</li> </ul>
<b>Maintenance</b>	<b>Individual</b>	Was PA continued post-intervention?	Continued changes in PA participation	PASIPD at three-month follow-up
	<b>Organisational</b>	Are CRnQ team confident that APAP can continue as part of the programs offered at the service?	Recommended strategies to embed APAP at CRnQ	Whole CRnQ team interviews

PASIPD=Physical activity scale for individual with a physical disability; SOC=stage of change; CR=cardiorespiratory; 6MWT= six-minute walk test; 6MAC=six-minute arm crank

**Table 3.5 Outcome measures used and supporting evidence of validity and reliability**

Outcome measure	Validity	Reliability	Reference
<i>Physical activity scale for individuals with a physical disability (PASIPD)</i> , levels of PA, including leisure time, household and occupational activity time			(Washburn et al., 2002)
<i>Social Support questionnaire</i> , frequency of support received from family and friends in the three months prior	☑	☑	(J. F. Sallis, Grossman, Pinski, Patterson, & Nader, 1987)
<i>Decisional Balance questionnaire</i> , avoidance of exercise (cons) and positive perceptions of exercise (pros)	☑	☑	(B.H. Marcus, W. Rakowski, & J. S. Rossi, 1992)
<i>PA Stages of change questionnaire</i> , individual's PA intentions and actual PA behaviour	☑	☑	(Marcus & Simkin, 1993)
<i>Six-minute walk test (6MWT)</i> , cardiorespiratory fitness, distance walked with and without aids	☑	☑	(Balke, 1963)
<i>Six-minute arm crank (6MAC)</i> , modified 6MWT for individuals with NMS conditions whose primary means of locomotion is not walking; cardiorespiratory fitness, distance cycled with arms with and without aids			

### **3.4.1. Reach**

All CRnQ participants will be eligible to participate. To ensure that the different populations who attended CRnQ are represented (e.g. inclusion of Indigenous people, people who live rurally, people with severe disability and people with aphasia) an element of purposive sampling will take place. As a sample size calculation was deemed inappropriate by statisticians for the predicted heterogeneous population, the aim is to include 40 people with NMS conditions in APAP over a 12-month period. This aim is based on the high volume of participants with NMS conditions who attend CRnQ and allowed for potential dropouts due to the high-risk nature of the conditions. To allow this to occur, the knowledge broker will increase working hours from one day a week to full-time during the study period, thereby increasing EP availability from 1.6 FTE to 2.4 FTE. Recruitment to APAP will occur via usual channels for referral to a CRnQ program, which includes direct referral, during the intake assessment process, or by referral from within the service. Additional strategies employed to prompt referrals will include the addition of stage of exercise behaviour questions during intake (Marcus & Simkin, 1993) presentations by the knowledge broker to the clinical team and to community support groups (e.g. stroke support), and attendance at weekly clinical meetings to provide feedback on APAP participant progress. Once sufficient APAP participant numbers are achieved during the study period, the knowledge broker will return to part-time hours (0.2 FTE). Discussions will take place between EPs and the clinical leader about a shift in the EPs' focus from facility-based PA programs to delivery of APAP.

To evaluate APAP reach, CRnQ participant characteristics and flow will be collated from the CRnQ health record system. In addition, at the conclusion of the study period, focus groups and interviews with the full CRnQ team will be conducted by an independent researcher to assess how reach can be improved.



### **3.4.2. Effectiveness**

#### *Primary outcome measure*

As the aim of APAP was to increase the adoption and maintenance of PA, the primary outcome measure will be the Physical Activity Scale for Individuals with Physical Disabilities (PASIPD) (Washburn et al., 2002). The PASIPD was chosen because it closely reflected the goals of APAP, which was the promotion of physical activities and was easily administered in a community rehabilitation setting, by telephone or by email. Like all of the other questionnaires that had been explored for the purpose of this study, validity and reliability had not been established for individuals with NMS conditions with various levels of function. The literature reports the PASIPD has preliminary support for construct validity (Washburn et al., 2002) and test-retest reliability and criterion validity (van der Ploeg et al., 2007).

#### *Secondary outcome measures*

Social support and decisional balance will be assessed as these theory- based mediators of PA were targeted by APAP evidence-based PA promotion strategies (e.g. goal setting, self-monitoring, social support, self-reward). Measures will include the Social Support Scale (J. F. Sallis et al., 1987) and the Decisional Balance Scale (B.H. Marcus, W. Rakowski, & J.S. Rossi, 1992). The PA Stage of Change (SOC) questionnaire (Marcus & Simkin, 1993), utilised during the CRnQ screening process, will also be applied as a measure to assess changes to the APAP participant's PA motivational readiness. The six-minute walk test (6MWT) (Balke, 1963) is commonly used at CRnQ and was chosen to indicate changes to APAP participant fitness levels. APAP participants who are unable to walk will be assessed with a modified version of the 6MWT for this context, the six-minute arm crank (6MAC). EPs and EP students, during weekly meetings and evaluation interviews, will be asked about

APAP participant attitudes and coping during the intervention. As CRnQ is person-centred and goal-driven, CRnQ participants are asked to set goals when they enter the service. Goals are typically function related and are regularly reviewed throughout their rehabilitation plan. Goals will be reviewed at the commencement of APAP and when unrelated to PA, the EP will explain how regular PA contributes to their goals (e.g. slow the progression of symptoms related to their health condition and prevent the occurrence of another stroke). Short-term goal setting related to PA frequency and adherence will be applied as a strategy during the intervention in an attempt to build PA self-efficacy.

#### *APAP participant satisfaction*

APAP participants will be invited to provide feedback on the program by participating in structured interviews.

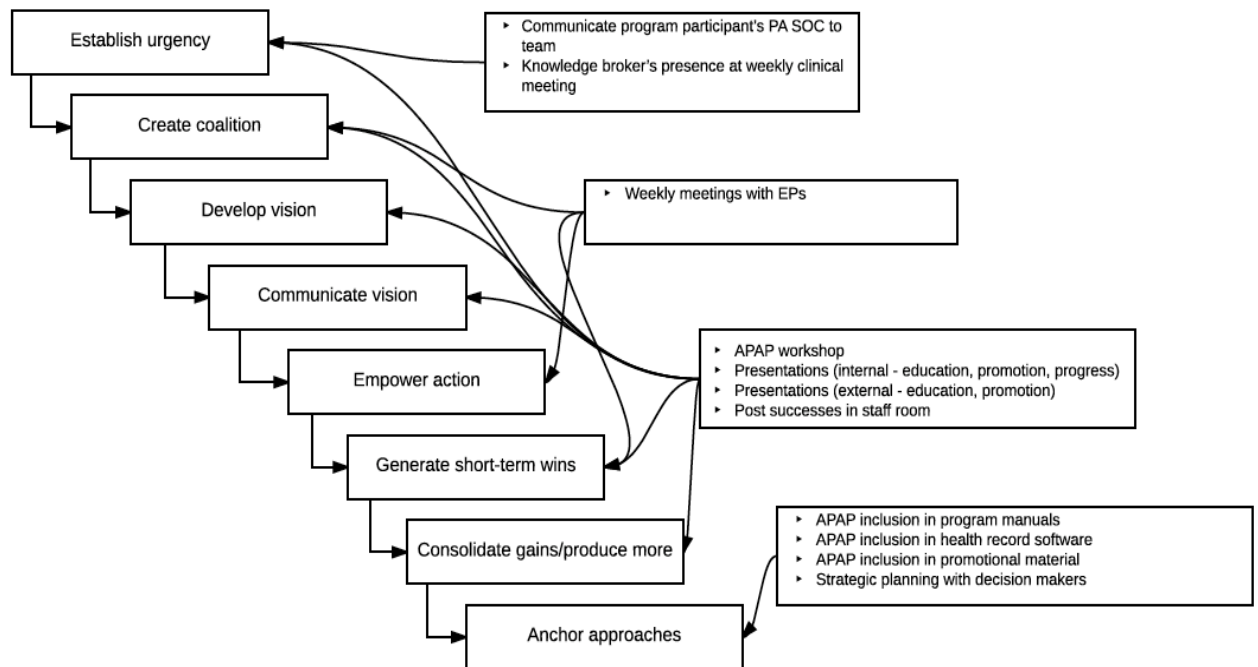
#### *APAP intervention delivery costs*

According to CRnQ decision makers, occasions of service are directly related to the time and personnel required for delivery of CRnQ programs. Occasions of service will be recorded automatically with each entry in a participant's electronic record. Logbooks and diaries will be used to record any costs incurred by the CRnQ team during APAP delivery such as private vehicle usage during community visits, intervention materials and equipment required for delivery of APAP.

### **3.4.3. Adoption**

To optimise adoption of APAP at CRnQ, where possible, the intervention will be integrated and embedded into the service in line with other programs offered by the service. For example, APAP will be included in the CRnQ promotional booklet and media events, in program scheduling and in the custom-designed electronic health record software. Additional

strategies employed to enhance adoption will include regular presentations and feedback by the knowledge broker to the clinical team to promote and report on the benefits of a physically active lifestyle for CRnQ participants. Protocol strategies for reach, effectiveness and adoption align with the steps described in the Phases of Change model (Kotter, 1997) illustrated in Figure 3.1. It is hoped that these strategies will provide sufficient support to the team to endure the iterative processes required to fully integrate APAP into CRnQ. Evaluation of APAP adoption will involve focus groups and interviews with the full CRnQ team to determine whether they are confident that APAP can be part of the organisation in the long term.



**Figure 3.1 Alignment of implementation strategies with Phases of Change Model** (Kotter, 1997)

### **3.4.4. Implementation**

To ensure implementation fidelity, APAP protocols (Appendix 3), developed by the UQ intervention developers, will be utilised. To ensure EPs have the skills for delivery of APAP, a Motivational Interviewing training module (Appendix 4), developed by the knowledge broker and based on the Motivational Interviewing course (W.R. Miller & Rollnick, 2012) will be utilised. The knowledge broker will meet with the UQ intervention developers periodically and, based on what is learnt in these meetings, will deliver weekly training sessions to EPs prior to and during implementation. Training sessions will be booked into the EPs' schedules well in advance. Prior to the study period EPs will have the opportunity to pilot APAP strategies with existing CRnQ participants. A fidelity checklist containing elements of the intervention, developed by the knowledge broker, will be used to guide fidelity (Appendix 5). EPs will record adherence and non-adherence and reasons for changes. Lastly, EP students will be provided with pre-reading before, and training during the first week of their five-week practicum, as well as the opportunity to observe and practice the skills involved in delivery of APAP.

Implementation of APAP at CRnQ will be piloted as a continuous service for a one-year period. The knowledge broker will lead the implementation process and act as the lead clinician for APAP and assist other EPs in delivery of the program. Other members of the clinical team will contribute to APAP according to each individual APAP participant's needs, and, according to standard CRnQ procedure, administrative staff will arrange booking of sessions and booking of transport to attend sessions or booking of the CRnQ vehicle for community visits. EPs will utilise the APAP protocols and will capitalise on their community connections with local gyms, pools and Sporting Wheelies and Disabled Association. In addition to the standard CRnQ procedure of obtaining a GP clearance for all participants

registered with CRnQ, EPs will complete a standard Exercise and Sport Science Australia (ESSA) risk assessment form (Appendix 6) and send a letter to the participant's GP outlining the exact nature of the PA, intended progressions, and the frequency and duration of the PA. The letter template that will be used was designed by UQ intervention developers and used in the efficacy study (Appendix 7).

The plan for evaluation of the implementation of APAP at CRnQ includes an audit of the electronic health records to count the number of APAP participant sessions and between session contacts; read the content of APAP sessions; verification of the electronic health records with fidelity checklists, and regular case meetings with EPs to discuss audits, challenges, successes and obtain feedback. Lastly, EPs and EP students will participate in interviews, conducted by an independent facilitator, to assess satisfaction with training; understanding of APAP goals; confidence with delivery of APAP; and program challenges and barriers to implementation of APAP at CRnQ.

### **3.4.5. Maintenance**

To evaluate maintenance at the individual level, in order to assess long-term changes to PA behaviour, APAP participants PA behaviour will be assessed at baseline, after delivery of APAP and at three-month follow-up. Measures administered will include the PASIPD, Social Support Scale, Decisional Balance Scale and the PA SOC questionnaire.

At the organisational level, mid-way through the research period, an electronic survey will be prepared and administered to the clinical team. The survey will assess levels of satisfaction with issues related to each RE-AIM element and ask for any recommended changes. With regard to reach, the team will be asked about satisfaction with recruitment methods. Effectiveness questions will cover unanticipated outcomes for APAP participants and

themselves, and the value of the intervention to APAP participants. With regard to adoption, the clinical team will be asked to rank their satisfaction with the APAP workshop, clarity of APAP goals, role expectations and supportiveness from the knowledge broker and decision makers. Implementation questions will address matters related to satisfaction and recommended changes to training, confidence with delivery of APAP, satisfaction and challenges associated with completing the required APAP components, and satisfaction with APAP tools and resources. Lastly, the clinical team will be asked whether they would recommend continuing APAP at the service. Meetings will take place between intervention developers and intervention implementers to discuss results from the survey and changes will be effected where necessary. The knowledge broker will be in close communication with the clinical team throughout the study period to obtain and act on feedback. Upon completion of the intervention study period, strategies to compensate for a reduction in the knowledge broker's hours will be discussed with CRnQ decision makers.

### **3.5. Methods**

Evaluation aims, study participants, procedures for data collection and data analysis are described for the primary and secondary aims in the hybrid effectiveness-implementation type 1 study design.

#### **3.5.1. Primary aim: Acceptability and feasibility of APAP's implementation approach at CRnQ**

A mixed methods approach will be utilised to collect information on the RE-AIM dimensions at individual and organisational levels and data collection methods will include (i) In-depth interviews with EPs and EP students; (ii) focus groups and individual interviews with the full

CRnQ team; (iii) an audit of electronic health records and examination of fidelity checklists; and (iv) examination of intake and occasions of service statistics from CRnQ. The knowledge broker will monitor progress and obtain feedback from EPs and the clinical team, and report outcomes via methods outlined in the following sections.

### **3.5.1.1. Study Participants**

#### *Full CRnQ team*

As part of their role at CRnQ, clinical, administrative and management staff members and health professional students will participate in implementation of APAP and will then be invited to participate in evaluation of the implementation. After describing the study in detail, participants will provide written informed consent. The critical role of intervention delivery will be tasked to the knowledge broker and two other EPs on staff at CRnQ as APAP was designed to be delivered by an accredited EP with experience in exercise prescription for individuals with NMS conditions. The EPs will be, in effect, the key adopters of the intervention.

### **3.5.1.2. Data collection**

#### *CRnQ participant flow, occasions of service, fidelity and project artefacts*

CRnQ participant characteristics and flow (percentage approached, declined, completion, attrition) will be collated from the clinical team, the CRnQ electronic health record system and questionnaires. At the organisational level, occasions of service will be recorded automatically with each contact entry made into each APAP participant's CRnQ electronic health record.

EPs will complete a fidelity checklist for each intervention they deliver. They will be asked to record which APAP components they adhered to, changed and reasons for change. The knowledge broker will audit electronic health records for APAP sessions. Minutes will be taken for weekly EP meetings with CRnQ decision makers and periodical meetings with UQ intervention developers. EPs will be asked to keep a diary, as will the knowledge broker. EPs will record any private vehicle use in a logbook.

#### ***Full CRnQ team focus groups and interviews***

Post-implementation, the full CRnQ team will be invited via email, face-to-face and phone by the knowledge broker to participate in focus groups and interviews. Focus groups and semi-structured interviews will be conducted at CRnQ by an independent interviewer with experience in qualitative data collection methods. The RE-AIM components will be used to develop two semi-structured interview guides; one for interviews with EPs who deliver the intervention (Appendix 8) and the other for focus groups with the full CRnQ team members (Appendix 9). Focus groups and interviews will be recorded and transcribed verbatim.

### **3.5.1.3. Data analysis**

#### ***CRnQ participant flow, occasions of service, fidelity and project artefacts***

The percentage of CRnQ participants approached to participate in APAP will be calculated by comparing the total number who register with CRnQ during the 12-month period, the number who participate in APAP and the number who decline.

Occasions of service will be extracted from the electronic health record system for the three EPs delivering APAP and, for further comparison, one other clinical team member delivering other CRnQ programs. Recording another clinical team member's occasions of service will provide a benchmark for APAP occasions of service. CRnQ's research assistant will extract



occasions of service from the system for each clinician for each day of practice producing totals on an Excel spreadsheet. Analysis will involve totalling the Excel columns. Totals for each clinician will be compared for the study period.

The knowledge broker will audit the APAP participant electronic health record recorded by EPs, read fidelity checklists at the completion of the intervention and discuss adherence or changes to APAP components with EPs at weekly meetings. Costs for private motor vehicle will be calculated by multiplying the number of kilometres travelled by 78 cents, the rate paid by CRnQ for the current financial year. In-depth interviews with EPs facilitated by an independent researcher will delve further into intervention delivery.

#### ***Full CRnQ team focus groups and interviews***

Data from the focus groups and interviews will be collected, transcribed, analysed and compared with the literature. Initial analyses for the interviews and focus groups will be conducted, firstly, by the knowledge broker by transcribing the data verbatim, followed by reading and re-reading. The transcripts will initially be read through in entirety and then multiple times conducting a line-by-line analysis to identify themes, patterns or concepts. Initially, data will be coded into elements of the RE-AIM framework. A constant comparison method will be applied to identify connections and relationships between the data and to explore the properties, context, interactional strategies and consequences of those strategies (Green, 2009). To ensure overall rigour and credibility, two other researchers (FB, RB) will follow these methods and results, and descriptions of the data will be compared with that of the knowledge broker (investigator triangulation). Disagreements related to coding between the knowledge broker and researchers will be dealt with on a case-by-case basis. A narrative accuracy check will be conducted with participants to review content and accuracy.

### **3.5.2. Secondary aim: Impact of APAP on participant outcomes**

The secondary aim of the hybrid effectiveness-implementation type 1 trial is to evaluate whether APAP's core components, applied in CRnQ's context and setting, will be effective in increasing the adoption and maintenance of PA for individuals with NMS conditions. Secondary measures used will assess changes to physical fitness, changes to the PA SOC, and the impact of APAP's PA promotion strategies on theory-based mediators of PA, namely social support and decisional balance. Additionally, APAP participant satisfaction will be evaluated.

#### **3.5.2.1. Study participants**

##### *APAP participants*

APAP participants will be those CRnQ participants enrolled in the trial i.e. adults with a NMS condition who are attending CRnQ including those who live regionally, rurally or remotely, those who have mild, moderate or severe disability, those with and without communication impairment and both Indigenous and non-Indigenous people. After describing the study in detail, participants will provide written informed consent.

#### **3.5.2.2. Data collection**

##### *APAP participant questionnaires*

Trained EPs will administer face-to-face electronic survey questionnaires with APAP participants in the CRnQ on-site interview rooms. It is expected these questionnaires will take 30-45 minutes. Rural APAP participants will be able to complete the questionnaires via Skype with the EP. These survey questionnaires will be conducted with APAP participants at

baseline, during their first APAP appointment; post-intervention, during their final APAP appointment; and at three-month follow-up. Appointments will be made through administration at CRnQ and transport will be provided if required.

Levels of PA will be assessed using the PASIPD (Washburn et al., 2002), which consists of 13 items: 6 leisure time, 6 household and 1 occupational activity item (Appendix 10). Physical activity stage of motivational readiness for change will be assessed using the Physical Activity Stages of Change questionnaire (B.H. Marcus et al., 1992), a four-item questionnaire measuring an individual’s PA intentions and actual PA behaviour in general (Appendix 11). The stages of change are summarised in Table 3.6. Social support will be measured using a 13-item scale. A 5-point Likert type scale will be used to rate the frequency of support received from family and friends in the three months prior, with one indicating “none” and five indicating “very often” (Appendix 12). Decisional balance will be measured using a 16-item scale, which includes six items representing the avoidance of exercise (cons) and ten items representing the positive perceptions of exercise (pros). A five-point Likert type scale will be used to rate how important each statement was with one indicating “not at all important” and five indicating “extremely important” (Appendix 13).

**Table 3.6 The Stages Exercise Behaviour**

<b>Stage No.</b>	<b>Description</b>
1	Inactive and not thinking about become more active
2	Inactive and thinking about becoming more active
3	Doing some physical activity
4	Doing enough physical activity*
5	Making physical activity a habit

\*Accumulating at least 30 minutes of moderate-intensity PA at least five days per week

### ***APAP participant physical measures***

The 6MWT will be administered by trained EPs with individuals who can walk during the initial session of APAP and the final session of the program. APAP participants will be instructed to walk around a track that measures 121 metres as many times as possible at a fast but safe speed. Verbal encouragement will be standardised and APAP participants will be informed of the time at every minute. Chairs will be placed at points around the track and APAP participants will be informed that they can rest at any time if needed. Timing will continue during rests. The duration and timing of rests will be recorded. The distance travelled will be recorded in metres after completion. In order to minimise the burden of testing on APAP participants and clinicians, no practice trials will be included.

The 6MAC will be performed by trained EPs with individuals who cannot walk during the initial session of APAP and the final session of the program. APAP participants will be seated at a MOTomed viva 2 (Reck-Technik, GmbH & Co., Betzenweiler, Germany) either in their wheelchair or a chair to perform arm cycling. Active hand gripping aid (The Active Hands Company Ltd, Birmingham, UK) may be required for APAP participants with upper limb weakness/paralysis/spasticity. The MOTomed will be set to upper limb training, level 5. APAP participants will be asked to cycle with their arms at a fast but comfortable speed. Distance will be recorded from the MOTomed. Passive time will be recorded if rests are required.

### ***APAP participant interviews***

At three-month follow-up APAP participants will be invited to participate in an interview-style questionnaire (Appendix 14). Interviews will assess satisfaction with APAP and will include questions about the good parts of the program; negative points; program expectations; goal achievement; whether the activities were enjoyable and whether they would recommend

it to others with health conditions. Interviews will be conducted between the knowledge broker and the APAP participants either face-to face in the interview rooms at CRnQ or via telephone. Appointments will be made through administration at CRnQ and transport will be provided if required. Interviews will be audio recorded and transcribed verbatim.

### **3.5.2.3. Data analysis**

#### *APAP participant questionnaires*

Total PASIPD scores will be calculated with a scoring algorithm (Appendix 15): the average hours daily multiplied by a metabolic equivalent value and summed over items. The maximum possible score is 199.5 MET hour per day. The PA SOC will be determined using a scoring algorithm (Marcus & Simkin, 1993). Social support scores will be calculated for family and friends separately by computing the sum of the items on the measure. Higher scores reflect more perceived social support. For the decisional balance scores, the average of the ten pro items and the six con items will be computed. The difference in the averages will be taken as the decisional balance score. Scores greater than 0 show that APAP participants see more benefits than barriers to being active. The larger the score, the more benefits the APAP participant sees relative to barriers. A score less than 0 shows that the APAP participants sees more barriers than benefits of being physically active. The larger the negative score, the more barriers the APAP participant sees relative to benefits. Differences in PA, social support and decisional balance from baseline to post-intervention and baseline to three-month follow-up will be calculated using the Statistical Package for Social Sciences (SPSS) repeated measures Analysis of Variance (ANOVA) with SPSS software (Version 19.0, SPSS Inc., Chicago, IL). Statistical significance will be set at an alpha level of 0.05. Participant characteristics and flow will be collated from CRnQ electronic health record system.

### ***APAP participant 6MWT and 6MAC***

Differences in distances achieved for the 6MWT and 6MAC from baseline to post-intervention will be calculated using repeated measures ANOVA with SPSS software (Version 19.0, SPSS Inc., Chicago, IL). Statistical significance will be set at an alpha level of 0.05.

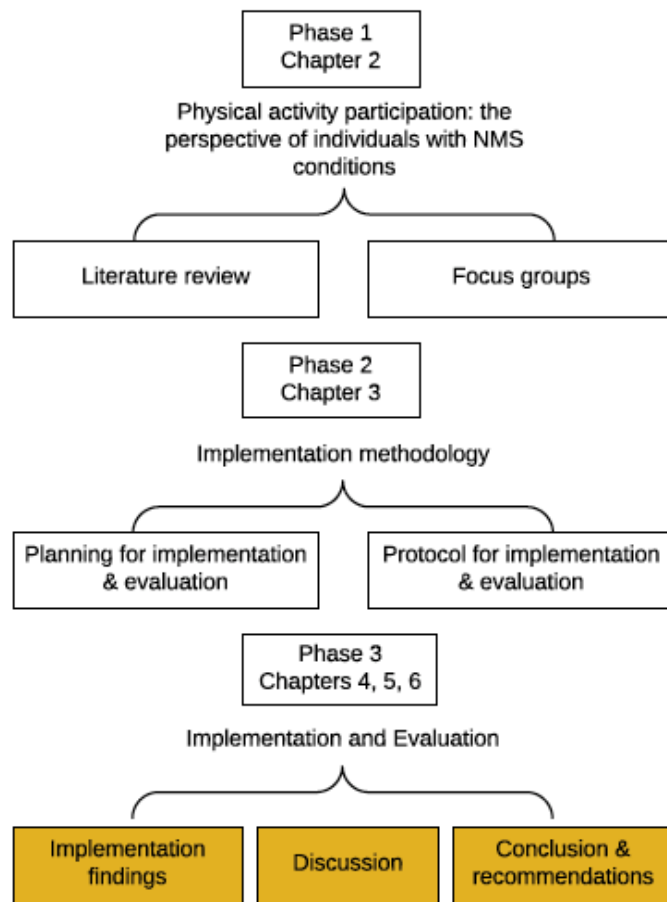
### ***APAP participant interviews***

Qualitative analysis will involve transcription of interviews verbatim by the knowledge broker. Two researchers will independently read and re-read transcripts to identify emerging themes. The researchers (RN, FB) compared their analyses and, together, developed the final themes and allocation of responses to themes via consensus.

# Chapter 4

## Evaluation of APAP at CRnQ: Implementation findings

This chapter describes how implementation of APAP at CRnQ transpired. Consistent with a hybrid effectiveness-implementation Type 1 study design, objective 1 was to test the feasibility and acceptability of APAP’s implementation approach at CRnQ. Objective 2 was to test the intervention’s impact on participant outcomes. Results, including barriers and facilitators to implementation and evaluation are presented under the RE-AIM domains.



# Introduction

Implementation and evaluation of APAP at CRnQ was facilitated by a number of processes that included familiarisation with the APAP intervention; familiarisation and comparison between the two settings; familiarisation with a translational framework and the subsequent application of that framework to plan, implement and evaluate the translation. A protocol was developed with strategies to overcome barriers and enhance facilitators to implementation that were anticipated. These strategies aligned with the eight steps of the Phases of Change Model (Kotter, 1997). A hybrid effectiveness-implementation Type 1 study design was part of the protocol. The primary aim of the study was to test the feasibility and acceptability of APAP at CRnQ. The secondary aim was to assess the effect of the intervention on participant outcomes.

## 4.1 Study Overview

The effectiveness-implementation study was conducted at CRnQ between July 2014 and July 2015. The pragmatic iterative approach used in the preparation of the protocol continued into the implementation phase with an expectation that the many dynamic interacting variables would present challenges along the way. Implementation was driven by the knowledge broker who worked in a fulltime capacity throughout the study period. The knowledge broker led the team of three EPs and EP students in delivering APAP. The program was integrated into CRnQ's usual systems and processes. With other service demands and increases in APAP referrals throughout the study period, EPs reached full capacity. The study period changed from 12 to seven months. Commencement dates for each APAP participant were staggered, therefore the study period was reduced to allow for a staggered



three-month follow-up data collection period. Additionally, intervention durations were different for some participants due to health setbacks e.g. 10 weeks versus 15 weeks. Due to time restrictions, midway assessment for APAP did not occur, although weekly feedback was obtained from the clinical team and acted upon directly by the knowledge broker. At the completion of the study period, the knowledge broker returned to one day per week and the other EPs on staff delivered APAP thereafter. Evaluation with the CRnQ team occurred post-study period. As a result of feedback obtained from the CRnQ team and the pragmatic approach taken, changes were made to the protocol and these are explained in detail in the findings below.

#### **4.1.2. Study participants**

##### *Full CRnQ team*

CRnQ full-time and part-time multi-disciplinary clinical team, administrative and management team (n=18) and students who attended for five-week to 7-week placement cycles (n=49) contributed to implementation. After describing the study in detail, participants provided written informed consent. Roles for the full CRnQ team differed according to their position at CRnQ. Exercise physiologists (EP), including the knowledge broker, assisted by EP students, delivered the intervention to APAP participants. As the adoption process can be dependent upon the characteristics of individuals (e.g. self-efficacy, perceptions of the organisation, learning styles) (Greenhalgh, Robert, Macfarlane, Bate, & Kyriakidou, 2004), their characteristics are described in more detail compared to the other intervention implementers at CRnQ (Table 3.1). The first EP, at the time of implementation, had been practising full time for two years, with CRnQ their first appointment after graduation. This EP had a positive attitude about the intervention and high self-efficacy with regard to delivery capability. The EP was motivated, preferred to learn on-the-job and, as an

advocate for the ICF framework of which CRnQ's principles and values are based, was strongly committed to CRnQ. The second EP worked part time (0.4 FTE) at CRnQ, had seven years' experience in clinical practice and had been at CRnQ for just over two years. The part-time nature of this position meant limited inclusion in regular team planning days, weekly service and clinical meetings resulting in a relatively moderate commitment to the organisation. This EP preferred systems and processes and was meticulous in following processes. Other allied health professionals and students in the team adopted the role of recruiting/referring CRnQ participants to APAP.

The clinical team referred participants to APAP. The Clinical Leader led the team, managed clinical meetings and allocated participants to programs. The Education Leader scheduled student placement and training, and the Service Director managed the business aspects of CRnQ including costs and promotion. The full CRnQ team attended at least one APAP presentation given by the knowledge broker.

The CRnQ clinical and management team were invited to participate in the evaluation. Members of the clinical team who chose to participate in evaluation included EPs, including the knowledge broker, EP students, occupational therapists, social worker, nurse, dietitian, speech pathologist, physiotherapists, and the Clinical Leader (n=14). The views of the management team were represented by the Service Director (n=1). Semi-structured interviews were conducted with the EPs by an independent researcher as per the protocol in Chapter 3. Two focus groups were conducted in the boardroom at CRnQ with other members of the clinical team by an independent researcher and a note-taker. There were three participants in each focus group. Members of the clinical team who could not attend the focus groups participated in individual interviews with the independent researcher (n=4). Exercise Physiology students also participated in interviews with the independent researcher (n=2). Data analysis occurred as per the protocol in Chapter 3.

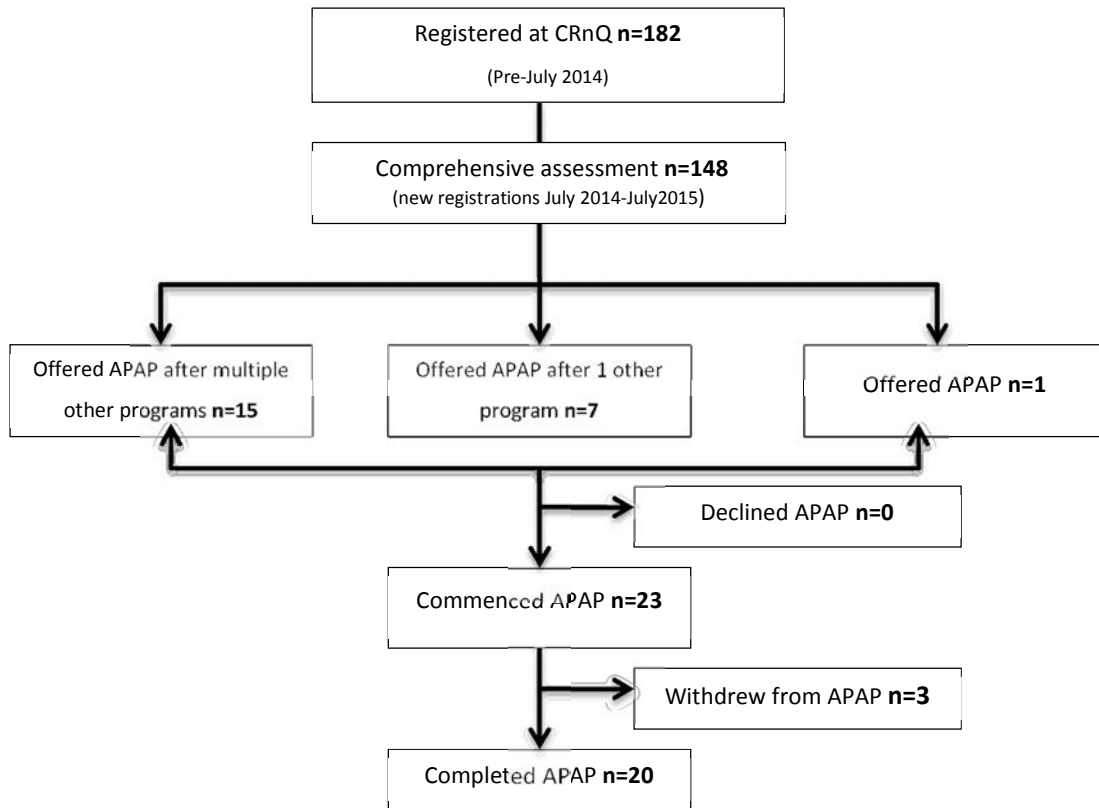


## **4.2. RE-AIM domains**

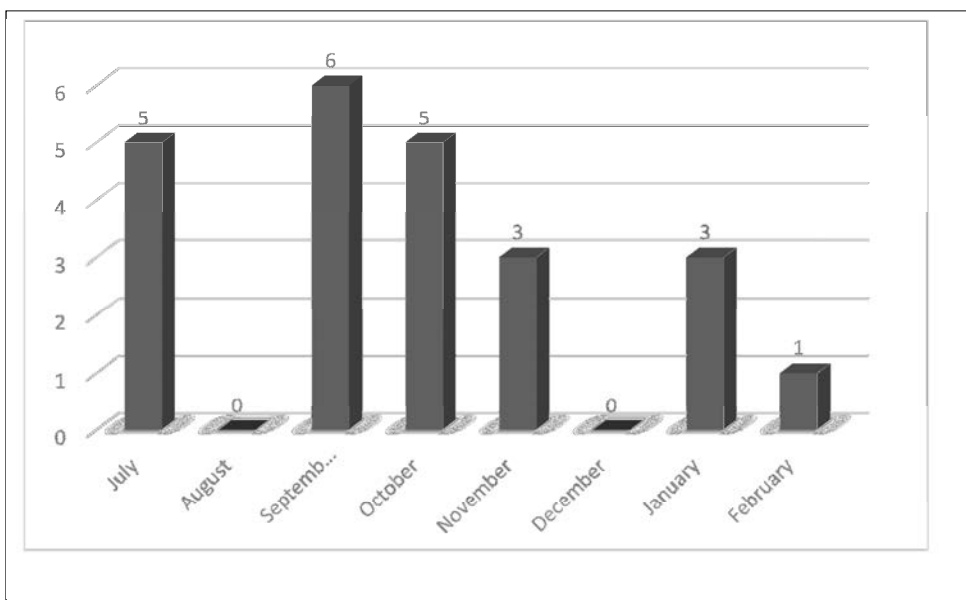
### **4.2.1. Reach**

Reach is reported in terms of recruitment rates including numbers of CRnQ participants approached, accepted and declined. For APAP participants who accepted, completion and withdrawal rates are presented and their characteristics.

Referral pathways to APAP are illustrated in Figure 4.1. The monthly recruitment pattern over the seven-month period is illustrated in Figure 4.2.



**Figure 4.1 Referral pathway to APAP throughout implementation**



**Figure 4.2 APAP participant intake**

Two per cent of the 148 new CRnQ registrations were recruited during the seven-month period and 11% were recruited from existing CRnQ registrations. The number of participants recruited was lower than anticipated for four reasons. Firstly, two of the three EPs delivered limited APAP interventions due to other service/program demands and, consequently, their capacity to support APAP participants was more limited than anticipated. Secondly, the allocated timeframe for appointments was typically two hours. This period of time was allocated to allow for sessions in the community and to allow for the complex nature of the sessions, which included PA, behaviour-change activities and planning with the APAP participant for between-session activity. Thirdly, program duration was longer than expected due to APAP participant health setbacks, and to a certain extent, inexperience with delivery of the APAP intervention. Lastly, to allow for three-month follow-up measures with a staggered intake, delivery of APAP occurred over a seven-month period, which included a Christmas period of reduced rehabilitation programs and CRnQ participant numbers.

No CRnQ participants declined the invitation to participate in APAP. Eighty-seven per cent of APAP participants completed the intervention (n=20). Session adherence rates were high. Program satisfaction results reported in the effectiveness domain are a reflection of the high completion rates. Of the three APAP participants who withdrew from the intervention, one experienced rapid health decline and was transferred from home to high care; one had knee surgery scheduled and did not want to risk infection and one ceased attending after five sessions for personal reasons.

APAP participants (n=23) and their characteristics are reported in Table 4.1. Compared with APAP participants in the APAP CCT (Clanchy et al., 2016), a sample more reflective of a 'real-world' setting was achieved in the current study. This included adults who were over 60 years of age, people who were unable to walk, lived rurally and who had severe communication impairment. In addition, two APAP participants received botox therapy during the intervention; one had knee surgery scheduled, and one expressed suicidal ideation. Health conditions of APAP program participants are outlined in Figure 4.3. The majority of program participants were stroke survivors. The NMS conditions included congenital, acquired and non/progressive. As recruitment rates were lower than expected, purposive sampling occurred toward the end of the research period in order to increase representativeness of CRnQ participants (e.g. aphasic, rural). To assist with the referral process during implementation, a simplified description of the purpose of APAP and the research project was developed by the knowledge broker and the EPs to assist the team with recruitment (Appendix 16).

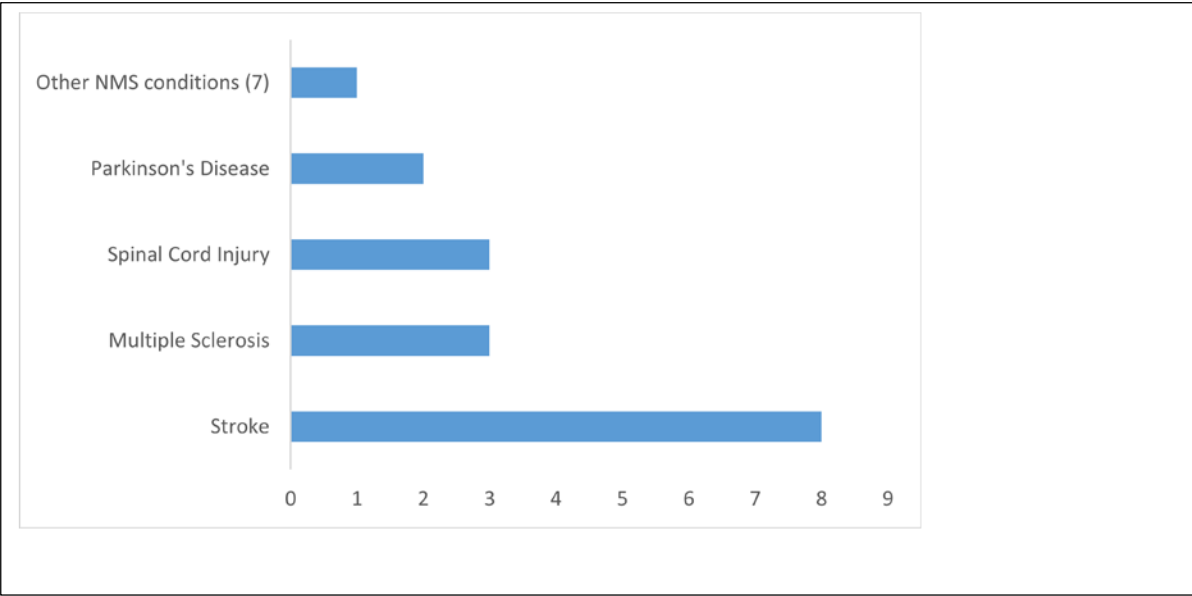
The participant's stage of exercise behaviour was obtained from the telephone screen and announced at clinical meeting; however, direct recruitment to APAP did not result from this strategy. During the comprehensive assessment, the majority of CRnQ participants set goals related to restoration of function. As service at CRnQ was person-centred and goal-driven, in most cases, participants were first allocated to a rehabilitation program to work toward their goals. Referral to APAP followed on from these programs. In some cases, APAP was delivered concurrently with other CRnQ programs (e.g. two sessions per week in a rehabilitation program, one session in APAP). During the telephone screen, participants were also asked what they would like to gain from CRnQ. During implementation, the knowledge broker audited the clinical notes of CRnQ participants over a one-month period during implementation to gather responses to this question. The audit revealed that the majority of

responses were related to PA (Table 4.2). These responses were presented to the team during one of the APAP presentations. Over time, the clinical team began to refer CRnQ participants to APAP earlier in their care pathway.



**Table 4.1 APAP participant characteristics**

<b>Characteristics</b>	<b>Total participants</b>
<b>Age</b> (yrs)	61.3 ± 12.8
<b>BMI</b> (kg·m <sup>2</sup> )	29 ± 6.7
<b>Sex</b>	
Male (n)	13
Female (n)	10
<b>Race/Ethnicity</b>	
Caucasian (n)	22
Aboriginal (n)	1
<b>Location</b>	
Regional (n)	20
Rural (n)	3
<b>Primary means of locomotion</b>	
Walk with aid (n)	10
Walk with nil aid (n)	7
MWC (n)	3
PWC (n)	3
<b>Living alone</b>	
Yes (n)	4
No (n)	19
<b>Driver's Licence</b>	
Yes (n)	11
No (n)	12
<b>Employed/Volunteer</b>	
Yes (n)	1
No (n)	22
Values signify mean ± unless otherwise indicated	
MWC = motorised wheelchair	
PWC = push wheelchair	



**Figure 4.3 APAP participant health conditions**

**Table 4.2 Participant telephone screen responses for one month during the study period**

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**What would you like to gain from CRnQ?**

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- Improve balance
- Improved walking & UL function
- To get right side moving to improve ability to walk & attend aquatic program
- Weight loss
- Regain confidence with exercises following recent seizure (Get back to where I was)
- Fitness, UB strength, self-manage symptoms better, independence in a gym program
- To become more active; to do more without pain
- Post-botox – right UL intensive rehab & improve mobility
- Build muscle condition so can care for wife; feels weak and tired all the time
- Improve use of right UL & LL
- UL & LL strength & fitness
- Confidence with mobility
- Spend time with grandchildren but has declined invitation as feels like a burden – lacks motivation
- More strength to walk better; increase fitness
- Follow-up to hospital rehab; community participation
- Improve strength for pending overseas trip
- To get vision & everything back on track so that he can drive again
- To get more core muscle strength to improve mobility & reduce backache
- To be able to stretch legs in order to straighten as sitting in bent posture causing back pain

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UL = upper limb, UB = upper body, LL = lower limb

#### **4.2.1.1. Full CRnQ team views on reach**

Clinical team members felt that APAP reached those it was intended to reach, namely people with NMS conditions, but that many who were suitable missed out, due to the limited capacity of the program. Some clinical team members considered all people attending CRnQ suitable for APAP on the basis that all were at risk of chronic conditions due to inactivity associated with a disability. Others felt APAP was only suitable for people who expressed PA as a goal on the basis that CRnQ strived to be person-centred and hence tailored a person's service to their goals.

Clinical team members felt that people who participated in APAP chose to do so because they were already active or at least wanting to be more active (Stages 2 to 4 of exercise behaviour). People who were often overlooked for the program were those in the precontemplation stage of exercise behaviour as staff felt they lacked the skills to motivate CRnQ participants. Some of the clinical team suggested that they be upskilled in Motivational Interviewing to encourage precontemplators to participate in APAP.

More often than not, people participated in APAP while also attending other individual or group programs concurrently or after they had completed all other programs and were ready to transition back into their own lifestyle. Others participated in APAP because it meant they could stay with the service longer. Some people had such complex physical and psychological health issues and family issues that this limited their capacity to participate, or led to a setback in their APAP intervention. Others fully engaged in the program through to completion due to satisfaction with the one-to-one aspect and also the assistance received by EPs with community activities.

To enable more people to participate in APAP, an increase in EP hours was seen as a simple but limited solution. Some members of the clinical team felt APAP would reach more people

if it was fully integrated into the interprofessional service model, for example, an EP would be lead clinician and APAP could be delivered by other members of the team both individually and in groups.

*“Maybe if there’s aspects of it [APAP] that could be done as a group, that way more people can receive that program with less staffing resources.”*

*“I think some of the education could happen in a group setting...lots of peer discussion and peer support could happen with that...I think it’s then being able to have some one-to-one time though...It’s beneficial to get out and actually try the activity and having a go more than just once...being able to follow up with that. I think that’s where we’re limited here, there isn’t the opportunity to do a lot of the practice where they want to do it.”*

Alternately, others thought the intervention worked well as an individual program; that the one-to-one approach was essential to its success. Several clinical team members suggested that one EP should exclusively deliver APAP.

*“I certainly heard feedback from family to say that they [APAP participants] enjoyed the intensive nature of it [APAP]...it was the one-to-one and there was a plan.”*

*“It’s that one-to-one focus as well...rather than being in a group, actually have that individual focus to assist them and just really problem solving around what are the barriers to them accessing the community to their goals.”*

*“I like the way that EPs are problem solving and doing the Motivational Interviewing and all that...I guess if we brought social work and psych into it, then it wouldn’t be APAP...I think it’s good that it’s a program led by EPs.”*

### **4.2.2. Effectiveness**

Effectiveness findings relate to the intervention's impact on APAP participant outcomes and certain organisational outcomes by way of costs associated with delivery of the intervention. The primary aim of the intervention was to increase the adoption of PA for APAP participants. Furthermore, it was expected that with an increase in PA, there was an expected increase in cardiorespiratory fitness. The PASIPD measured any changes in amounts of PA and increases in 6MWT and 6MAC distances indicate changes to cardiorespiratory fitness. The program utilised evidence-based PA promotional strategies to highlight the benefits of PA, overcome the perceived barriers to PA and increase social support, therefore theory-based mediators were assessed using the social support and decisional balance scales. It was also important to understand the intervention's impact on APAP participants. This was achieved through observation by EPs who delivered APAP, and interviews with APAP participants. Lastly, during focus groups and interviews, the clinical team were asked about outcomes they had observed their CRnQ participants achieve as a result of participation in APAP.

APAP participant questionnaire outcomes are illustrated in Table 4.3 and described below. For the PASIPD, social support and decisional balance scales, data for 19 of the 20 APAP participants were included as questionnaires were unsuitable for one APAP participant. For the participant with severe communication impairment, an adapted evaluation interview was conducted and results are presented in section 4.2.2.8.

### *Primary outcome measure*

#### **4.2.2.1. PASIPD**

The PASIPD scores pre- to post- intervention,  $z = -1.61$ ,  $p = 0.11$ , with a medium effect size ( $r = 0.26$ ). There was no statistically significant increase in PASIPD scores pre-intervention to three-month follow up,  $z = -0.362$ ,  $p = 0.72$ , with a small effect size ( $r = 0.06$ ).

The mean baseline score for the PASIPD was 10.6. Just over half of the APAP participants in the current study scored zero for eight items in the PASIPD, which means they did not participate in moderate sport and recreational activities, strenuous sport and recreational activities; heavy housework or chores; home repairs; lawn work or yard care; gardening outdoors; care for another person; and work for pay or as a volunteer. Figure 4.4 demonstrates the number of APAP participants who participated in each individual PASIPD item. The PA that APAP participants chose to do as a result of behaviour-change strategies and, to an extent, the tropical climate, included structured strength and cardiorespiratory exercise at their local gym and home, and walking, cycling and swimming/aquatic exercise in their local community. The increases in these activities coincide with increases in the single PASIPD items shown in Figure 4.5 such as muscle strength and endurance and light sport and recreation.

## *Secondary outcome measures*

### **4.2.2.2. Social support**

A Wilcoxon Signed Rank Test revealed a statistically significant increase in *family* social support scores pre- to post-intervention,  $z = -2.480$ ,  $p = 0.01$ , with a medium effect size ( $r = 0.40$ ). There was no statistically significant increase in *family* social support scores pre-intervention to three-month follow-up,  $z = -1.730$ ,  $p = 0.08$ , with a medium effect size ( $r = 0.3$ ). There was a statistically significant increase in *friend* social support scores pre- to post-intervention,  $z = -3.729$ ,  $p = 0.000$ , with a large effect size ( $r = 0.60$ ). There was a statistically significant increase in *friend* social support scores pre-intervention to three-month follow-up,  $z = -3.165$ ,  $p = 0.002$ , with a large effect size ( $r = 0.5$ ).

Increases in social support are reflective of the efforts of the EPs to facilitate social support. Seven of the APAP participants attended the same local gym and a Facebook group was established. In some cases, gym programs were developed for family members so that they could attend with APAP participants. Introductions were made between past and present CRnQ participants, facility staff and other gym members. In one case, transport barriers were overcome through social support. Many of the APAP participants were acquainted as they attended the same health services and support groups. EPs also ensured introductions were made at other gyms and pools between facility staff and APAP participants.

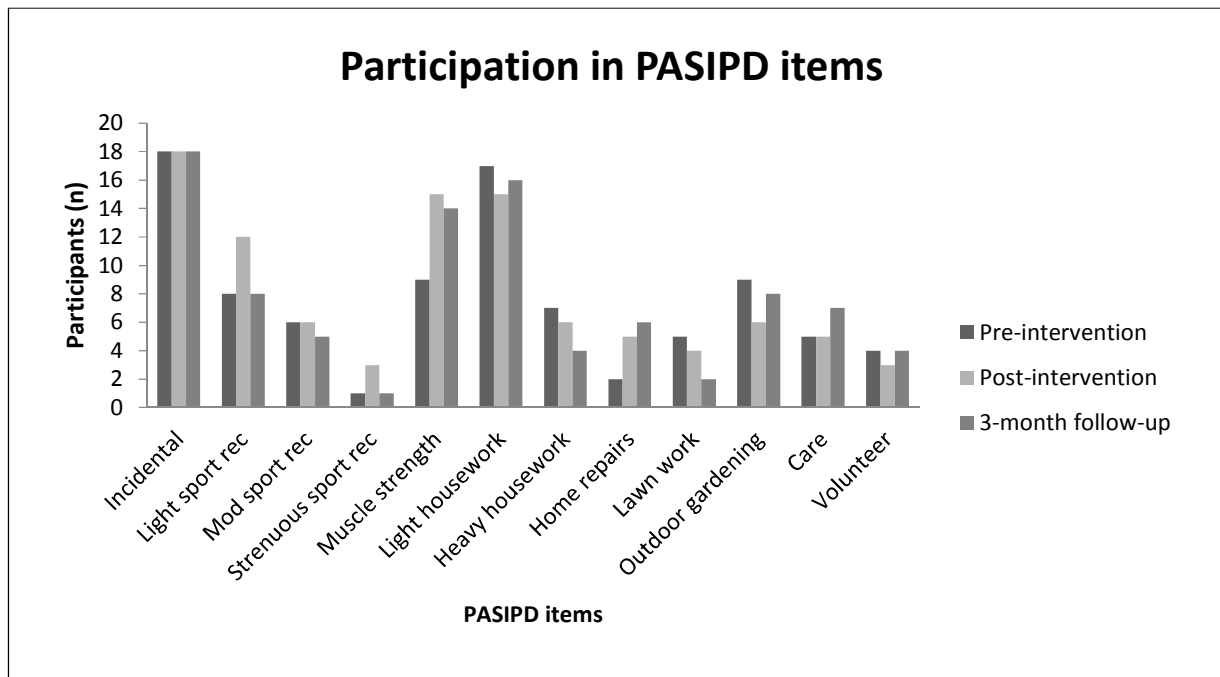


**Table 4.3 Program participant questionnaire results**

Variable	Baseline to Post Intervention			Baseline to 3-month Follow Up		
	Pre	Post	p value	Pre	Follow-up	p value
PASIPD	10.13 (IQR=14.15)	11.95 (IQR=17.37)	.11	10.13 (IQR=14.15)	7.64 (IQR=12.27)	.72
Family social support	29.00 (IQR=27.00)	32.00 (IQR=17.00)	.013*	29.00 (IQR=27.00)	29.00 (IQR=13.00)	.08
Friend social support	20.00 (IQR=17.00)	29.00 (IQR=14.00)	.001**	20.00 (IQR=17.00)	25.00 (IQR=13.00)	.002*
Decisional balance	1.77 (IQR=1.14)	1.40 (IQR=0.37)	.015*	1.77 (IQR=1.14)	1.03 (IQR=1.1)	.07
6MWT (metres)	254 (IQR=345)	263 (IQR=273.25)	.605			
6MAC (metres)	1540 (IQR=1207)	1700 (IQR=1025)	1.00			

\*Denotes a significant within-group difference (P ≤.05)

\*\*Denotes a significant within-group difference (P ≤.01)



**Figure 4.4 Participation in each PASIPD item for program participants**

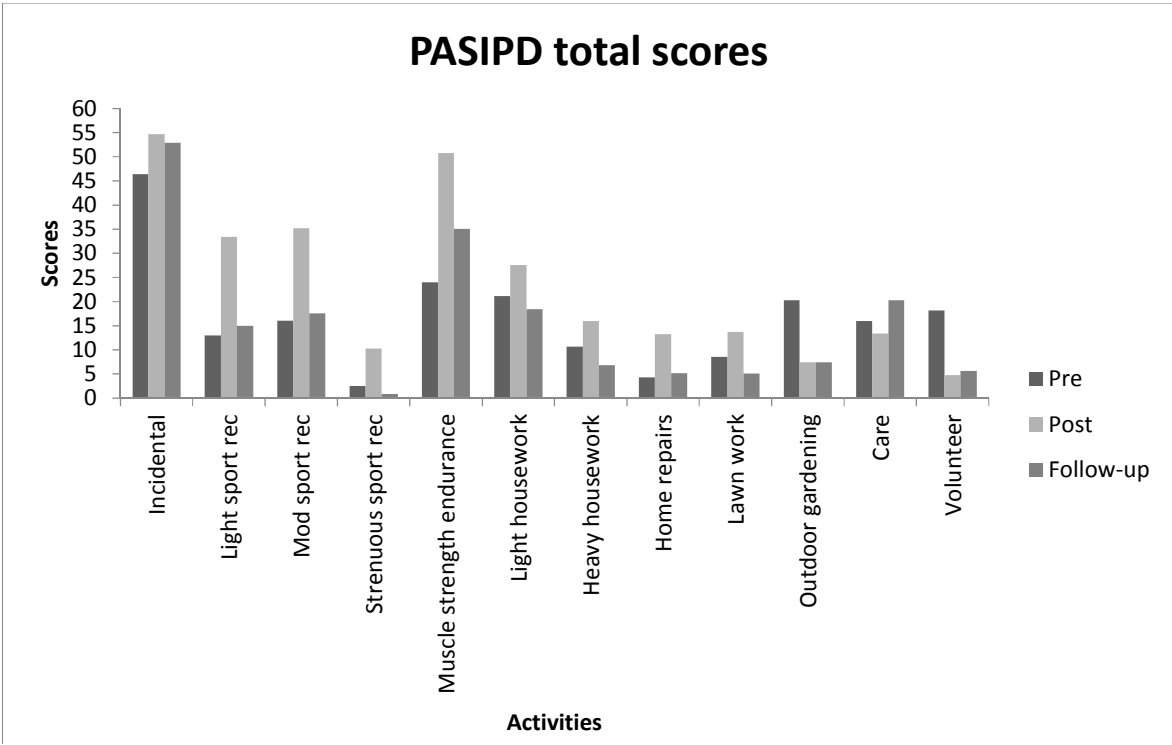


Figure 4.5 Total PASIPD scores

### **4.2.2.3. Decisional balance**

There was a statistically significant decrease in decisional balance scores pre- to post-intervention,  $z = -2.435$ ,  $p = 0.015$ , with a medium effect size ( $r = 0.4$ ). There was no statistically significant decrease in decisional balance scores pre-intervention to three-month follow-up,  $z = -1.811$ ,  $p = 0.07$ , with a medium effect size ( $r = 0.3$ ).

Median scores for pre- and post-intervention and three-month follow-up were above 0, which means that APAP participants identified more benefits than barriers to being physically active. A decrease in scores post-intervention and at three-month follow-up indicates an increase in perceived barriers. A possible explanation for this result is that, with the low function level of many of the APAP participants, at times, effort required for activities did outweigh the benefits and enjoyment.

### **4.2.2.4. 6MWT and 6MAC**

A Wilcoxon Signed Rank Test revealed no statistically significant increases in distances walked over six minutes pre- to post-intervention,  $z = -.517$ ,  $p = 0.605$ , with a small effect size ( $r = 0.09$ ). There was no statistically significant increases in hand-cycle distances over six minutes pre-to post-intervention,  $z = .000$ ,  $p = 1.000$ , with a small effect size ( $r = 0.00$ ). The results for the 6MWT and 6MAC are best represented in Figures 4.6 and 4.7 where it can be clearly seen that most APAP participants maintained their distances. As the majority of APAP participants had practised walking in rehabilitation programs prior to APAP, with their low levels of mobility, they may have reached a level close to their maximum capacity. Decreases in distances were related to health setbacks, health condition symptoms and the tropical climate on the day of assessment.

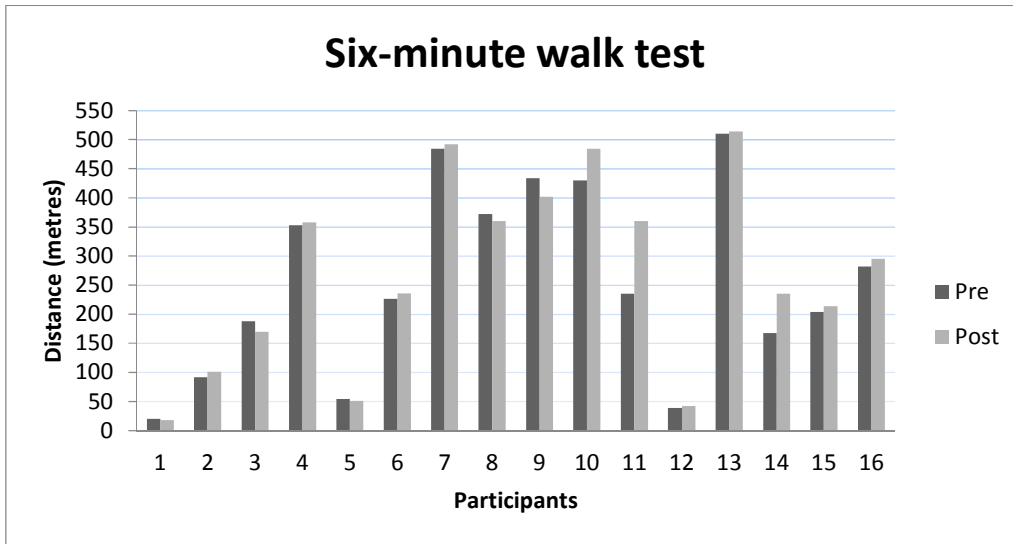


Figure 4.6 Six-minute walk test results from baseline to post-intervention

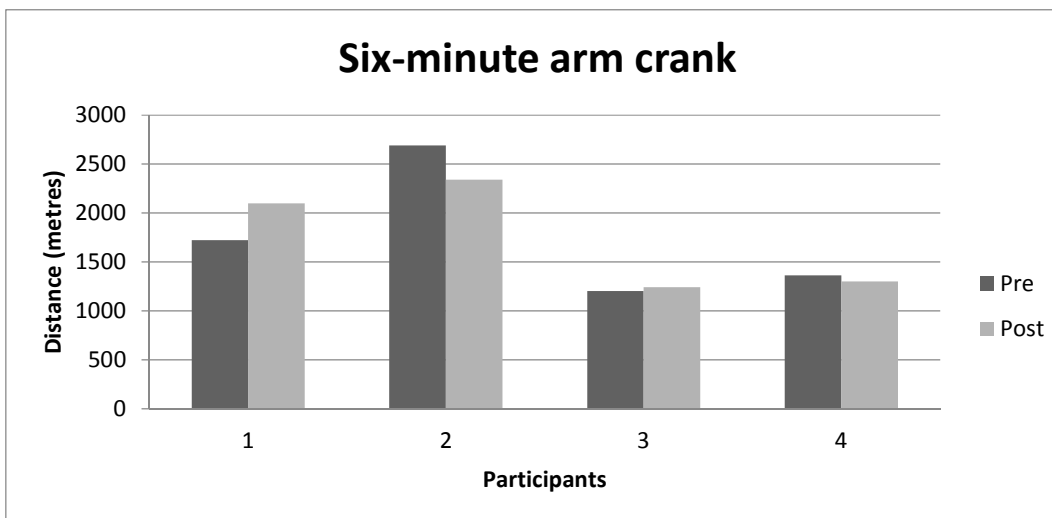
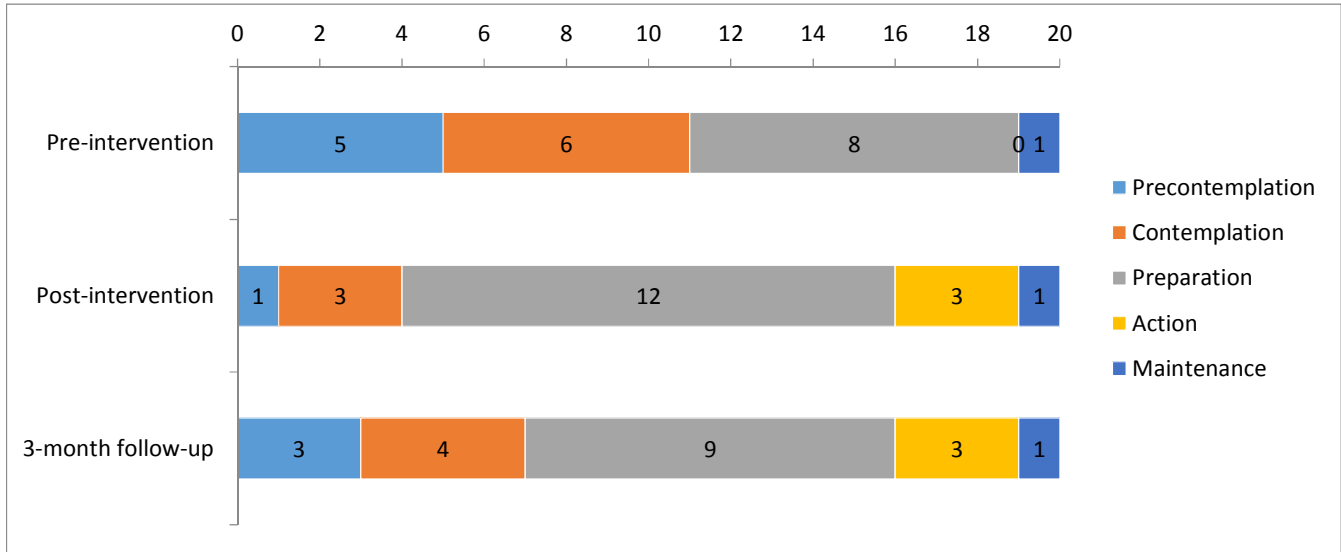


Figure 4.7 Six-minute arm crank results from baseline to post-intervention

#### **4.2.2.5. Stage of exercise behaviour**

Eight APAP participants went from no PA to some PA and five continued their PA at three-month follow-up. Seven APAP participants increased their PA and seven continued those increases at three-month follow-up. Five APAP participants increased their PA during the intervention, but ceased post-intervention. Figure 4.8 illustrates changes to PA stages of change pre- and post-intervention and at three-month follow-up. The ideal result for PA interventions is a decrease of APAP participants in stages 1, 2 and 3 (pre-contemplation, contemplation and preparation), and an increase in stages 4 and 5 (action and maintenance) and for these changes to remain long term. In the current study, there were decreases in APAP participants in stages 1 and 2 pre-to post-intervention but only some maintained increases in PA at follow-up. In stage 3, however, there is an increase in APAP participant numbers from pre-to post-intervention with a small decrease to follow-up. Interestingly, over the three time periods in this study, the preparation stage (Stage 3) consistently contained a large scope of participants. Individuals who increased their PA dramatically (e.g. no PA to three to four days per week) still remained in stage 3 because to enter stage 4, one must be accumulating 30 minutes of moderate intensity activity on five days of the week to meet the PA guidelines for health (Haskell, 2007). The national PA guidelines may be unrealistic for APAP participants in this study due to low levels of function and the effort involved in doing PA near daily. APAP participants with a higher level of function achieved the recommended amount of PA and maintained these increases through to follow-up. The one APAP participant who commenced APAP at stage 5 remained consistent throughout the intervention. This APAP participant only required advice with regard to exercise, therefore, the other APAP steps were not applied in this case.



**Figure 4.8 Physical activity stages of change for APAP participants**

#### **4.2.2.6. Unanticipated outcomes**

An unanticipated outcome observed and reported by EPs was a potential increase in workload for the family carer of an individual with a low level of function. Participation in other CRnQ rehabilitation programs was, in a way, respite for the family carer as they would deliver the CRnQ participant to the facility for two hours and gain some personal time. APAP participants returned to their own surroundings to do regular PA. For an APAP participant with a low level of function, assistance was required either by family carers or paid carers. The EP worked with the APAP participant’s family carer to find a solution. Suggestions included training their paid carer or training an allied health student who would be paid by the family. The family carer preferred to utilise the paid carer’s limited time on household chores rather than assisting with PA, therefore, the EP facilitated introductions with a student. Ultimately, arrangements did not proceed as the APAP participant’s health declined dramatically toward the end of the intervention resulting in a transfer to high care.

#### **4.2.2.7. APAP participant satisfaction**

Twelve of the 20 APAP participants agreed to participate in a structured interview. Of the four who declined, two lived rurally, one had communication impairment, and the other two did not have time. Two APAP participants were diagnosed with cancer and one relocated to another city due to marital breakdown.

Overall, APAP participants were satisfied with the intervention with all stating they would recommend it to others. Reasons for recommending the program were varied and include: “Gives people something to do”; “suitable for anyone”; “makes you think about what you’re doing and whether you want to get ahead”; “support – one-to-one thing”; “no real pressure but advice and choice”, more freedom and a bit more everything.” Alternately, one APAP participant stated the program was more suitable for people without disabilities. As this person’s SCI was recent, he was still managing major life changes (e.g. job loss, mourning the loss of his former self). Physical activity up to the time of his accident had been incidental through his job (e.g. walking, climbing ladders) and he did not enjoy structured exercise. The main benefits outlined by APAP participants were improved confidence, improved walking, social interaction, increased motivation, skills and strength. Five APAP participants said they achieved their goals, four stated that they partly achieved them and three said no goal achievement. Five APAP participants expected improvements in function from the program and four expected support and assistance with PA. Others did not know what to expect or had no expectations with regard to the intervention. The majority of APAP participants said they do not enjoy PA but they do PA because it is good for them and they like the social interaction.

#### **4.2.2.8. Adapted evaluation interview for APAP participant with aphasia**

Under the guidance of a speech pathologist, the interview was adapted to accommodate for a APAP participant with aphasia. The interview-style evaluation was conducted using visual aids and the process was videotaped. The interview took place in an interview room at CRnQ between the knowledge broker and the APAP participant. The APAP participant's paid carer, who was also considered a friend, was also present. In terms commensurate with the APAP participant's level of understanding, the purpose of the interview was explained. Evaluation involved the use of photos of activities undertaken during APAP; photos of people involved in the activities; photos of the locations where PA was conducted; visual aids used during the program and a visual analogue scale with the ratings: "good", "don't mind" and "bad". The APAP participant was asked about PA, people involved in the activities, specific exercises performed at the gym, and the frequency, duration and intensity of exercises and asked to indicate a rating on the scale. The paid carer was also asked about the practicability of visual aids for the APAP participant's care team.

The APAP participant indicated 'good' for gym activities and 'don't mind' for pool activities. It was indicated that all paid carers who assisted with activities were good. With regard to social interaction with other members of the gym, a preference was indicated for some people, but not all. The APAP participant indicated that it was good that a sister attended sometimes at the same time to do her exercises; that most exercises were good; walking was good when feeling strong and that right arm pain was experienced and with some exercises. In these instances the APAP participant said: 'I try', and 'But I've got to do it.' It was indicated that three times per week at the gym for 30-60 minutes was good and exercises were not too hard. The paid carer stated that some exercise goals placed pressure on the

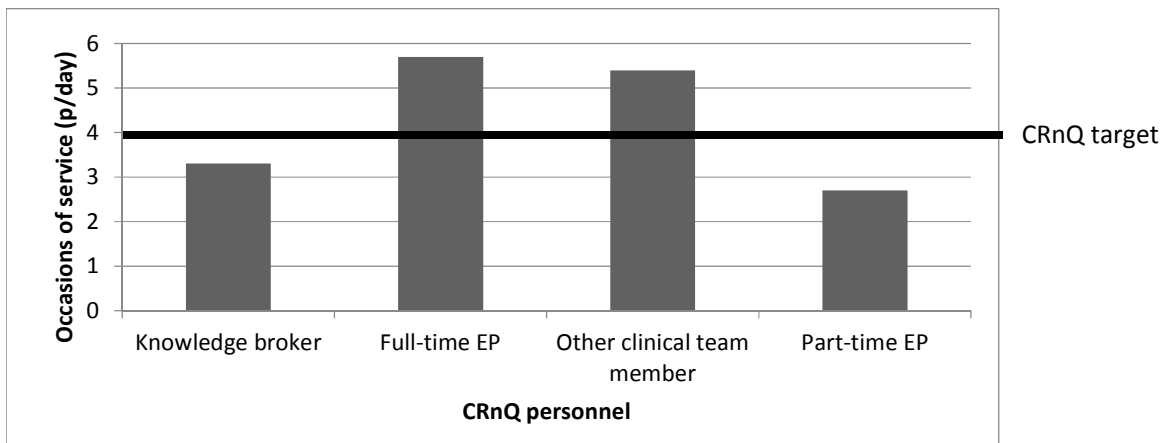


APAP participant and that adherence and frequency goals were better with short-term session goals. The paid carer also stated that the visual weekly planner was difficult to manage with many paid-carer and family-carer changes (four paid, two family) throughout the week. It was mentioned that the APAP participant was quite familiar with her weekly routine with the same scheduled outings each week. The APAP participant stated: ‘I would like to do things myself’, and when referring to the paid carers and family carers said, ‘they want their own way’ and agreed it was frustrating at times. At the end of the interview the APAP participant indicated that they would like to continue going to the gym saying, ‘I’d like to have exercise.’

#### **4.2.2.9. APAP delivery costs**

##### *Occasions of service*

At CRnQ, personnel and time are represented by the number of occasions of service achieved. These were recorded from July to February for all EPs and, for comparison, one other clinical team member. Decision makers at CRnQ stated that in order for the organisation to reach a target amount of occasions of service, each member of the clinical team must achieve a minimum of four occasions of service per day. Figure 4.9 illustrates the occasions of service per day from July to February for EPs and one other member of the clinical team for comparison and benchmarking.



**Figure 4.9 Occasions of service per day for EPs other clinical team member**

It is important to note that during this period, the delivery rate for EPs to 23 APAP participants was as follows: full-time EP (n=1), part-time EP (n=3), knowledge broker (n=19). Consequently, daily occasions of service for the full-time EP and the other full-time clinical team member were achieved through other programs that CRnQ offered that were a combination of both facility-based and community individual and group sessions. So, essentially, one EP delivered APAP full time during the data collection period. Table 4.4 provides a breakdown of services provided by the EPs during a typical CRnQ week during the seven-month data collection period.

**Table 4.4 Services provided by EPs for one week during the research period**

Service	EP1 Knowledge broker	EP2 Full time	EP3 Part time
APAP Appointments (n)	17	1	1
Other CRnQ program appointments (n)	1	20	1
APAP Hours	26	1	2
Other CRnQ program (hrs)	2	23.5	1
Clinical Meeting, training, preparation (hrs)	5	4	1
Outreach programs, project work (hrs)	0	8	8
Total (hrs)	33	36.5	12

Essentially, clinical team members delivering other programs achieved the target occasions of service and EPs delivering APAP did not. Ten per cent of the knowledge broker's occasions of service can be attributed to service demands in other CRnQ programs. As predicted, one-on-one sessions delivered in the community are more time consuming than facility-based sessions and group sessions produce more occasions of service. Preparation time (e.g. visual aids and consultation with speech pathologist) for the APAP participant with aphasia was greater than usual.

### *APAP materials, equipment and space requirements*

With regard to material resources, consumption of stationery for APAP delivery was similar to other CRnQ programs. Due to the changing nature of the APAP sessions (e.g. time of day, location), electronic scheduling required regular liaison with administration support. This made it particularly difficult to fit in with the student schedule, other members of the clinical team and for the part-time EP who attended two days per week. After-hours sessions in the community and between-session phone calls, texts to APAP participants were also impractical for the part-time EP. Resource availability at CRnQ was dependent upon other program demands (e.g. work vehicle, interview rooms). These resources were booked in advance by other members of the CRnQ in other programs when planning the participant's ICP. Room bookings were required for initial and final sessions, however facility equipment and space were not required during community sessions. As the CRnQ motor vehicle was often booked in advance for other CRnQ service demands, EPs were required to use their private vehicle for many community visits. Private vehicle kilometres totalled 1052 for the study period. At 0.78 cents per kilometre, the total cost was \$830.

#### **4.2.2.10. Full CRnQ team views on effectiveness**

The clinical team defined an effective program as APAP participant integration into the community, sustained PA and the non-return of CRnQ participants to the service. The clinical team viewed achievements by APAP participants as program effectiveness including: increases in PA, fitness, motivation and mood; a sense of well-being; enjoyment of activities; regaining social interaction and some control in life, independence and confidence. They saw the enablement and empowerment of their CRnQ participants; the reassembling of a lifestyle and the emergence of an identity.

*“It has a really positive effect on their mood...and gives them a sense of well-being.”*

*“It lets people explore things that they might not necessarily explore.”*

Some members of the clinical team believed that APAP participants were more aware about the benefits of PA and were also able to maintain gains from other programs. APAP participants achieved other goals through increased participation in the community.

The clinical team said that the effectiveness of APAP can be attributed to adaptiveness to the individual's needs and their stage of readiness. Others observed APAP participants gain independent access in the community through the adoption of PA, something they would not otherwise have gained in other programs offered by the service. The clinical team reported the biggest contributors to effectiveness were the one-to-one nature of the sessions and the sessions in the community where APAP participants had the opportunity to explore their PA potential and to meet peer role models.

*“It's the one-to-one focus...rather than being in a group, actually have that individual focus to assist them to problem solve around what are the barriers to accessing the community to achieve their goals.”*

They were of the view that the EPs' expertise and local knowledge and the duration of the program allowed time for the identification and resolution of barriers and time to effect behaviour change.

*"It was good to have someone else that I could go, 'This is what they need, can you help?'...I felt they [EPs] were the best person to do that."*

The facilitation by EPs of social support in the community, which included a Facebook group for APAP participant gym attendees, was a major contributor to PA adoption and maintenance in the community. EPs believe that an interprofessional approach contributed to the effectiveness of the program and cited APAP strategies and activities such as 'information sharing', 'value identification' and 'identifying activities of interest' as most effective. EPs were of the opinion that APAP participants coped well with the intervention and applied a positive attitude toward all activities and tasks.

*"No-one said, 'I don't want to do the program.' I didn't have any real issues...I had a few people ask, 'Why do I need to do this?', but then after I explained to them, they were fine. It was just a knowledge thing, they were just interested to know why they were doing that particular strategy. Most were generally pretty enthusiastic or willing to learn as well, but, yeah, I never really had anyone that disagreed or just blatantly came out and said, "No, don't want to do it.'"*

EPs found the outcomes from APAP rewarding with the intervention provided a defining role for them in the service. Similarly, it was reported that the program activities were challenging and draining. One EP felt quality service could not be provided in a part-time role; that this limited between-session activities and after-hours activities in the community. Other EPs noted the difficulties with selecting appropriate measures to show outcomes to decision makers and commented that some APAP participants were disappointed that

participation in APAP showed no improvement in function. EPs felt they still had a lot to learn with regard to Motivational Interviewing skills; that, upon reflection, the activities and sessions could have been delivered more efficiently and competently. A member of the management team suggested that some of the between-session preparation could have been included in face-to-face sessions (e.g. phoning facilities to enquire about equipment).

### **4.2.3. Adoption**

Adoption of APAP at CRnQ is reported primarily through the views of the full CRnQ team, which includes EPs delivering the intervention, members of the clinical team referring to the intervention and the decision makers. The team were asked whether APAP added value to the organisation and whether they were confident the intervention could be part of CRnQ.

CRnQ was a receptive context with regard to the inclusion of APAP to its service. The clinical leader identified a need for a PA intervention and APAP was ready to be tested under 'real-world' conditions. CRnQ showed commitment to APAP by its adoption as a permanent program and its inclusion in program guides and the electronic health record. APAP's value to CRnQ was demonstrated by way of referrals to the program by the team, the program's influence on the way the team practiced and the utilisation of APAP strategies in other programs. The team were confident that APAP could be part of CRnQ, however, changes were required to increase the program's capacity.

APAP was adopted by some members of the clinical team as a transition program; the final step in the CRnQ participant's ICP where they were integrated into the community. Generally, inexperienced staff or those who perceived a lack of time to facilitate CRnQ participant re-entry into the community referred to APAP for the purpose of community integration. These tended to be CRnQ participants who had mentioned PA as part of their goals during the screening process or comprehensive assessment, or whose conditions were complex requiring participation in multiple CRnQ programs.

#### **4.2.3.1. Full CRnQ team views on adoption**

CRnQ team members reported that the workshop between intervention developers and implementers highlighted that the principles of the program aligned with those of CRnQ and were of the view that APAP would add further value to the service. All viewed APAP as completely consistent with CRnQ's principles and well and truly within the organisation's scope of practice.

The clinical team spoke about the influence APAP had on the way they practice with some clinicians utilising APAP strategies in individual sessions with CRnQ participants:



*“...made me think about the way in which I work...adapting to their situations...honing in on those barriers”*

*“I think it would be good if we all got a bit of an update regarding that [Motivational Interviewing] as well ‘cause we all did it as part of uni, but it’s been a long time for some of us.”*

The clinical team were confident that APAP could be a part of CRnQ, however changes were required to enable a better fit. A number of the clinical team had the view that APAP had become embedded in the service with routine referrals, while others believed further integration was required; that the intervention was still seen as a research project and separate to permanent programs.

*“It [APAP] just needs to be in the big pool with everything else....There’s not a natural flow because it’s a bit separate.”*

Some of the clinical team reported that during the research period, there was stability in the organisation with secure funding and the champions of the intervention were in secured positions. Others commented that there was a shortage of physiotherapists and occupational therapists at the time, which resulted in increased demands for the EPs. Some members of the team indicated that, with staff shortages, there was no time to integrate their CRnQ participants into the community.

*“Say someone’s goal is to go shopping, it takes up your whole afternoon because you’ve got to go there, catch the bus there, spend an hour at [the shopping centre], spend half an hour getting the bus back... It just takes time and I think that’s maybe where APAP is really good too ‘cause you seem to have more flexibility and time...”*

*“You’d see people [program participants] who might have been attending [CRnQ] for a really long time and it was hard to see ‘where to from here’...and there’s been a*

*lot of those people that have been involved in APAP and are now out and about doing a lot more than what they used to.”*

*“...we [EPs] generally do get those participants that people are just unsure of how to transition on, so they pop them into the APAP program.”*

The clinical team believed that the recent addition of new members of the team necessitates further education sessions and a name change as the current name did not describe the purpose of the program. They also suggested the allocation of one full-time EP to APAP, although others suggested further integration with other programs and the upskilling and role extension of other members of the clinical team. Also, due to the complexity of the intervention, to date, students have not value-added to the program and EPs do not have a solution to this challenge.

#### **4.2.4. Implementation**

The key findings for the implementation domain are related to intervention fidelity. Firstly, the methods for training EPs and EP students are described including barriers and facilitators to the protocol. Secondly, intervention delivery methods are described as well as barriers and facilitators associated with delivery of APAP in a very different context to UQ; a context that included a more heterogeneous sample of individuals with NMS conditions. Lastly, the EPs and EP students evaluate training and describe their experiences delivering the intervention at CRnQ.

#### **4.2.4.1. Training EPs and EP students**

The majority of the one-hour weekly training/meetings were attended by all EPs. Meeting minutes were completed and distributed to all parties present. Initial sessions involved learning and practising the APAP activities in the protocols and Motivational Interviewing. During the pilot and data collection periods, EPs exchanged experiences, challenges and successes with APAP delivery and advice and assistance was given as needed. Advice was often obtained from the UQ intervention developers during this period by way of phone call from the knowledge broker and was relayed to EPs at the weekly meetings.

Toward the end of the research period, the knowledge broker and part-time EP shared one APAP participant throughout the intervention. Sharing occurred because the APAP participant required two sessions per week and the part-time EP was not available for one of those sessions. This method not only solved challenges faced with delivery of APAP by part-time staff, but it proved highly beneficial to training as both EPs had the same in-depth understanding of the APAP participant's health condition and their challenges with PA participation. Further, the APAP participant chose to participate in an after-hours boot camp in their community and only one EP was available for this activity.

EP students were limited to a two-hour APAP training session with the knowledge broker during the first week of their five-week practicum. Students reported they had not accessed APAP introductory information on the student portal prior to their practicum. Students observed and participated in a limited amount of sessions with APAP participants both at the facility and in the community as most of their time was committed to other CRnQ programs with the full-time EP. They did not have the opportunity to observe an APAP participant complete the entire program.

#### **4.2.4.2. Fidelity**

Two of the three EPs utilised the fidelity checklist resulting in checklist completion for 21 of the 23 APAP participants. With regard to pre-participation risk assessment, two of the three EPs utilised the letter outlining APAP participant intended activities (e.g. frequency, duration, intensity) to the GP. GPs responded promptly with positive recommendations for PA with one requesting the EP attend a community meeting with the APAP participant's care team to discuss falls risk.

The fidelity checklists, together with audits of electronic clinical notes, show that each APAP intervention delivered at CRnQ averaged  $10 \pm 3$  sessions with average intervention duration of  $15 \pm 6$  weeks. APAP, delivered at UQ, provided 10 sessions over a 10-12 week period. Program completion for the current study was determined by successful transition to independent PA in the community. The main reason for extended intervention duration at CRnQ was APAP participant health setbacks (e.g. falls, illness, reactions to medication), paid carer scheduling and training, holidays, botox therapy delivered during the intervention and mental health conditions. As CRnQ offered a free service, sessions resumed once APAP participants were well again, and continued until they were independently physically active in the community. Between-session contacts with APAP participants by way of phone calls, texts and emails averaged four per intervention and ranged from one contact to 10 per intervention.

The fidelity checklist also demonstrated that most of the APAP activities and strategies were utilised among different APAP participants. The information sharing and value card identification activities were utilised for all APAP participants as they were compulsory components of the intervention. Short-term goal setting and social support were employed with the majority of APAP participants. Less than half of APAP participants participated in

the decisional balance, importance and confidence rulers, personal time audits and ‘what worked, what didn’t?’ activities. Other activities that were utilised occasionally were the leisure diagnostic tool, PA monitoring, reward systems and relapse prevention.

Exploration of an individual’s values and personal factors and the delivery of behaviour-change activities are usually accompanied by lengthy clinical notes. An audit of the electronic health record system revealed that, initially, during the pilot period, notes were written in detail by some EPs and then throughout the study period the volume diminished. During weekly meetings, EPs expressed dissatisfaction with the time required to complete notes. The issue was partly resolved by scanning activity sheets into the APAP participant’s health record and referred to in the written note. To further reduce workload, an electronic template for between-session phone calls, texts and emails was created by the knowledge broker and added to the electronic health record system by the administrator.

#### **4.2.4.3. Implementation variations**

All EPs viewed APAP as an essential, but time-consuming intervention. During the implementation period the full-time EP (FTE 1.0) was involved in three other CRnQ programs, the part-time EP (FTE 0.4) was involved in one other CRnQ program and committed to a half day community project, and the knowledge broker (FTE 1.0) focused almost exclusively on APAP. EP students spent the majority of time participating in other CRnQ programs with the full-time EP, resulting in limited exposure to the program. With limited opportunity to deliver the intervention, some APAP activities and strategies were implemented into other PA programs by EPs. Further, as awareness of APAP increased, other members of the clinical team implemented APAP activities and strategies to enhance existing and new CRnQ programs. The new programs aimed at providing additional assistance to CRnQ participants to achieve their goals and to improve health and well-being. APAP

activities and strategies adopted in other programs include information sharing, barrier identification and resolution, decisional balance (pros and cons), short-term goal setting, building self-efficacy, personal time audits and the provision of informational, emotional and appraisal social support. The extent to which APAP activities and strategies were utilised, the quality of delivery and the impact on CRnQ participant outcomes, however, was not measured for other programs. Furthermore, although use of APAP activities and strategies was viewed as a good result for CRnQ participants, there was a risk of duplication for those participating in multiple programs at the service.

Meetings between the knowledge broker and lead clinicians of these programs were conducted to discuss ways to avoid duplication of services with CRnQ participants or the possible distribution of APAP activities to 1) involve professions with expertise in behaviour change; and 2) alleviate the EP workload. As a result of discussions, clinicians were to ensure previous electronic health system records were read prior to APAP sessions; the one participant journal would be utilised in all CRnQ programs, including APAP, and the health and well-being program could potentially act as an introductory program to APAP whereby participants transition from group discussions and facility-based PA to one-to-one sessions in the community.

The final variation to implementation of APAP was for an APAP participant who had experienced stroke resulting in aphasia and apraxia of speech. The APAP participant was diagnosed with schizophrenia, had word finding difficulties, impaired sequencing of information in conversation, difficulty with reading and writing and receptive language difficulties, with the ability to understand simple instructions. The APAP participant had attended multiple programs at CRnQ prior to participation in APAP. Prior to the first sessions, the EP spent considerable time reading clinical notes and spoke extensively with the APAP participant's sister to enquire about the personal and professional history, the

personality and the likes and dislikes of the APAP participant; consent and baseline survey questionnaires were completed by her sister. Initial sessions involved the information sharing and the value card identification activities. These activities were adapted to pictures that related to the APAP participant's life. There was uncertainty as to whether the method of delivery was effective and, at this point, assistance was obtained from an experienced speech pathologist from Edith Cowan University who had previously conducted workshops with the clinical team. Advice obtained was that activities and strategies were too complex for the APAP participant to understand and relate to PA, and that sessions would have to be more intensive (e.g. three times per week rather than once per week). The adapted approach still aligned with the APAP's principles of participant centredness and individual tailoring however, the behaviour-change protocols were modified. Strategies that were utilised were the facilitation of modelling; social support; goal setting; family carers and paid carers assisted with a personal time audit, barrier ID and resolution, building self-efficacy, fostering enjoyment, building self-efficacy and reward systems. The EP designed a PA routine to fit with the APAP participant's lifestyle and the facilitation of community access took place. The spirit of Motivational Interviewing was maintained by utilising visual aids to provide choice and motivation.

#### **4.2.4.4. Interprofessional involvement by the clinical team in APAP**

As demonstrated in section 4.2.4.3, clinical team involvement occurred on a needs basis throughout the intervention for matters that were beyond the scope of EP practice and related to mental health, energy conservation, family mediation, communication impairment, walking balance, gait and accessibility. Different members of the clinical team who contributed to APAP included an occupational therapist, psychologist, physiotherapist, social



worker, dietitian, medical practitioner and speech pathologist. Table 4.5 outlines the reasons for involvement, nature of the sessions and APAP participant outcomes from the sessions. There were 10 APAP participants and 11 interventions with interventions comprising a one-off session to sessions throughout the duration of the APAP intervention. Nine interventions were very specific to the task and were dealt with on an individual level. The other two interventions involved education about diet and energy conservation and involved the APAP participant's family.

#### **4.2.4.5. Rural APAP**

The intervention was successfully delivered to APAP participants who lived rurally through a combination of face-to-face, Skype and telephone sessions. Throughout most of the intervention, rural APAP participants received other CRnQ services concurrently, which required attendance either in one- or two-week intensive blocks or one day per week. All three rural APAP participants had a low level of function and EPs managed to set up support with other health professionals in two rural locations with the third APAP participant choosing independent home-based PA.

**Table 4.5 Interprofessional involvement by the clinical team in APAP**

AP	Professions of clinical team	Reason & nature of clinical team Involvement	Location	Assist with Adoption (A) or Maintenance (M) of PA	Session outcomes
1	Social worker	Family mediation – family indicated frustration and conflict with APAP participant’s lack of motivation & activity in general; face-to-face sessions with APAP participant & family carer	CRnQ	M	Counselling helpful to family carer; insight for both parties into source of frustration
2	Occupational therapist	Repeated injury to arm when walking and bumping into objects; face-to-face session with APAP participant	CRnQ	M	Arm splint fitted
2	Psychologist	Depression/Suicidal ideation; face-to-face sessions with APAP participant	CRnQ	M	Cessation of suicidal ideation
3	Physiotherapist	Access to residential pool for aquatic exercise; face-to-face session with APAP participant & EP in pool at residence	Community residence	M	Identified ways to access pool with assistance from family
4	Physiotherapist	Assistance with transfers after health setback – identified by family; face-to-face sessions with APAP participant at CRnQ & residence to teach APAP participant & family and paid carers technique/safety	CRnQ	M	Re-trained in transfer techniques; able to apply at gym and home with family and paid carers
4	Speech pathologist	Adaptation of APAP for APAP participant with aphasia; advice required for delivery and evaluation of APAP to APAP participant with aphasia	Tele-conference with ECU, Perth	A	Successful delivery of APAP using visual aids, simplification of activities; spirit of MI adapted
5	General practitioner	Falls risk; GP concerned with continued falls & additional PA; allied health meeting in the community to discuss risk reduction during activities	Community medical practice	M	Strategies developed to reduce falls risk in community when physically active
6	Occupational therapist	Energy conservation; face-to-face sessions with APAP participant & family & EP; identify life priorities; allocation of energy to priority tasks	CRnQ	M	Prioritising and conservation of energy to combine ADLs and PA
7	Dietitian	Nutrition education as goal related to weight loss; face-to-face sessions with APAP participant & family carer	CRnQ	M	Learned to read food labels, make better nutritional choices
8	Psychologist	Anxiety with PA & possible reoccurrence of seizure; face-to-face sessions with APAP participant; increasing confidence	CRnQ	A	EP applied graded exposure to PA during intervention
9	Exercise physiologist	Assistance/physical support required for exercises in rural gym; weekly PA sessions post-APAP intervention	Tele-conference to rural community	M	APAP participant attends rural gym with local EP two times per week
10	Physiotherapist	Improve gait to make walking easier; requested by APAP participant; face-to-face session with APAP participant to trial walking with Bioness foot-drop system	CRnQ	M	Bioness foot-drop system unsuitable for APAP participant’s impairment – APAP participant chose to cycle rather than walk

AP = APAP participant; EP = exercise physiologist; HP= health professional; GP=general practitioner; CRnQ= Community Rehab nQ; ECU-Edith Cowan University

#### 4.2.4.6. Full CRnQ team views on implementation

The majority of the full CRnQ team said they had a good understanding of APAP, which was gained through the APAP workshop between stakeholders; regular presentations and attendance at weekly clinical meetings by the knowledge broker, and through their participants' involvement in the program. Alternatively, newer members of the team and those who worked part-time had some uncertainties about where the program fitted in.

EPs were of the view that the individually-tailored nature of the program made it complex to learn and, to gain skills required training and practice. EPs stated that APAP is best learned on the job. Suggestions from EPs to improve training include an overview of the APAP before commencing other parts and video footage demonstrating methods of Motivational Interviewing with people.

*“Learning the APAP program is very difficult ‘cause it’s so different and it changes all the time.... So, I mean, that’s a good thing for the participants because it does have to change ‘cause everyone’s so different.”*

*“...Once we got the protocols with the sample dialogue in them, they were really good to follow and, before a session, you would read through it to refresh your memory ...The protocols were very helpful, they were well done.”*

EPs felt that being involved in the delivery of APAP provided them with useful skills that can be applied to any program and enabled them to be better clinicians.

*“The biggest thing that I found was good, for the program, was to be able to know that, as exercise physiologists, there’s definitely an avenue for us with behaviour change. You know, that’s our speciality as well...so that was probably one of the*

*biggest components is finding that that's something that we can do and really strive in."*

*"I would probably never have had that opportunity to learn the Transtheoretical model...those sorts of things ...so that was a good thing...as well as being able to implement the APAP strategies into my own individual programs or individual sessions was something that was really quite good...I don't know if I would have had those discussions with the participants"*

Fidelity checklists indicated that EPs utilised the majority of the APAP activities and strategies and did not report any deviations from the program elements, except when providing the intervention to an APAP participant with aphasia. EPs stated that they were satisfied with all of the activities and strategies and found certain activities to be essential to developing a rapport and getting to know the APAP participant. They believed the most successful activities were information sharing, value identification and activities of interest. EPs reported that some APAP participants just wanted to get on with PA rather than do behaviour-change activities however witnessed benefits from the activities in future sessions. In some instances, EPs found activities challenging to deliver with, what seemed like, no effect.

*"[APAP], as a whole I think is very important, but if I was to categorise it a little bit more, I would have to say the value cards would be probably the biggest thing that I got out of it. Because once you, sort of build that rapport and relationship with that person, everything else sort of fits into place."*

*"I think one of the challenges is that you do put so much effort in and you see that the participant is still not doing anything... they're all motivated when they leave you and*

*then they go home to that same situation... and I guess you can only do so much. You just want to see them succeed.”*

All EPs said that they require more practice with Motivational Interviewing with one reporting that some methods could be confronting at times for the APAP participants.

*“I think that’s [Motivational Interviewing] something that takes a lot of practice and a lot of time to learn...only now [after the research] I’m starting to gain some idea on how to do it. I think I’ve still got a lot to learn really. Looking back, I think I could have done a lot better with these [APAP] activities, and whether it would have made a difference and got more people physically active, I don’t know.”*

*“I think, too, when you’re trying to establish that cognitive dissonance and put people in that position where, ‘Well you say you want to do this, but you’re not’, it makes me feel uncomfortable that I’m putting them in that position.”*

With regard to delivery, as mentioned in the findings for the reach domain, the delivery of APAP in the community was time consuming compared with facility-based programs. Two of the three EPs found that time, the part-time nature of their position and other service demands, as well as the pressure for occasions of service, were barriers to the delivery of an intervention.

*“I found the biggest barrier was probably time, and that was in relation to having to run other programs as well. So that’s why I tried as much as I could to bring those APAP strategies into the other programs that I run”*

*“I could probably do the APAP strategies by just sitting down with them, going through those strategies, not building a rapport – you’ve still got a little bit of rapport and relationship through doing those particular strategies, but if you started it, it was quite a big project to sort of do with that person, and then other commitments that*

*I've got here at Community Rehab sort of got in the way of really, you know, doing a targeted amount of participants. I really feel that if it's something that can be used here in this service, someone is basically designated to that program."*

*"...seems to be a lot more pressure about occasions of service...and I think we are struggling to demonstrate outcomes...'cause with a program like this [APAP] that does require more preparation time and follow up, that kind of data isn't collected and not reported on...we are only reporting on the time we're spending physically with the participant."*

The EP who mostly delivered APAP reported that these conditions were, indeed, less challenging.

*"I was just full time doing the program throughout the whole week. I could book appointments when I needed to. I could even work around a participant's health condition. If they say, 'Look, I'm way better in the morning; you're not going to get anything out of me if you make an appointment in the afternoon.', I could easily do that. I didn't have to work around a lot of other programs at Community Rehab, so it worked rather well. And I also had time in between to do preparation because there was a lot of between-session preparation required for this program, especially for somebody with a communication impairment who required visual aids and if I needed to consult with the expert, somebody like a speech pathologist, I had the time to make that call as well. So I think that probably wasn't a challenge delivering the program."*

#### **4.2.5. Maintenance**

Maintenance was assessed at the individual and organisational levels. At the individual level, APAP participant results include long-term continuation of changes to PA behaviour. At the organisational level, maintenance was assessed by whether entrenchment of APAP occurred at CRnQ. The full CRnQ team gave recommendations on whether the intervention should continue at CRnQ and strategies for long-term continuation.

#### **4.2.5.1. Individual level**

Twelve APAP participants continued PA at three-month follow-up. Of the 12 who continued PA, nine relied on social support (instrumental, emotional and appraisal), and three were self-motivated.

Eight APAP participants discontinued PA. Of those, two were diagnosed with cancer; one was hospitalised with a health setback; one experienced a marriage breakdown, moved to another town and asked for a referral to a similar service in that town; the two APAP participants who underwent botox therapy during APAP did not experience improvements in function and lost motivation to do any activity; one APAP participant had a newly acquired SCI and was experiencing multiple life adjustments including job loss, and the final APAP participant required social support to be physically active, but lived out of town and had no transport. This person reported, during the three-month follow-up interview, that, with recently acquired transport assistance from a care agency, plans were in progress to commence aquatic exercises (obtained from the CRnQ aquatic program) at the local public swimming pool.

#### **4.2.5.2. Organisational level**

APAP was considered to be a permanent program at CRnQ in that it was added to the electronic health record system, a program manual was prepared, it was included in the yearly program schedule and promoted in the same way as all other CRnQ programs. After the study period, APAP participant numbers reduced from approximately 20 to five. The reasons for this reduction are outlined below.



Firstly, the planned mid-way assessment did not occur. The implementation midpoint was October/November, which was when the intervention reached a peak number of APAP participants. As time was limited, a decision was made by the knowledge broker to continue monitoring progress through regular meetings with EPs and to address barriers as they arose. A key barrier identified through this process was the EPs' limited opportunity to deliver the APAP intervention. Meetings were held between the Clinical Leader and EPs to understand the role of the EPs at CRnQ. A document was drafted that outlined the EP scope of service and mission at CRnQ (Appendix 17). Additionally, a diagram was created that illustrated where the programs delivered by EPs were positioned in relation to the ICF areas of functioning (Appendix 18) (World Health Organization, 2001). The programs that EPs led or were involved in at CRnQ extended across all three areas of function: body functions and structure, activities and participation. The intention of these meetings was to determine whether EPs could devote more time delivering programs like APAP that focus on PA participation in the community. As the organisation continued to evolve with the emergence of further CRnQ programs that required input from EPs, and there was a shortage of physiotherapists at the service, negotiations were unsuccessful.

Secondly, the knowledge broker returned to a part-time position (FTE 0.2), acquired study leave and a new lead clinician for APAP was not appointed. Without a lead clinician, there was no-one to advocate, update or educate the team and students. Some members of the full CRnQ team were of the impression that APAP was the knowledge broker's research project rather than a permanent, continuing CRnQ program. In addition, high staff turnover was experienced post-study period, therefore, new clinicians had limited knowledge of the APAP intervention.

#### 4.2.5.3. Full CRnQ team views

The entire team perceived APAP as a valuable program with useful tools for CRnQ participants, an important part of the service and agreed it should continue as part of the permanent programs at CRnQ.

*“I think it’s a very valuable program. I see it as a really important part of the whole service that we offer. And it is really important because people do need that help.”*

The CRnQ team acknowledged that implementation of APAP occurred at a time when the service was continuously changing and evolving; there was a high turnover of clinical team members and service priorities and funding changes were occurring.

*“Just in terms of, the transition of staff, ‘cause we have had a huge transition of staff, that there’s probably been a drop-off in putting people into that program purely because they’re just getting their head around the service and it’s just difficult for them to grasp all of that. But I think most people have been here for at least a month now, so I think, it’s now a better time for them to be influenced again.”*

*“But if there were staff changes we’d just have to make sure that that was reinforced, so make sure it doesn’t slip away ‘cause it is a really good program and there’s some great concepts behind it, so we just don’t want them to miss any of that.”*

*“...the resource intensity of the program and the pressures that are on us now with the changes in the funding and what’s going to be happening in the future. A program like that [APAP] would be under threat because you’re not producing the intent of these outputs.”*

While some of the clinical team believed there was a good understanding of APAP within the team and that the program was still considered at clinical meetings, several suggest that

APAP is thought of as the knowledge broker's research program and requires further integration to be entrenched. Suggestions by the clinical team included the appointment of a lead clinician, capping the amount of APAP participants entering the program and finding a more structured referral pathway to APAP (e.g. running concurrently with and/or as a continuation from the balance and mobility program). Members of the clinical team felt that the current EPs possess the skills to have APAP continue and suggested that the entire team be upskilled in Motivational Interviewing.

With funding uncertainties and a change in service priorities and withdrawal of the intervention champions, some of the senior clinical team members were of the opinion that continuation of APAP will be dependent upon support from decision makers.

*“It [continuation of APAP] has to come from the organisation. It can't just be from the staff. I think it has to be a commitment from the organisation. So I think there has to be support from clinical lead to be able to do that, and I think there is already acceptance of the staff who had that knowledge of it from last year. Like, new staff won't, but I think there has to be support from higher than that. I think we have to probably bring it back into the forefront, know what we're offering with APAP and what's our capacity and talk a bit more about it than we currently are.”*

In order to secure permanent adoption at CRnQ, decision makers requested concrete measures to show outcomes (e.g. good outcomes for program participants). It was also suggested that APAP's strategies could be an approach applied in all programs rather than creating further programs (e.g. behaviour-change, motivational strategies, barrier identification and resolution).

*“We ramped up the Goal, Plan, Go stuff so that it was an actual program, where I was saying that this should actually be integrated across the lot [all programs]*

*anyway rather than people coming in for another group...it needs to be part of everything we do. Well, is APAP the same sort of thing?"*

# Chapter 5

## Discussion

### Introduction

The aim of this project was to translate APAP from UQ, a metropolitan educational setting, to CRnQ, a regional community rehabilitation setting. Translation of APAP from UQ to CRnQ was achieved through three phases with the following objectives: Explore the perspective of individuals with NMS conditions on PA participation; development of a protocol for implementation and evaluation; and finally, implementation and evaluation of the translation of APAP to CRnQ. This project has highlighted that factors that influence PA participation for individuals with NMS conditions are complex and require complex solutions. APAP was chosen as a suitable intervention for translation on the basis that it is an efficacious multifaceted PA lifestyle intervention designed to address these complex factors. It is acknowledged that APAP is effective for increasing the adoption and maintenance of PA in the regional community rehabilitation setting of CRnQ. Yet, according to the views of the CRnQ clinical team, for it to be practicable and feasible in the context of CRnQ, adaptation of the intervention is required. In this chapter, outcomes of these objectives, and strengths and weaknesses associated with translation strategies will be discussed and compared with the literature. Elaboration of key points that emerge from the project will generate implications and offer directions for future APAP applications in community rehabilitation settings.

## **5.1. The perspective of individuals with NMS conditions on factors that influence PA participation**

Exploration of the factors that influence PA participation for individuals with NMS conditions was an important first step to the implementation of APAP at CRnQ. From the perspective of individuals who have a NMS condition, participation in PA is challenging due to various functional, environmental and personal factors. Investigation of these factors in Studies 1 and 2 determined that even though they are common universally, they present uniquely to each individual according to their environment and their personal beliefs and attitudes. Consequently, PA interventions need to be participant-centred and individually tailored. An intervention that is participant-centred evolves around the participant and involves them in all decision-making processes (Van de Velde, Devisch, & De Vriendt, 2016). Based on a participant-centred model of service delivery, PA is individually tailored to the participant's needs, values, preferences and expectations (Ponte, 2003). Person-centred, individually-tailored PA interventions for individuals with complex health conditions require input from EPs and from other health professionals as psycho-social issues that arise often go beyond the EP's scope of expertise (Newitt et al., 2016). The perspective gained from individuals with NMS conditions during the Phase 1 exploratory phase informed Phase 2, planning for implementation and evaluation of APAP into CRnQ.

## **5.2. Planning for Implementation and Evaluation of APAP at CRnQ**

Translation occurred at a time when both APAP and CRnQ were evolving. APAP had been developed and evaluated in a CCT, however a structured APAP package ready for translation was yet to be developed. CRnQ's standard procedures and processes were still emerging as

part of service development and continual service improvement. Implementation of APAP at CRnQ was part of that development as it provided an opportunity to enhance the service by offering its participants a PA lifestyle intervention program to improve their health. Implementation of APAP at CRnQ also offered intervention developers from UQ an opportunity to assess APAP in a community-based rehabilitation context and assess its impact with a more heterogeneous population than previously investigated. This study has demonstrated that the integration of research and community health professionals has the ability to expedite translation of evidence-based principles within typical practice (Harden, Johnson, Almeida, & Estabrooks, 2017). The integrated approach adopted to develop the APAP intervention throughout this project meant that evidence from both the research and practice environments were considered to determine effectiveness for behaviour change and the fit of APAP within CRnQ.

Results from the exploratory phase indicated that PA interventions for individuals with NMS conditions must be participant centred and individually tailored to address the complex interacting factors that influence PA participation. Additionally, an interprofessional approach may be required to address psychosocial issues that go beyond the scope of an EP. Results from the planning phase established that APAP was a complex intervention. The UQ intervention developers had indeed designed a person-centred, individually-tailored intervention that addressed the factors that influence PA participation for people with NMS conditions outlined in the exploratory phase. During planning, it was also established that CRnQ's context was complex. Health services, like CRnQ, have had to become increasingly complex to address complex public health issues such as chronic disease (Brownson et al., 2012). Consequently, complex systems were involved in this study. A system can be described as a set of elements that interact dynamically on multi-levels with multi-actors to make a complex whole (Cilliers, 1998). Systems can be categorised as simple, complicated or

complex (Westley, 2007). Whilst simple and complicated systems can be understood by being disassembled and analysed, a complex system is unpredictable, cannot be reduced, and to understand it is to study how it operates (Finegood, 2011). The RE-AIM framework was chosen to guide implementation and evaluation because of its multilevel multidimensional components.

Planning checklists included as part of RE-AIM assisted with strategic planning for implementation and evaluation as they highlighted potential barriers and facilitators for consideration for each of the five domains. Intervention implementers adapted RE-AIM's adoption domain to the individual level and the implementation domain specifically to CRnQ's organisation. The RE-AIM framework was adopted in another study that implemented a multi-faceted intervention comprising behaviour-change components into a health setting (Damschroder, Moin, et al., 2015). In addition to RE-AIM, the authors were guided by The Consolidated Framework for Implementation Research (CFIR) (Damschroder et al., 2009) to systematically assess contextual factors that influence adoption and implementation. Frameworks like CFIR and the Promoting Action on Research Implementation in Health Services (PARIHS) framework (Kitson et al., 2008; Stetler, Damschroder, Helfrich, & Hagedorn, 2011) have acknowledged that the transfer of knowledge from evidence to practice is not a linear set of steps moving information from one source to another (Brownson et al., 2012). Accordingly, the frameworks contain domains that influence implementation. The CFIR's domains, for example, include characteristics of the intervention and individuals who deliver the intervention; the outer and inner setting and the implementation process itself. Each domain consists of constructs including the adaptability of an intervention (intervention characteristics domain); the extent to which a program participant's needs are known and prioritised by an organisation (outer setting domain); an organisation's culture (inner setting domain); the individual implementer's attitude towards



and value placed on the intervention (characteristics of individuals domain), and intervention champions within an organisation (process domain). CFIR's menu of domains and constructs can be individually tailored to each implementation project and, as demonstrated in Damschroder's (2015) study, can be integrated with RE-AIM to tackle the theoretical and methodological challenges associated with translations such as that of APAP from UQ to CRnQ. Nevertheless, RE-AIM was selected as a guide for implementation and evaluation of APAP at CRnQ and the mixed-method evaluation provided intervention developers and intervention implementers with results and feedback that will contribute to future APAP implementation strategies, which will be discussed in the evaluation findings.

### **5.3. Evaluation of APAP at CRnQ: Implementation findings**

Strategies included in the protocol were designed to recruit all individuals with NMS conditions at CRnQ who were physically inactive; to persuade the clinical team that APAP was essential for participants with NMS conditions and added value to their organisation; to assess whether APAP could be delivered with fidelity to its core components at CRnQ; and lastly, to embed the intervention at CRnQ. Evaluation of the RE-AIM strategies revealed that the target audience was represented, completion rates were high, but recruitment was lower than anticipated. Overall, APAP influenced the way the clinical team practised and all agreed that it was a valuable part of the service. All APAP participants adopted PA with some maintaining their activity and the 12 out of 20 who were interviewed were satisfied with the intervention. The intervention was delivered with fidelity to its original form; as well as with fidelity to the function of its core components; and as a value-add approach to other CRnQ programs. The EPs reported that the program was best learned on-the-job and delivery in its original form was time intensive. APAP was included as a permanent program at CRnQ, but

further integration strategies were required for entrenchment at CRnQ. These points will be discussed in more detail under each of the RE-AIM domains below.

### **5.3.1. Reach and adoption**

Recognition of the intervention's value at CRnQ occurred as a result of reach and adoption strategies led by the intervention champion. The champion drove the project as knowledge broker, researcher and as one of the EPs who delivered the intervention. The champion had strong internal relationships with the team and had the opportunity to establish good communication; two aspects that are fundamental to change (Khan, 2006). The clinical team at CRnQ though were accustomed to change as, at the time of implementation, the service continued to evolve with the addition of several new programs. Integration of other programs occurred as per standard procedures that included the appointment of a lead clinician, referrals to the program and capped participation numbers, however these other programs were not evaluated to the same extent as APAP. Similar procedures were applied to the integration of APAP, however, with an increase in participation by the knowledge broker, the implementation's relationship to a PhD project, and extra time and effort applied to internal promotion, some of the CRnQ team viewed APAP as the knowledge broker's research project rather than a standard program offered. Hence, when the knowledge broker withdrew, participation in APAP declined.

An increase in the knowledge broker's hours was one strategy applied that presented both advantages and disadvantages. Two key advantages emerged from this strategy. Firstly, as intended, it increased delivery capacity and ensured adequate numbers to assess the program's impact on participant outcomes. Secondly, it enabled the knowledge broker to gain an in-depth understanding of the challenges associated with delivery of APAP to participants with complex needs whilst adhering to CRnQ's standard procedures. These advantages

contributed greatly to the aims and objectives of this study which were to assess the intervention's impact on a more heterogeneous sample; determine potential barriers and facilitators to 'real-world' implementation of APAP; highlight problems associated with delivery of APAP and how they translate, or not, to real-world implementation; and determine potential intervention modifications required to maximise implementation (Curran et al., 2012). Engagement of key individuals who are dedicated to the implementation task and who have elements in common with other key individuals (e.g. same role as the EPs) is said to be a vital to implementation success (Edmondson, Bohmer, & Pisano, 2001). Future APAP implementations will be better informed by the knowledge broker's in-depth understanding of delivery challenges.

In contrast, the knowledge broker's increased involvement was disadvantageous in that, had it not occurred, more effort may have been invested in finding ways to implement APAP utilising CRnQ's existing resources. Whilst the commitment of resources does not guarantee successful implementation, it has a positive association (Rabin et al., 2008). In effect, having the knowledge broker deliver APAP almost full time replicated delivery in the original context, which was vastly different to the context at CRnQ where EPs are faced with other service demands. The person-centred design of APAP equates to lengthy delivery, and resources will have to be a key consideration with future APAP applications.

Throughout the planning process, it was highlighted that CRnQ was a receptive context and that the setting provided optimal penetration to APAP's target audience. Adoption methods by the clinical team indicated that strategies applied by the knowledge broker were not completely successful as all did not view PA as essential to the CRnQ participant's needs. Even though attendance at a primary healthcare setting is an opportune time for the promotion of PA as part of routine healthcare, most clinicians do not do so (Glasgow, Eakin,

Fisher, Bacak, & Brownson, 2001). The majority of participants registered with CRnQ attended the service with a goal to gain improvements in function. Allocation to rehabilitation programs was, therefore, the priority. As a result, participation in PA occurred in facility-based fitness sessions to enhance rehabilitation or, depending on their goals, they graduated to aquatic PA in groups or walking groups in the community post-rehabilitation with some achieving independent PA in the community. As the team began to see successful integration into the community, graduation to APAP occurred sooner in the CRnQ participant's ICP.

### **5.3.2. Implementation**

As per the RE-AIM implementation element, strategies focused on intervention fidelity and the associated training of EPs and EP students to achieve intervention fidelity. Scheduled training with EPs went to plan and EPs progressively gained and improved skills throughout delivery of the program. Scheduled training with EP students was brief and inadequate. Time limitations and involvement in other CRnQ programs meant that students were not able to learn APAP's complex components during their practicum period. EPs reported that APAP was delivered with fidelity; however, some were unsure how effectively they delivered behaviour-change activities and strategies. The fidelity checklist designed by the knowledge broker provided information about the APAP components utilised in the study and the number and nature of sessions and between-session activity required for APAP participants. It did not distinguish delivery competency and quality, which components worked and why, and, subsequently, which factors contributed to low program capacity. Evaluation of complex interventions in a real-world setting involves assessing a whole range of effects, for example, its practical effectiveness, variation of effects among recipients, the causes of variation, and determination of the active ingredients (Craig, 2006). The ASPIRE Coaching Fidelity Checklist (ACFC) is a practical and valid fidelity assessment tool that was designed to

measure complex behavioural weight management programs (Damschroder, Goodrich, et al., 2015). The checklist assesses adherence to session structure, namely, whether actions prescribed by the intervention are covered; and adherence to session process, namely, how well the actions are delivered. Examples of subscales for session structure include: 1) set goals and monitor progress; and 2) assess and personalise self-regulatory content. There are three subscales for session process, which include: 1) manage the session; 2) creates a supportive and empathetic climate; and 3) stays on track. Together, the subscales contain 26 assessment items that are rated 0 = did not cover; 1 = partially covered/demonstrated; and 2 = fully covered/demonstrated. The ACFC is an evaluation tool that would assist in understanding APAP's causal mechanisms, which will then lead to intervention refinement and the establishment of structured training for both EPs and EP students. The ACFC is freely available and, with adaptation to suit the components of APAP, would be a logical next step to assess fidelity of the intervention.

The RE-AIM evaluation conducted in the current study provided researchers with preliminary insight and potential solutions to implementation barriers encountered at CRnQ. Feedback obtained during evaluation was primarily related to APAP in its original form and referred to its complex and time-consuming nature and the subsequent effect on program capacity (e.g. low recruitment rates, low numbers of occasions of service and Motivational Interviewing strategies). Potential solutions were also recommended by the CRnQ team to address these perceived barriers to implementation of APAP, but firstly, possible contributors to those barriers will be discussed.

It was established during planning that both CRnQ and APAP adopt the same bio-psycho-social paradigm and that their person-centred principles align. To promote PA adoption and maintenance, Step 1 of APAP comprises a comprehensive assessment, based on domains of

the ICF (World Health Organization, 2001), that aims to obtain information that is relevant to the development of the intervention. It includes identifying participant activities of interest, home and community facilities, disposable income, levels of independence and support, activity or mobility limitations and other time commitments. The person's bodily functions and structures and activity limitations are considered; however, APAP's emphasis is on participation in PA. Step 2 of APAP comprises a menu of individually-tailored staged-matched behaviour-change activities that provide the EP with strategies to explore, in an informal way, what is meaningful to the person, their perspective on PA, and gather personal information relevant to PA participation. Through sessions conducted at both the facility and in the person's surroundings, the EP establishes trust and rapport, and is able to gain a more valid image of the person; information that is essential to goal setting (Van de Velde et al., 2016). This person-centred practice adopted in APAP ensures that the EP becomes the APAP participant's partner with regard to psycho-social issues rather than adopting a medical-model approach to exercise prescription (Robinson, Brown, & O'Brien, 2016). The basis of person-centred care is the development of mutually beneficial partnerships between the health professional, the participant and their family. It has been demonstrated in rehabilitation settings that although clinicians acknowledge the value of person-centredness, few incorporate all elements into their daily clinical practice citing time restrictions and cost-related matters (Robinson et al., 2016; Van de Velde et al., 2016). This is consistent with some CRnQ clinical team members who report time and the pressure to achieve occasions of service as barriers to providing all elements involved in person-centred care, for example, participant integration into the community.

Reports from the clinical team may be warranted as, at a time of straitened resources in healthcare, there is a call for streamlined services (Lamont et al., 2016). For this reason, the proposal by EPs that one EP be designated to deliver the intervention full time, similar to the

knowledge broker's circumstances during the data collection period and consistent with delivery of APAP at UQ, may be unrealistic. In effect, proposed models of service delivery are contrary to this suggestion (Nancarrow, Moran, Wiseman, Pighills, & Murphy, 2012; R. Smith & Duffy, 2010). In a similar community rehabilitation setting, role extension through transprofessional practices achieved increases in occasions of service and decreases in the cost per occasion of service (Patterson, 2015). This was achieved by moving service locations from a predominantly home-based setting to a centre-based setting. APAP's person-centred individually-tailored design was in response to common barriers experienced by people with NMS conditions (e.g. accessibility, costs, transport), and these barriers were confirmed in the two studies conducted in phase 1 of the program translation. Delivery of sessions in the environment that PA would ultimately be adopted and maintained addresses barriers and would likely increase the success of the intervention, reduce the participant's potential to relapse and, thereby, reduce future service provision (Tweedy, 2007). One of the limitations recorded in the Patterson et al. (2015) study was that the aims were narrow in focus and did not explore client satisfaction or functional outcomes. These are benefits that outweigh increases in costs and enhance the quality, validity, relevance, cultural competence and accountability of health research (Woolf, 2015). Economic evaluations in health care are often performed from the health system perspective rather than the wider societal perspective (Drummond, 2005). In order to promote sustainability and provide recommendations regarding the use of behavioural interventions, it has been suggested that researchers conduct a budget impact analysis that, not only assesses changes in costs and revenues for organisations over the short term, but also the monetary value of the intervention to the participants (Brown, Cameron, & Ramondt, 2015). As it has been difficult to determine adequate physical outcome measures for the APAP intervention, this type of analysis may provide a solution to determining the effectiveness of future APAP implementations.

A further possible contributor to the APAP time and complexity implementation barriers is the utilisation of ICPs at CRnQ, namely, structured multidisciplinary care plans that detail essential steps in the care of participants with NMS conditions (Campbell et al., 1998). Each CRnQ participant had a case coordinator who booked programs, session times and locations, transport and organised any interprofessional involvement in advance over a period of five weeks. APAP's individually-tailored, person-centred design, as well as its focus on PA behaviour change, for individuals with complex conditions and complex needs make it difficult to plan session times, locations and interprofessional involvement over the 10-week intervention duration. ICPs are said to be less effective at producing quality service and efficiency gains when participant trajectories are variable (Allen, Gillen, & Rixson, 2009). It is unclear whether barriers can be attributed to challenges associated with delivery of the intervention amongst other CRnQ programs with ICPs, or the fact that APAP does not fit with an ICP. Either way, when an intervention is deemed a poor fit for the organisation, resistance may be encountered by members of the team who are involved in the intervention (Damschroder et al., 2009). In the current study, rather than resist the intervention, EPs adapted delivery of APAP. Firstly, one EP who had limited opportunity to deliver APAP in its original form utilised some of the activities and strategies in other PA programs, but in 12 cases referred CRnQ participants to other EPs in APAP for community integration. Three clinical team members adopted some of the intervention components in existing CRnQ programs or were influenced to create new programs to assist program participants to achieve their goals, whilst others, mostly inexperienced members of the clinical team, referred participants from other CRnQ programs to APAP for the purpose of community integration. These different methods of implementation highlight the alignment of both the APAP and the CRnQ principles and that the intervention's individually-tailored combination of stage-matched behaviour change activities are highly adaptable and can be adopted by members of



the clinical team to enhance those principles. Consequently, it provides merit to the suggestion by a member of the CRnQ management team that rather than implement APAP as a separate intervention at CRnQ, its menu of strategies and activities be implemented as a value-add approach to existing CRnQ programs.

The final potential contributor to time and complexity barriers for EPs is their inexperience with delivery of the intervention. Effective Motivational Interviewing skills enhance delivery of activities and strategies in APAP. Optimal strategies for teaching and supervising Motivational Interviewing are yet to be established (W. R. Miller & Moyers, 2006). Not only does it take a considerable amount of time and effort to effectively learn and apply Motivational Interviewing skills, but clinicians must adopt a new frame of mind which involves collaboration with the APAP participant's own expertise (Söderlund, Nilsen, & Kristensson, 2008). Feedback from EPs that APAP is best learned on the job is consistent with new learning approaches that focus on gaining Motivational Interviewing proficiency over a year with one's clients following the provision of a two-day workshop that emphasises the underlying assumptions and spirit of Motivational Interviewing (W. R. Miller & Moyers, 2006). The one instance in the current study where two EPs shared delivery to one APAP participant proved an effective way of learning as this enabled the collaboration of ideas and advice on an individual who was familiar to both. Individual clinician performance feedback was also recommended to enhance learning (W.R. Miller, Yahne, Moyers, Martinez, & Pirritano, 2004). Furthermore, as APAP was still evolving at the time of implementation, a formal structured training course for the intervention had not been developed. Application of the ACFC (Damschroder, Goodrich, et al., 2015) during future implementation of APAP will provide guidance to the development of such a course.

Potential solutions offered by the clinical team to the barriers identified above were to acquire the expertise of the social worker or psychologist for Motivational Interviewing and

behaviour-change components and/or deliver components of APAP in groups. Studies evaluating health promotion programs for people with disabilities, including those with NMS conditions, comprising both group and interprofessional components have been conducted (Block et al., 2010; Horner-Johnson et al., 2011). Methods of delivery included full-day intensive sessions comprising seminars and recreational activities as a one off or two times per month over a period of five months. Additional social support included case coordination and follow-up peer counselling and group support sessions. Outcome measures chosen were self-efficacy questionnaires and healthy behaviour questionnaires.

There are similarities between the two health promotion programs outlined above and APAP whereby the aims are to empower individuals with disabilities by teaching skills and providing tools and strategies to perform independent activities in the community. The current study's focus was independence in the community to achieve PA goals, while the other studies' focus were independence in the community to achieve life goals, for example, employment, education, health responsibilities, and healthy behaviours such as nutrition, stress management and PA. All studies demonstrated initial increases in measures, including PA, with decreases at follow up. A key difference between APAP and these studies was time spent with participants. For APAP, on average, EPs provided 20 hours of one-on-one service per person plus one-on-one interprofessional services. Block's (2010) study provided six hours of group service per person plus an unknown number of individual sessions with staff from the centre for independent living. In Horner-Johnson's (2011) study, group services provided amounted to eight hours per person. Another difference was APAP's inclusion of individuals with NMS conditions with low levels of function and severe communication impairment. Functional levels of participants in the comparative studies were not explicitly stated. Most experienced mobility impairment and required the use of mobility aids, but individuals with severe communication and cognitive impairment were excluded. Physical

activity precontemplators and contemplators were also referred to APAP whereas, due to the nature of the other studies and the recruitment process, individuals volunteered to participate in the health promotion programs, which would typically mean they were in the preparation phase for lifestyle change.

Behaviour-change strategies such as information sharing, value identification, building self-efficacy, modelling, barrier identification and resolution, social support and goal setting were delivered in group sessions in the comparative studies. All of these strategies are included in Item 3, Step 2a of APAP's TIDier checklist (Appendix 2); however, they are delivered to the APAP participant according to their stage of motivational readiness (e.g. precontemplation, action). Goal setting, for example, would not be an activity delivered to an individual who is at the PA precontemplation phase. Delivery of these behaviour-change strategies in groups in the comparative studies may account for the high number of participant dropouts. In one case dropouts (n=90) occurred immediately post-orientation session and during and post-workshop (Horner-Johnson et al., 2011), and the self-selected comparison group participants (n=9) in the other study chose not to participate in the intervention (Block et al., 2010).

Consideration should be given to some group activities in APAP as group discussions are believed to create a more natural setting where people will be likely to interact as they do in their everyday lives with sensitive issues more readily discussed (Green, 2009). The decisional balance activity (B.H. Marcus et al., 1992) is included as part of APAP's strategies and would be an ideal group activity. As part of this activity, participants list pros and cons to being physically active. Individuals may hear advantages to being physically active from their peers that they never would have considered. Cons of PA participation outlined by the group can lead to the identification of barriers to PA and the group can offer/share solutions. Group sessions may provide the opportunity to establish a shared identity and social support between CRnQ participants (Ravenek & Schneider, 2009).

Social support is a strong mediator of PA motivation amongst the general population and individuals with disabilities (Damush et al., 2007; Marcus & Forsyth, 2003; Rimmer et al., 2004). The potential establishment of social support gained through group sessions satisfies a PA participation need identified by individuals with NMS conditions at CRnQ during the focus groups and interviews in phase 1 of the project. The aim, however, is to establish social support in the community rather than at the service. Figure 4.1 demonstrates that 15 of the 23 APAP participants had participated in multiple CRnQ programs prior to APAP. In some cases, participation in multiple CRnQ programs was necessary due to the complex nature of their condition. Others continued to be referred between CRnQ programs for periods of one to two years by the clinical team because the time was not taken to integrate them into the community and they became reliant on the social support provided by the clinical team. In the current study, social support was established via a local gym group and a Facebook group, and this group of APAP participants maintained their PA at three-month follow-up.

Factors that must also be accounted for are that group programs have to be facility based, which does not provide a truly enabling environment for people with NMS conditions who cite transport and cost as barriers to PA participation (Rimmer, 2002). Further, individuals with lower levels of function or complex psychosocial issues require increased support to participate in PA (Rimmer, 2002). High levels of support can be difficult in a group setting where there are various levels of function (Driver, Irwin, Woolsey, & Pawlowski, 2012). Particular instances of clinical team interprofessional involvement in APAP during the data collection period (Table 4.4) demonstrated this need for individual support.

The first instance was when an APAP participant experienced anxiety with the commencement of PA believing that participation would result in the occurrence of another

seizure or stroke. The APAP participant attended sessions with the psychologist throughout the duration of APAP. Graded exposure to PA was advised by the psychologist as well as one-to-one counselling sessions to work through the anxiety. The participant had ceased PA post-intervention, but had overcome anxiety with PA, and at three-month follow up, reported plans to attend aquatic exercise with carer agency transport assistance.

In the second instance, interprofessional intervention occurred for an APAP participant with communication impairment. The EP obtained assistance from the speech pathologist regularly throughout the APAP intervention via phone and email. Advice was that the intervention's activities in their original form were too complex for the APAP participant with aphasia to understand and that the frequency of sessions should be more intense. APAP protocols were not strictly followed, however the intervention's principles of participant centredness and individual tailoring were still applied through the use of visual aids (e.g. photos relevant to the participant, drawings), discussion with family carers and paid carers, modified exercise prescription in the community and the facilitation of instrumental, informational, emotional and appraisal social support (Marcus & Forsyth, 2003). In effect, the aphasic APAP participant was the central point around which the intervention evolved, where PA was tailored to their needs, values, preferences and expectations, but participant involvement in goal-setting occurred to a lesser extent. Duration of the APAP intervention was longer for this participant due to health setbacks, carer scheduling and time taken to prepare visual aids, but regular PA continued through to three-month follow up.

This particular APAP intervention demonstrated that adoption and maintenance of PA for individuals with NMS conditions could be achieved with fidelity to the principles of APAP whilst varying the intervention's form. Furthermore, it demonstrated that interprofessional input can be managed in a practical, efficient way. Advice was exchanged between the CRnQ

EPs and non-local health professional via telephone and email. This advice was then applied to delivery of the intervention by the EP independently. This has implications for the EP in a rural and remote context who can be isolated from other health professionals and supports the allied health generalist role which is being utilised as a strategy for retention of the rural allied health professional workforce (Keane, Lincoln, Rolfe, & Smith, 2013). Currently, as PA facilities and services are limited in rural and remote settings, individuals experience poorer health in comparison to their metropolitan counterparts (Boehm et al., 2013).

Further instances of individual interprofessional involvement in APAP were with regard to the maintenance of PA and involved assistance with accessibility to a residential pool, assistance in a rural gym and counselling for depression and suicidal ideation. These examples show that elements of APAP do require one-to-one service by health professionals. Considering all factors, these comparative studies demonstrate that interprofessional and delivery of at least some components of the intervention to participants in groups is a potential solution to increasing APAP's recruitment rates and occasions of service.

### **5.3.3. Effectiveness**

At the individual level, multiple methods were chosen to assess effectiveness in this study due to the multifaceted nature of APAP, the varying range of health conditions and levels of function of participants and elements suggested by the RE-AIM framework. In effect, this included the amount, the regularity and the effects of PA, as well as participant satisfaction with APAP and any unanticipated outcomes. Additionally, as there was a behaviour-change component in APAP, social support and the perceived disadvantages and advantages of PA were measured. Although the PA SOC questionnaire indicates that eight of the 23 APAP participants adopted PA and seven increased their PA throughout the course of the

intervention, PASIPD total scores did not demonstrate any significant increases in PA and did not reflect the PA progress made with individuals in the current study. A key contributor to the low PASIPD scores obtained by APAP participants is that just over half did not participate in eight of the 13 items included in the scale. This is consistent with another study that evaluated the PASIPD with individuals with SCI where more than 70% never performed heavy housework, lawn work and paid work (De Groot, Van Der Woude, Niezen, Smit, & Post, 2010). Reversion of PASIPD scores at three-month follow-up may be attributed to the added burden on carers and subsequently, loss of PA social support. Obtaining effectiveness measures that are valid, reliable, accurate and practical for a population with complex and disabling health conditions is problematic (Warms, 2006). The behaviour-change component and multiple PA characteristics (e.g. incidental, recreational) in APAP add another layer of complexity to the measurement problem. A similar multifaceted behavioural-change program was conducted with individuals with PD during a randomized controlled trial (Van Nimwegen et al., 2013). The primary measure was the LAPAQ (Stel et al., 2004), and secondary measures included an activity diary, accelerometer, quality of life (QOL) questionnaire and 6MWT. Results indicated that the program did not promote overall physical activities as measured with the LAPAQ, however the activity diary and accelerometer showed increases in PA and the 6MWT showed increased fitness. The authors acknowledged the difficulties with measurement of a multifaceted behavioural-change program and recommended further research focus on developing comprehensive, valid and reliable instruments to accurately measure all aspects of PA behaviour.

With regard to the regularity of PA, or habitual activity, the PA SOC questionnaire results indicated that some members of this APAP cohort progressed from Stages 1 and 2 to Stage 3, but remained in Stage 3 as they did not have the capacity to meet the PA national guidelines of 30 minutes of moderate intensity PA near daily (Department of Health and Aged Care,

2005). For the general population, evidence is unequivocal that when individuals meet these guidelines health benefits will be achieved (Lee et al., 2012). For populations with disabilities, the association between PA and health benefits is still unclear (Fernhall, Heffernan, Jae, & Hedrick, 2008). Reviews investigating the effects of PA on NMS conditions including stroke (Saunders et al., 2016), SCI (Fernhall et al., 2008), TBI (Hassett, Moseley, Tate, & Harmer, 2008), peripheral neuropathy (White, Pritchard, & Turner-Stokes, 2004), MS (Garrett & Coote, 2009) and down syndrome (Andriolo, El Dib, Ramos, Atallah, & da Silva, 2010) indicated that further trials were needed to determine optimal exercise prescription for individuals with different impairments. Further, the majority of these reviews reported that data could not be pooled due to the heterogeneity of diagnostic groups and the diverse outcome measures. Until guidelines for optimal exercise prescription are developed for individuals with NMS conditions, a stage of exercise behaviour questionnaire suitable for this population cannot be developed.

From the participants' perspective, 12 of the 20 APAP participants who agreed to be interviewed reported high levels of satisfaction with the program. Person-centred approaches in rehabilitation settings, which include shared decision making about the intervention, close collaboration in problem solving and empowerment of the participant typically report high levels of program satisfaction (Cohen, 2007; Guidetti, 2011). A similar person-centred approach was adopted with individuals with MS and, again, process outcomes such as treatment satisfaction and interaction between the participant and the health professional were greater than the non-person-centred approach (Eyssen, Dekker, & de Groot, 2014). Interestingly, these three studies reported similar functional outcomes or poorer outcomes for the person-centred intervention group compared to the traditional, non-person-centred approach. Eyssen et al. (2014) attributed this to a greater number of sessions spent in diagnostic consultation; greater time taken to formulate the first treatment goal; greater



number of goals directed to diagnostic issues and more hours spent on indirect issues resulting in a longer total therapy period. The authors recommend a more proportional distribution of time devoted to diagnostic evaluation versus actual treatment in order to produce functional outcomes. These studies compare to the current study and may explain the lack of change in 6MWT distances pre-and post-intervention. Responsiveness and validity of the 6MWT has been established with individuals with TBI in a post-acute rehabilitation facility (Mossberg & Fortini, 2012). Inclusion criteria for participants in this study were the ability to ambulate independently with or without an assistive device at a speed of  $\geq 13.41$  metres/min for  $\geq 50$  metres over level surfaces with minimal supervision. Participants attended sessions three to five times per week that focused on physical rehabilitation (e.g. treadmill, elliptical training, stationary and community cycling and aquatics) rather than PA lifestyle change. During CRnQ facility-based rehabilitation and PA programs, participants engage in similar exercise prescription. Short-term session-to-session goal setting with repetitions and times ensures progression, which, according to the principles of sport science, will result in improved physical outcomes.

The significant increases in both family and friend support in the current study can be attributed to APAP's social support strategy. During delivery of APAP, EPs placed emphasis on this strategy given the results of the literature review (Newitt et al., 2016) and the focus group study in Chapter 2. Introductions between APAP participants and staff and members of local facilities, relationships between CRnQ participants, as well as a Facebook group were the key areas of social support. Individuals with NMS conditions in every study included in the literature review (Newitt et al., 2016) reported social support as a facilitator of PA participation. The types of social support listed were exercise buddies, group exercise, family, friends, health professionals, care givers and peers. CRnQ participants who participated in the local focus group listed the same social support and further added support

from social interaction at community rehab, members of the public and support groups. The results from Studies 1, 2 and 5 in this thesis confirm that social support is indeed a mediator of PA adoption and maintenance.

The scores for the decisional balance questionnaire pre- and post-intervention and at three-month follow up were greater than zero. This indicates that APAP participants perceive that PA advantages outweigh disadvantages. The scores, however did decrease significantly from pre- to post-intervention, and further decreased at three-month follow up. Individuals with mobility impairments, especially those with low levels of function have reported that the effort required to participate in PA can far outweigh the return (Damush et al., 2007; Kehn & Kroll, 2009). As there were quite a few low-functioning APAP participants in this study, effort to participate in PA may have seemed great compared to the benefits gained from PA. Caution should be exercised with regard to the results for the social support and decisional balance questionnaires due to the small and heterogeneous sample in the current study.

In real-world settings, researchers may need to consider what the increases in outcome measures (e.g. increases in PA) actually represent to both the participant and the organisation. From an economic perspective, improved health outcomes for the participant and policy makers may include avoidance of complications, reduced health-care utilisation and health-care cost, wider benefits through participation in society, reduced carer burden among others (Sepucha, 2004). Difficulties encountered in finding adequate measures to show improvements in PA may be better demonstrated with a full economic evaluation. This type of evaluation includes a cost-effectiveness analysis (CEA) where costs are related to a common outcome between alternative programs; a cost utility analysis (CUA) where costs are related to a measure of program effect (e.g. cost per health year of cost per quality-adjusted life year (QALY) gained); and lastly, a cost-benefit analysis (CBA) which values all

costs and benefits in the same monetary value (e.g. ratio of costs to benefits, or a sum representing the net benefit or loss of one program over another) (Nolte, 2014).

With regard to cost effectiveness, one final suggestion from a member of the CRnQ management team with regard to increasing occasions of service was that some of the between-session preparation undertaken by EPs (e.g. phoning local facilities to enquire about services, accessibility, costs et cetera) could occur face-to-face with APAP participants. Steps 2C (community access/adaptation) and Step 3 (relapse prevention strategies) of APAP are aimed at fostering physical independence and teaching community re-entry skills. Considering the purpose of these steps and the overall aim of APAP, this suggestion has merit and should be assimilated. It must be noted that EPs delivering APAP will encounter individuals with NMS conditions who will always require a high level of assistance. In cases such as these, either the health professional or the individual's caregiver will have to take the time to conduct preparation for PA in the community thereby increasing their workload. This was an unanticipated outcome in the current study. The APAP participant required a high amount of assistance to do gym and pool exercise at his residence. His family carer preferred to perform daily tasks while he was exercising with a health professional and did not wish to allocate the paid carer's time to PA with the APAP participant. The EP, in consultation with the family, set in place arrangements for a paid allied health student to attend home PA sessions. A study investigating barriers and facilitators to optimising function in people with PD, paid carers and family carers would not allow the person with PD to do activities for themselves citing the challenge of time constraints as a barrier (Pretzer-Abhoff et al., 2009). Realistically, there are going to be cases where an individual with a NMS condition with high needs cannot independently participate in PA in the community. Barriers may include a lack of social support, a lack of disposable income, limited healthcare resources or simply, that the effort of PA participation far outweighs the return.

### **5.3.4. Maintenance**

At the individual level, the facilitation of social support by way of a gym group and social media proved to be the most beneficial strategy for maintenance of PA. Informed by the perspective of individuals with NMS conditions in the literature (Newitt et al., 2016) and from focus groups and interviews with CRnQ participants, EPs facilitated instrumental social support and provided informational, emotional and appraisal support to APAP participants during the course of the intervention. Regardless of the level of support provided, eight APAP participants discontinued PA at three-month follow-up. This is consistent with findings from APAP's CCT where significant increases in PA post-intervention were not maintained at follow up (Clanchy et al., 2016). The authors suggested a more gradual reduction in the frequency and duration of home visits and the provision of remote support strategies such as phone, text and email. In Horner-Johnson's (2011) study, the group that received longer follow-up support maintained significant increases up to 10 months. Consequently, the authors recommend longer-term support for participants. Individuals with CP with levels of function ranging from II to IV according to the Gross Motor Classification System report that lifelong supportive healthcare from health professionals is a prerequisite for continued PA (Sandström et al., 2009). As demonstrated in the current study, health setbacks are common for individuals with NMS conditions, therefore, long-term support via electronic means, group sessions with health professionals or peer mentors ought to be considered in future APAP applications.

A further contributing factor to maintenance of PA was the interprofessional model of service delivery at CRnQ where nine interventions from other allied health professionals assisted with the establishment of PA in the community. Interprofessional involvement for matters

related to family mediation; injury reduction/safety when walking; depression/suicidal ideation; access to home pool; training carers to assist with transfers; reducing falls risk; energy conservation; nutritional advice; rural support and gait training assisted with the maintenance of PA.

At the organisational level, although APAP was included as a permanent program at CRnQ, the number of CRnQ participants referred to the intervention declined dramatically following the completion of the data collection period. Withdrawal of the intervention champion was a predominant contributor to the decline for three reasons. Firstly, designation of a replacement APAP lead clinician to act as a champion for APAP did not happen, therefore APAP no longer had an advocate. According to primary health care (PHC) stakeholders, intervention champions not only have a significant influence over the adoption and implementation stages of PA interventions, but also the continuation stage (Huijg et al., 2015). Secondly, as the knowledge broker was champion, PhD candidate and one of the EPs delivering APAP, members of the clinical team saw the intervention as the knowledge broker's research project rather than an ongoing program. Lastly, the knowledge broker was the EP who predominantly delivered APAP to CRnQ participants as, with other service demands, the other EPs perceived the intervention as too time-consuming and complex. Rather than deliver APAP in its original form, EPs adopted components of APAP to enhance existing CRnQ programs. Unfortunately, other CRnQ programs were not evaluated to the same extent as APAP so uncertainty remains as to whether CRnQ participants in other PA programs adopted and maintained PA in the community.

In effect, APAP, in its original form, was not maintained, but its menu of strategies and activities had a lasting influence on the way the clinical team practiced. APAP was valued by

the clinical team because it enhanced the person-centred, individually-tailored principles of CRnQ.

## **Chapter 6**

### **Conclusions**

This final chapter draws together the information gathered and the conclusions generated. Attention is given to implications of the findings and areas that remain to be explored, including those that arise from study limitations. The direction this provides for clinical practice and future research is discussed. The thesis is drawn to a close with the aims restated, the results summarized and the conclusions conferred.

## **6.1. Implications**

The impetus for this study arose from the belief that the low rates of PA participation by people with NMS conditions was unacceptable and that existing PA interventions did not address the most common barriers to PA participation for this population. The context for the study was one of an increase in the prevalence of NMS conditions due to prolonged ageing and increased survival rates of children born with neurodevelopmental disorders, leading to an increase in the number of inactive individuals with disability. As individuals with NMS conditions experience the same benefits from PA as the general population, there is a priority to translate PA interventions that are participant centred and individually tailored into real-world settings. An increase in PA rates among individuals with NMS conditions may lead to a reduction in costs and burden to the health system.

Consequently, the overall aim of this research was to translate APAP, an efficacious lifestyle PA intervention, from UQ, a metropolitan educational setting, to CRnQ, a regional community rehabilitation setting. The objectives of this thesis were to determine, from the perspective of individuals with NMS conditions, factors that influence participation in PA; develop a plan, based on the RE-AIM framework for implementation of APAP into CRnQ based on the views of individuals with NMS conditions, information gathered from intervention developers and intervention implementers; and evaluate, through a hybrid effectiveness-implementation Type 1 study design, the implementation of APAP at CRnQ.



## **6.2. The perspective of individuals with NMS conditions**

Exploration of the perspective of individuals with NMS conditions revealed that barriers and facilitators to participation in PA are complex and common and that it is the individual's context that determines how those factors influence participation in PA. Accordingly, an interprofessional person-centred, individually-tailored approach is needed to address barriers and enhance facilitators.

## **6.3. Planning for implementation and evaluation of APAP at CRnQ**

Engagement and familiarisation with APAP and the context and setting for implementation confirmed that the intervention's person-centred individually-tailored principles align with the principles of CRnQ. As intervention pathways for the original and new context and setting did not align, and both the intervention and health setting were multifaceted, planning for implementation and evaluation required a systems-thinking approach and a multi-level, multidimensional translational framework. Guided by RE-AIM and the intervention implementers' knowledge of CRnQ, a protocol was developed for implementation and evaluation of APAP at CRnQ. The protocol comprised strategies to overcome anticipated barriers and enhance facilitators during implementation and evaluation of APAP at CRnQ. The protocol was designed to test the feasibility and acceptability of APAP's implementation approach at CRnQ, as well as the intervention's impact on participant outcomes. The pragmatic iterative approach adopted during planning continued into the implementation and evaluation phase as, with the many dynamic interacting variables, deviations from the protocol were anticipated.

## **6.4. Evaluation of APAP at CRnQ: Implementation findings**

### **6.4.1. Reach and adoption**

Evaluation findings demonstrated that APAP was an appropriate intervention to reach a population representative of individuals with NMS conditions. Reach for the target numbers was less than anticipated. There were four possible contributors: community visits required longer session durations; individuals with health setbacks required longer intervention durations; EP resources for delivery of APAP were limited due to other service demands; and EPs were inexperienced in the delivery of APAP. As the majority of CRnQ participant goals were related to the restoration of function, allocation to rehabilitation programs was a priority over allocation to PA lifestyle programs. APAP participant success had the greatest influence on referrals by the clinical team. APAP's menu of individually tailored, stage-matched behaviour change activities and strategies positively influenced the way the CRnQ team practised. The CRnQ team were confident that, with modification and further integration, APAP would be a valuable part of the services offered.

### **6.4.2. Implementation**

Training EPs and EP students to deliver APAP takes time and practice as the skills required go beyond traditional undergraduate training. Five-week student practicum durations limited the opportunities to train EP students.

The fidelity checklist designed for the current study demonstrated that APAP was delivered with fidelity to session structure. It did not demonstrate whether the intervention was delivered with fidelity to session processes. As delivery of APAP was considered complex and time consuming by EPs, the menu of behaviour-change activities and strategies were

implemented as an add-on approach to other PA programs. CRnQ participants were able to participate in APAP as a stand-alone program or concurrently with other CRnQ programs. Components of APAP were delivered to participants via Skype, telephone, email and text. For the APAP participant with severe communication impairment, APAP was delivered with adherence to the principles but not the protocol. Direct and indirect interprofessional involvement was essential to delivery of APAP in this study as the facilitation of independent PA in the community often resulted in needs that were beyond the scope of the EP.

To reduce delivery time for EPs, the CRnQ clinical team suggested delivery of behaviour-change components by other allied health professionals and/or delivery to participants in groups. Alternatively, members of the clinical team attributed APAP participant success to the program's one-on-one focus to address barriers to PA participation.

### **6.4.3. Effectiveness**

According to the CRnQ clinical team, effectiveness was achieved by way of increases in PA, motivation, mood and participation in the community; a sense of wellbeing, enjoyment of activities and the retrieval of independence, confidence and some control in life. Outcome measures chosen for the current study were designed to measure amounts of exercise and exercise habits but were insensitive to progress achieved for individuals who had low levels of function. APAP participant satisfaction was high due to the participant-centred nature of the program; however, the focus on psychosocial issues may have contributed to non-achievement of the primary aim of the program, which was to increase the adoption and maintenance of PA.

At the organisational level, APAP did not achieve the target number of occasions of service, which was the KPI for CRnQ. The one-on-one nature of the program, longer session and intervention durations and between-session preparation were believed to have contributed.

An unanticipated effect of APAP was an increase in the workload for family carers with the facilitation of independent PA in the community for individuals with NMS conditions who require high levels of assistance.

#### **6.4.4. Maintenance**

Social media and a buddy system were effective methods to facilitate support for PA participation in this study. In regional Townsville, the facilitation of social support was enhanced by APAP participants as they had become acquainted through attendance at local health services. Interprofessional involvement for matters related to family mediation; injury reduction/safety when walking; depression/suicidal ideation; accessibility; carer training; energy conservation; nutritional advice; rural support and gait training also contributed to the maintenance of PA in this study. Longer-term social support was required for individuals with complex NMS conditions who experienced regular health setbacks

The multiple roles undertaken by the knowledge broker led the clinical team to believe that APAP was the knowledge broker's research project rather than a permanent CRnQ program. Additionally, intervention implementers neglected to designate an intervention champion once the knowledge broker withdrew from a full-time role. These factors contributed to a decline in referrals to APAP after the study period.

## **6.5 Future directions**

### **6.5.1 Integration of APAP at CRnQ**

Evaluation of the reach, adoption and implementation elements highlighted factors that enhanced integration of APAP and inhibited integration. The first factor that contributed to enhancement of integration was that APAP was effective when run concurrently with rehabilitation programs at CRnQ, as a program to transition CRnQ participants from the service to the community and also as an add-on approach to other CRnQ programs. Consideration should be given to linking APAP with other rehabilitation programs, for example, the balance and mobility program, where participation in APAP occurs alongside rehabilitation. Complete graduation to APAP would then occur upon completion of the balance and mobility program. For implementation into any community rehabilitation context that follows participant-centred, individually-tailored, goal-based principles, the adaptability of APAP's menu of activities and strategies could be applied as an add-on approach to any program offered in the service. Consideration should be given to the adoption of APAP's strategies and activities as a value-add approach to existing CRnQ PA programs rather than implementation of APAP as a stand-alone intervention.

Secondly, the availability of a team of health professionals at CRnQ provided APAP participants with an interprofessional model of care that is essential to the facilitation of independent community PA. Furthermore, interprofessional involvement was delivered effectively through direct face-to-face sessions and indirectly via electronic communication with the EP. This finding indicates an opportunity to consider future dissemination of APAP with EPs who practice in rural and remote locations with interprofessional involvement.

Lastly, APAP successes or positive outcomes were reported to the clinical team via clinical meetings, the posting of photos in the staff room and individual conversations with members of the clinical team. It is recommended that this practice continue, as it appeared to have the greatest influence on referrals to APAP and educated the team about the purpose of the program.

Factors that may have contributed to the inhibition of APAP's integration into the processes and systems at CRnQ include, firstly, the increased involvement by the knowledge broker as champion who led and delivered APAP. It is recommended that during the planning of future iterative cycles or APAP implementations, strategies should address barriers with regard to the utilisation of existing human resources for delivery of APAP. This strategy should clarify any misunderstanding by the clinical team that implementation of APAP is a separate research project rather than an ongoing part of the service. Additionally, it is recommended that an EP from the existing resource pool, if possessing the right characteristics, should be designated as intervention champion at the adoption and implementation and continuation stages.

The second factor was that EPs considered APAP to be too time consuming and complex with possible contributors including longer sessions and intervention duration, participant health setbacks, inexperience with delivery and between-session preparation. As EPs in the current study delivered APAP to a wider range of individuals with NMS conditions, which included individuals with progressive conditions, severe communication impairment and severe mental health issues, it is understandable that health setbacks were experienced and session and intervention duration increased. From the decision-maker's point of view, two-hour sessions and 15-week intervention duration may be unacceptable at a time of straitened healthcare resources. Delivery of APAP to groups of participants, as suggested by the clinical team, may decrease delivery time, which will increase reach and provide EPs with more time

to perform other service demands. This suggestion may be achievable as other health promotion programs for individuals with disabilities have demonstrated increases in PA utilising this method of delivery. Additionally, delivery to groups may provide instrumental, informational, emotional and appraisal social support that proved an important strategy in the adoption and maintenance of PA for individuals with NMS conditions during the intervention. Alternately, as some members of the clinical team consider the individual focus vital to APAP's success, it is recommended that only some components be delivered in group sessions. Individuals with more complex conditions and higher needs will require a more one-to-one focus to overcome the increased barriers to PA participation.

Inexperience with delivery of APAP may be a result of the advanced skills required for delivery of the intervention and the absence of a formal structured training program for this translation study. Development of an APAP fidelity checklist guided by the ACFC is recommended for the next APAP iteration at CRnQ or future settings. Thorough assessment of session structure and session processes will assist with the identification of APAP's core and peripheral elements enabling the establishment of a structured APAP training and implementation package. As optimal strategies for teaching and supervising Motivational Interviewing are yet to be established, it would be prudent to follow the current recommendations in the literature, which include a two-day workshop emphasising the underlying assumptions and spirit of Motivational Interviewing followed by on-the-job learning. As per the current study's findings, on-the-job learning may be enhanced by a buddy system where, if possible, two EPs share delivery of APAP with a participant. This system enabled EPs to tackle complex problems together by sharing experiences and ideas, and to overcome delivery issues with the part-time EP.

The final factor that may have posed a barrier to integration was the increased time required for between-session preparation. As suggested by one of the decision makers, consideration

should be given to more face-to face preparation with APAP participants as this aligns with part of the APAP strategies, which are to advance community re-entry skills. Additionally, it may boost occasions of service.

### **6.5.2 Effective outcome measures**

This study confirmed that obtaining effectiveness measures that are valid, reliable, accurate and practical for a population with complex and disabling health conditions is problematic. Additionally, optimal exercise prescription guidelines for people with complex NMS conditions have not been determined. Determining measures that demonstrate achievement of the aims of a program is important for the participant and the health professional as they represent progress, or a lack thereof. Progress motivates individuals and a lack of progress means barriers need to be addressed or exercise prescription reviewed. To measure changes in amounts of exercise, exercise habits and the benefits of exercise, further trials are recommended.

Unsuitable outcome measures for this population, or the disproportionate distribution of time devoted to psychosocial issues versus PA may have contributed to insignificant increases in the adoption and maintenance of PA. When compared with other CRnQ PA programs, APAP achieved greater success at transitioning individuals into participation in independent PA in the community. Ultimately, decision makers want to know what any significant increases in PA or social support actually represent with regard to the organisation's KPIs. It is recommended that future APAP implementation and evaluation studies consider a comparison study, either with usual care or other rehabilitation programs. This may distinguish which programs are incorporating all person-centred elements into daily practice and whether this practice fits with the service's systems and processes.



A further consideration is a full economic evaluation that includes analysis of costs related to a common outcome between alternative programs; costs related to a measure of program effect (e.g. cost per health year of cost per quality-adjusted life year (QALY) gained); and costs and benefits in the same monetary value (e.g. ratio of costs to benefits, or a sum representing the net benefit or loss of one program over another).

Transitioning individuals into independent PA in the community was viewed by the clinical team in this study as effectiveness. This was most certainly an achievement for the EP who transitioned individuals with severe impairment and high needs, however, there must be an awareness that transition into community PA can create extra workload for family carers. It is recommended that family be informed about the aims of the APAP and discussions early in the intervention make clear that extra support may be required.

### **6.5.3. Enhancement of the RE-AIM framework**

Implementation and evaluation of APAP into CRnQ was guided by the RE-AIM framework. Community health settings are considered to be complex systems with many dynamic interacting variables. Although RE-AIM is a multidimensional, multilevel framework designed to guide the translation of evidence into practice, implementation would be enhanced by a framework that delves deeper into the implementation element. The CFIR will provide a more systematic evaluation of factors that influence adoption and implementation.

As APAP is a complex, multi-faceted behavioural-change intervention, evaluation will be further enhanced by the application of the same systematic approach in the assessment of intervention fidelity. Assessment of both session structure and session process will determine

APAP's core and peripheral elements, an essential step in the development of a structured training program and, perhaps, a reduction in delivery time.

## **6.6 Limitations**

This study has several limitations that warrant consideration. The small heterogeneous sample size would have influenced statistical analysis. This makes it difficult to draw any conclusions about PA outcomes. With this sample, it is probably best to describe outcomes in terms of trends and patterns in trajectories.

The follow-up period of three months does not truly reflect maintenance of an intervention as per the RE-AIM definition. Although, in line with the efficacy study, there was a reversion in outcomes over this period. Future implementation studies should trial a six-month follow-up period.

The knowledge broker/intervention provider conducted interviews with APAP participants. This method may have inhibited full disclosure with regard to participant satisfaction with the intervention. Alternately, the knowledge broker had developed a rapport with the majority of participants and it was explained that any constructive criticism would assist in improving the intervention for future participants. Further, the intervention provider performed qualitative analysis on the interviews. This may be considered a potential bias, however methodological rigour by way of investigator triangulation likely addressed any bias. Full disclosure by clinical team members during focus groups may have been inhibited or influenced due to the presence of the clinical leader. It may have been more appropriate to conduct an individual interview with the clinical leader.



## **6.7. Conclusion**

The aim of this thesis was to translate APAP, an efficacious lifestyle PA intervention, from UQ, a metropolitan educational setting, to CRnQ, a regional community rehabilitation setting. The perspective of individuals with NMS conditions, both in the scientific literature and in the local regional area confirmed that PA interventions for this population should be participant centred and individually tailored. Familiarisation with APAP confirmed that the intervention was indeed participant centred and individually tailored and, additionally, comprised procedures and strategies that enhanced those principles. For these reasons, APAP aligned with the values and principles of CRnQ. Pathways for the original and new contexts and settings, however were not in alignment and a protocol was designed to enhance facilitators and overcome anticipated barriers to implementation. Implementation and evaluation findings revealed that APAP is suitable for individuals with a wide range of NMS conditions and that it is a highly adaptable intervention that was valued by all members of the clinical team at CRnQ. Skills to deliver APAP take time and practice to master. APAP requires further integration to fit with CRnQ's standard systems and processes to ensure entrenchment at the service. These findings represent a critical step towards dissemination of a PA intervention that will change the PA lifestyle of individuals with complex NMS conditions.

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# Appendices

## Appendix 1a Ethical approval focus groups

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Appendix 1b Ethical approval translation

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## Appendix 2 TIDieR checklist for APAP efficacy study

(Clanchy, Tweedy & Trost, 2016)

Item No.	Item	Description
1.	<b>Brief name</b>	Community based, stage-matched lifestyle physical activity (PA) intervention
2.	<b>Why</b>	People who are physically inactive have an increased risk of hypokinetic diseases such as heart disease, diabetes, high blood pressure, depression and some cancers. People who are inactive tend to have decreased strength and flexibility, lower fitness and higher body fat. People with a disability are 50% more likely to be physically inactive than the general population and therefore they are more prone to developing the diseases of inactivity and find physical movement more stressful, which can negatively impact independence, return to work and social interaction. Many people with NMS conditions will often face significant barriers to being physically active. Uncertainty about how to start, inaccessible facilities and special medical concerns can all reduce motivation and prevent action. The aim of the program is to promote physical activity adoption and maintenance.
3.	<b>What (materials)</b>	<p><b>Step 1</b></p> <ul style="list-style-type: none"> <li>• Pre-participation Assessment questionnaire based on domains of the ICF</li> <li>• PA Stages of Change (SOC) questionnaire</li> <li>• Information sharing activity</li> </ul> <p><b>Step 2a</b> Individually-tailored combination of staged-matched behavior change activities): <u>SOC 1 or 2 Strategies</u></p> <ul style="list-style-type: none"> <li>• Information sharing</li> <li>• Modelling</li> <li>• Decisional balance</li> <li>• Motivational interviewing (value card sort, importance and confidence rulers, expressing empathy, rolling with resistance)</li> <li>• Social support</li> <li>• Personal time audit</li> <li>• Barrier identification &amp; resolution</li> <li>• Build self-efficacy</li> <li>• Foster enjoyment</li> </ul> <p style="text-align: right;"><u>SOC 3 Strategies</u></p> <ul style="list-style-type: none"> <li>• Self-monitoring</li> <li>• Goal setting</li> <li>• Reward systems</li> <li>• Prompting/reminders</li> <li>• MI (I&amp;C rulers)</li> <li>• Social support</li> <li>• Personal time audit</li> <li>• Barrier ID &amp; resolution</li> <li>• Build self-efficacy</li> <li>• Foster enjoyment</li> </ul> <p><b>Step 2b</b> Tailored exercise prescription</p> <p><b>Step 2c</b> Community access facilitation</p> <p><b>Step 3</b> Relapse prevention strategies: work with participants and their primary caregivers to teach skills and develop strategies that will ensure ongoing participation, including:</p> <ul style="list-style-type: none"> <li>• What worked and what didn't (past successes);</li> <li>• Planning for high-risk situations;</li> <li>• Education on exercise progressions;</li> <li>• Community entry skills.</li> </ul> <p><b>Primary outcome measure:</b> ActiGraph GT1M accelerometer-based motion sensor <b>Secondary outcome measures:</b> Five-item self-efficacy scale; 13-item social support scale; 16-item decisional balance scale</p>
4.	<b>What (procedures)</b>	For detailed methods on all intervention steps and outcome measures refer elsewhere <b>Step 1</b>

- Pre-participation assessment conducted in order to permit each participant's PA intervention to be individual tailored. Includes participant's health conditions, impairments, activity limitations, participation restrictions and personal and environmental factors that would impede or enhance PA participation.
- Information sharing activity containing a short video discussing the definition and benefits of physical activity in order to develop a shared understanding of the concept PA (protocol developed)
- PA SOC questionnaire conducted to assess motivational readiness and permit stage-matching of the intervention.

#### Step 2a

Application of SOC strategies has been described elsewhere. For participants in Stage 1 and 2, emphasis was placed on developing a discrepancy between the participant's current PA behaviour and their broader goals and values, evaluating the benefits and barriers and eliciting change talk for increasing PA. For Stage 3 participants, emphasis was placed on strategies that would assist them to increase their activity from insufficient levels to sufficient levels. The selection of strategies used was based on the outcomes of Step 1 and any subsequent session.

#### Step 2b

Exercise prescription was dependent upon behaviour-change strategies implemented as part of Step 2a

#### Step 2c

Community access facilitation: Organisational and logistical activities undertaken in order to facilitate PA. Examples include:

- Education of activity stakeholders (e.g., coaches, administrators, instructors or potential team members);
- ID opportunities for increasing incidental activity (e.g. fostering physical independence rather than dependence on others or walking rather than using a wheelchairs for long distances);
- Equipment modification or other specialist information;
- Identification of potential funding sources available to the participant;
- Sourcing affordable, accessible transport options where necessary.

#### Step 3

Delivery of relapse prevention strategies: to work with participants and their primary caregivers to identify potential situations in which their PA routine may be disrupted or stopped and to formulate appropriate strategies to restart or continue with their PA program.

**Primary outcome measure:** ActiGraph GT1M accelerometer-based motion sensor worn for seven consecutive days at baseline, post-intervention (12 weeks) and follow-up (24 weeks) to measure daily wear time, daily average counts per minute (cpm) and daily time spent in moderate to vigorous physical activity (MVPA)

**Secondary outcome measures:** Self-efficacy scale, social support scale and decisional balance scale were conducted at baseline, post-intervention (12 weeks) and follow-up (24 weeks)

5.	<b>Who provided</b>	Intervention delivered by one Accredited Exercise Physiologist who had skills in behaviour-change techniques and experience in prescribing exercise for people with disabilities.
6.	<b>How</b>	The intervention consists of individual, face-to-face sessions; follow-up phone calls/e-mail/text and other between-session support.
7.	<b>Where</b>	In the home or surrounding community. No transport required, no special equipment needed.
8.	<b>When &amp; how much</b>	Approximately 10 sessions over a 12-week period. Session duration 1 hour. Session frequency varies depending on the needs of the participant and the stage of the program with typically more sessions in the first 6 weeks as community access was arranged, skills learned and habits established. Session frequency diminishes in the second 6 weeks with more emphasis on fostering independence and self-management. Follow-up phone calls/e-mail/text and other between-session support as necessary.
9.	<b>Tailoring</b>	Intervention pathway determined by participant's PA stage of change, goals, activities they do, life areas they participate in, resources, ability and level of fitness.
10.	<b>Modifications</b>	None
11.	<b>How well (planned)</b>	Assessed by way of a video-taped pilot with footage evaluated by all developers; regular case meetings conducted; case notes audited
12.	<b>How well (actual)</b>	Intervention administered by one Accredited Exercise Physiologist/developer; fidelity to protocols assured by way of assessments listed in item 11.

## Module 2

<b>Course name:</b>	<b>The APAP Strategies for Increased Physical Activity Participation</b>
<b>Period:</b>	<b>Week 1 or 2 of CRnQ Cycle</b>
<b>Duration:</b>	<b>Two (2) hours</b>
<b>Organisation:</b>	<b>Community Rehab nQ</b>
<b>Administered by:</b>	<b>Accredited Exercise Physiologists at CRnQ</b>
<b>Course coordinator:</b>	<b>Rose Newitt</b>
<b>Course level:</b>	<b>Undergraduate</b>
<b>Campus:</b>	<b>CRnQ, 16 Ryan St, Belgian Gardens</b>
<b>Delivery mode:</b>	<b>Internal and via CRnQ portal</b>
<b>Document last updated:</b>	<b>23 April 2014</b>

### 2.12 Course Description

Students will be required to apply knowledge and skills to activities in sessions of the Adapted Physical Activity Program (APAP). New skills will be developed providing students with the tools required to competently provide individuals with neuromusculoskeletal (NMS) conditions the opportunity to practice choice, control, responsibility and accountability for their lifestyle choices and actions; and to acquire knowledge and skills to increase self-efficacy for engaging in physical activity.

Students will be required to follow systems and processes implemented to ensure the principles of the APAP are applied with fidelity whilst allowing for flexibility to tailor to the CRnQ setting.

### 2.13 Learning outcomes

By the end of the course, students should be able to:

1. Demonstrate the competent performance of the following activities:
  - a) Information sharing exercise

- b) Value card sort exercise
- c) Decisional balance exercise
- d) Importance and confidence rulers
- e) Personal time audit
- f) Evaluation activities
- g) Identify activities of interest using the Leisure Diagnostic Battery
- h) Physical activity monitoring
- i) Goal setting
- j) Ongoing re-evaluation and relapse strategies

2. Understand the key principles of the APAP.
3. Understand when the key principles of APAP are applied within the intervention and when deviations are required.
4. Understand how to record systems and processes followed in the APAP

#### **2.14 Detailed description of subject content**

Students will be taken through a detailed protocol of the 10 activities used in the APAP sessions.

Students will learn about the purpose of activity choice in relation to goals, needs and stage of change.

Using the role-play method, students will practice the activities using the suggested dialogue in the protocols (section 3).

#### **The APAP Session Content**

**This section contains protocols for the activities employed in the APAP which include:**

- Information sharing exercise
- Value identification exercise
- Decisional balance sheet (pros and cons)
- Physical activity monitoring 1 and 2
- Identifying activities of interest
- Assessing importance and confidence
- Maintenance of physical activity levels/Relapse prevention

**Each protocol outlines the following:**

- Participant characteristics
- Sessions goals
- Purpose of activity
- Sample dialogue
- Potential follow-on activities

## Information Sharing Exercise

*“Raise doubt and increase client’s perception of risks and problems of current behaviour” (Miller & Rollnick, 1991)*

### **Participant characteristics:**

**All participants undertake this activity.** This strategy is particularly effective for participants who are unable to verbalise any individual benefits of physical activity or appear to be resistive to the concept of structured exercise (Stage 1- Precontemplation).

### **Session Goals:**

1. Build a shared understanding of the definition of physical activity- particularly relating to the distinction between physical activity and exercise.
2. Gain a perspective of what information participants find interesting or relevant and discuss how this information relates to the participants situation.
3. Discuss the benefits of physical activity in broad terms and the benefits relating to adults with an acquired brain injury in order to attempt to begin to explore the participant’s ambivalence regarding physical activity.

**Purpose:** To develop a shared definition of physical activity.

### **PROTOCOL:**

#### **Sample Dialogue:**

“This program aims to understand your perspective regarding physical activity, so to start with I would like to show you a video that is currently being used to discuss physical activity in relation to adults with neurological conditions and ask your opinion. “

### Follow Up Questions:

“What did you find interesting in the video?”

“Did you learn anything new?”

(Aims to verbalise the benefits of physical activity and identify information of interest to the participant.)

“What were the things you already knew?”

“What didn’t you like about the video?”

(Aims to identify information that is not relevant to the participant.)

“Do you think it is important that adults with a neurological condition are physically active? Why or why not?”

(Can identify information not included in the video that is relevant to the participant. Can also be used to gain a summary from the participant’s perspective the key factors that they feel relate to increased physical activity participation.)

### Session End:

Complete movie review sheet.

### Potential follow-on activities:

- **Value card sort exercise**- allows the benefits of physical activity to be investigated from the participant’s perspective. Can be introduced as a follow on activity from discussing the general benefits/ medical benefits of physical activity.
- **Leisure diagnostic battery**- can be used to expand on the different types of physical activity and to determine activities that the individual has previously participated in/ would be interested in participating in.
- **Decisional balance sheet**- can be used to gain a more well-rounded perspective of not just the benefits of physical activity but also the disadvantages of physical activity from the participant’s perspective.

### **Movie Review**

What did you find interesting in the video?

Did you learn anything new?

What were the things you already knew?

What didn't you like about the video?

Do you think it is important that adults with a neurological condition are physically active? Why or why not?



## Value Identification Exercise

*“Raise doubt and increase client’s perception of risks and problems of current behaviour” (Miller & Rollnick, 1991)*

### **Participant characteristics:**

**This activity is completed by all participants or revisited if done previously.** It should follow the information sharing exercise. This activity is particularly useful for participants who are in precontemplation stage of change. It allows them to see a link between their broader goals and values and physical activity participation.

### **Session goals:**

1. Identify values that are important to the participant – These values represent factors that intrinsically motivate the client towards change. Linking activities undertaken to these values is proposed to increase the likelihood of adoption and maintenance.
2. Create ambivalence – A central concept of MI is the identification, examination and resolution of ambivalence regarding changing behaviour. Ambivalence (defined as feeling two ways about behaviour change) is seen as a natural part of the change process. Most individuals are unaware that they are ambivalent about a behaviour (in this case PA). By linking the participant’s broader goals and values to PA participation, the clinician aims to develop ambivalence. This ambivalence can be further explored during the Decisional balance activity.
3. Develop cognitive dissonance – Developing cognitive dissonance involves amplifying from the client’s perspective a difference between current behaviour and their identified ideals or values. It aims to further develop the ambivalence regarding PA participation.
4. Discussing previous attempts at behaviour change - It is proposed that by identifying strategies/activities that the participant previously implemented successfully to change behaviour and applying them to PA that the participant will perceive a higher likelihood of success (outcome expectations).

**Purpose:** Helps the participant identify their most important values and evaluates them in relation to being physically active. This exercise aims to help the client to self-evaluate where these values fit in regards to their current behaviour.

### **Potential Traps/Situations to Avoid:**

Forcing the participant to choose a card. If the participant does not wish to undertake the activity, they should not be coerced to do so. In the absence of completing this activity, the participant should be encouraged to list the top 5 important things to them. Additionally a general discussion regarding the categories of the value cards e.g. health and wellbeing, self-confidence, family and friends and what each of those categories means to the participant can also be undertaken.

### **Instructions:**

- Ask permission
- Participant is given pack of cards with values printed on each one
- Place each card in one of three piles: Not important to me, Important to me and Very important to me
- Participant asked to chose top 5 very important to me cards
- Discuss the values in general terms
- Discuss the values in relation to general behaviour change
- Use reflections and questions to allow the client to fully explore the question
- Listen carefully and reflect change talk and discrepancy between what the client values and their current behaviour
- Summarise the whole exercise
- Don't make assumptions and avoid telling the participant about your own values

**Suggested dialogue:**

This program is about our attitude towards, or your thoughts regarding PA. To start this program I would like to gain an understanding of what is important to you in general. What I have here are cards with values on them. What I would like you to do is look at the cards and select the five that have statements on them that apply the most to you or are the most important to you. Similarly, I would also like you to pick five cards that have statements on them that don't relate to you or are not important to you at all.

N.B. The Value Card Sort activity can be modified to include statements derived from the initial screening e.g. if the participant identifies difficulties with maintaining friendships post injury as one of the primary effects of their injury, a card can be included for participants to include their own statements in the absence of applicable ones.

**Task 1: Value Identification**

“Why did you choose (insert value card statement) as one of your cards? What do you like about (insert value card statement here)?”

“Do you think you are (insert value card statement) as you would like to be?”\*\*\*

If no: “What stops you from (insert value card statement) from achieving this?”

“Why did you choose (insert value card statement) as one of your bottom 5? “ “Why don't you like (insert value card statement)?”

**\*\*\* Task 2: Previous successful attempts at behaviour change**

If the participant answers yes to “do you think you are (insert value card statement) as you would like to be?” – “Have you always (insert value card statement) as you would like to be?” If yes: “How did you achieve this?”

If no: “What changed? What did you do previously that allowed you to (insert value card statement) as you would like to be? Do you think you could use this strategy to help you (insert value card statement) as you would like to be?”

**Task 3: Create cognitive dissonance (where applicable)**

“Just to check that I understand, you value (insert value card statement), however currently you are (insert summary of current position in relation to the value)? Does this seem like a pretty accurate summary? Could you expand on it at all?”

**Session Ending:**

Complete the Value Card Sort activity sheet. Ask the participant to complete the “Things I have changed” column and “Things I would like to change” column.

**Potential follow-on activities:**

- **Decisional balance sheet** – this activity can be completed in order to further explore the ambivalence developed during the Value Card Sort activity.
- **Goal setting** – using the information in the Things I would Like to Change column, both short and long-term goals can be set. The importance of- and confidence in- attaining these goals can be evaluated using the **Importance and Confidence Rulers activity**

**GETTING TO KNOW YOU: VALUE CARD SORT**

Things I have changed in the past:

Things I would like to change in the future:

## Decisional Balance Sheet

*“Tip the balance – evokes reasons for change, risks of not changing and strengthens self-efficacy.”*

To be completed after the value card sort exercise.

### **Participant characteristics:**

This task is particularly beneficial for participants who are in the contemplation stage of change (i.e., who are thinking about increasing their physical activity levels and the possible need to make some changes). As a result, they may already be weighing up the pros and cons of increasing their activity and this activity can help assist them to tip the scales towards changing their behaviour.

For individuals who are currently completing some physical activity, the decisional balance exercise can be useful for identifying intrinsic motivators for-and barriers to- increasing physical activity levels.

### **Sessions goals:**

1. To reinforce the values of physical activity discussed in the Value Card Sort Exercise.
2. Explore the participant’s ambivalence towards increasing physical activity by identifying the benefits and costs from the participant’s perspective associated with behaviour change.
3. Identify the intrinsic motivators for physical activity (determined from the advantages column).
4. Identify barriers for behaviour change (determined from the disadvantages column).

**Purpose:** Mechanism used to explore ambivalence about behaviour. A central concept of Motivational Interviewing is the identification, examination and resolution of ambivalence regarding changing behaviour. Ambivalence (defined as feeling two ways about behaviour change) is seen as a natural part of the change process. The Decisional Balance sheet is used to identify and discuss what your participant perceives as the benefits and costs of being physically inactive as well as the costs and benefits of being physically active. It is your role to explore ambivalence rather than resolve it.

### **Potential traps/situations to avoid:**

**Providing answers:** In this task, participants are asked to identify the advantages and disadvantages of PA. In the absence of answers it can be tempting to provide multiple answers, especially in the benefits column. The questions provided in the protocol section aim to prevent “expert advice” and to gain a true perspective of the participant’s advantages and disadvantages of PA.

**Arguing for the side of change:** In this task the participant may be able to list more disadvantages than advantages of exercise. This is primarily due to the disadvantages or cons of exercising outweighing the potential health benefits of exercise. Providing additional information or further arguing for the health benefits of PA will not resolve this issue. A more effective strategy would be to explore and resolve the ambivalence towards change and to resolve the barriers preventing additional PA participation.

**Suggested dialogue:**

“This program is about discussing healthy choices. Part of the idea of healthy choices is looking at increasing your PA. During the card sort exercise last session, you identified things that you’ve changed in the past and things that you would like to change in the future – some of this related to PA and some didn’t. Sometimes when we aren’t sure about our feelings towards something, making a list of what we like or don’t like helps us clear our head. In this exercise I’d like to hear what you think the advantages and disadvantages of increasing PA are.”

**Complete the decisional balance sheet.**

Implementing the decisional balance sheet is divided into four categories:

1. Discussing the disadvantages of being physically active;
2. Discussing the advantages of being physically active;
3. Discussing the advantage of being physically active; and
4. Discussing the disadvantages of being physically inactive.

Examples of questions to ask:

**Disadvantages of being physically active:** “What would you have to give up to become more physically active? What would be some disadvantages of being physically active?”

**Advantages of being physically active:** “Has anyone ever discussed the benefits of being more active in the past? Do you consider any of your friends or family really active? Have you seen any benefits in them? Do you think physical activity will help you in the same way? Have you seen any ads/articles/television shows about the importance of being physically active? How important do you think being physically active is to your family/friends/doctors?”

**Advantages of not being physically active:** “What do you like to do when you are not being active? What would you have to stop doing or do less of?”

**Disadvantages of being physically inactive:** “Has anyone discussed being inactive with you in the past?”

**Upon Completion:**

1. Present a reflection of the participant's perspective using the participant's own words.
2. Ask the participant to include two additional points in the table in their own time.

**Potential follow-on activities:**

The follow-up activities after this session are determined from the answers provided by the participant. Activities that can follow on from this session include:

- **Identification of activity of interest** – this activity can be completed with participants who determine that they are unsure of the opportunities available to them or who are not able to identify any activities that they are interested in. The **Leisure Diagnostic Battery** can also be used.
- **Time audit** – this activity can be completed with participants who identify lack of time as a barrier to physical activity participation.
- **Physical activity monitoring** – this activity can be completed with participants who identify time as being a barrier to physical activity participation or identify that they were unaware of the different components of physical activity. This activity allows participants to identify the differences between an active and inactive day, identify opportunities for being physically active and to identify baseline activity levels. **Secondary to this activity, goal setting can be implemented.**

# MAKING UP YOUR MIND

## Yes vs. No

Sometimes when you aren't sure about your feelings towards something, making a list of what you like or don't like (otherwise known as the advantages and disadvantages) helps you clear your head. In this exercise, I would like to understand what you feel are the advantages and disadvantages of being physically active.

<b>Disadvantages of being physically active</b>	<b>Advantages of being physically active</b>
<b>Advantages of not being physically active</b>	<b>Disadvantages of being physically inactive</b>

**Challenge: Can you think of a couple more?**





**Action Card**

**What is my goal?**

**What do I have to do to achieve it?**

**Who can help me?**

**When will I have it done by?**

## Physical Activity Monitoring Session 1 and 2

*“Discrepancy between the desired goals, important values and actual behaviour creates cognitive dissonance, an opportunity to move towards action.”*

### **Participant characteristics:**

This activity is particularly effective in the contemplation and preparation stage of change. This activity is recommended for individuals who indicate that they don't know where to start regarding becoming more physically active, who are unable to recall their current level of activity or who identify time as a barrier for physical activity participation.

**Note:** This activity is not recommended for individuals who are in the precontemplation stage of change.

### **Session goals:**

1. Determining baseline physical activity levels - by completing this activity, participants are able to gain an understanding of their current physical activity levels. This is particularly effective for individuals in the contemplation stage of change. It moves their mindset from “I don't do any activity” to “I complete some activity, however I need to complete X steps/minutes more.” This allows the participant to see increasing their physical activity as more manageable.
2. Conceptualising physical activity levels - by completing this activity participants are able to identify a link between the activities that they complete during a day and their physical activity levels. Participants are able to identify the differences between an active and inactive day in regard to activities completed, but also in regard to other lifestyle factors including mood, sleep and/or fatigue. These lifestyle factors can be identified from the initial screening or from activities completed during the intervention period (e.g. the value card sort and decisional balance sheet).
3. Identifying opportunities for increased physical activity - by completing this activity participants are able to identify time periods (preferably in 10-minute blocks) where increased physical activity is possible.

### **Purpose:**

### **Potential traps/situations to avoid:**

Pressuring the participant into completing the monitoring period. This activity aims to increase the participant's understanding regarding their physical activity levels. The use of the monitor and the time audit are a means to facilitating this understanding. If the participant is unwilling to undertake the monitoring period, the same understanding can be facilitated through using the time audit to map a typical week for the participant. The activity levels of the participant and opportunities to increase activity can be estimated using this recall.

### **Protocol:**

## Quantifying Activity 1

Sample dialogue:

“In our previous sessions we’ve talked about the benefits and disadvantages of physical activity and how physical activity isn’t just exercise; it’s bodily movement that increases energy expenditure. Using this broad definition, I’d be interested in knowing what types of physical activity you are currently doing.

*Do you enjoy the activity you are doing?”*

If yes: “What elements of the activity make it enjoyable to you?”

If no: “What elements don’t you enjoy about this activity?”

(These elements will inform your exercise prescription)

*“Do you think this activity fits in with the cards or values that you picked during our last session?”*

If yes: “Which value that we discussed do you think this activity helps you achieve?”

If no: “Can you think of any particular activity that you think would help you achieve these values?”

*“Are you as active as you would like to be?”*

If yes: “Do you think there is any benefit relating to increasing your activity levels?”

If no: “How active would you like to be?”

“We also know from the video that we are meant to be trying to do 30 minutes of moderate intensity physical activity per day, which can sometimes feel like a lot of activity. What sometimes helps is to record how much activity you are doing and then compare it to that rule. I’ve found in the past that wearing a pedometer or writing down what activity you are completing is a really easy way of measuring how much activity you are doing. Do you think this would be something that you are interested in doing?”

Depending on the response of the participant, one of two monitoring activities can be completed:

Stepping Out... How active am I really?

Personal Time Audit

**Potential follow-on activities:**

- Quantifying Activity 2

## Stepping Out...

How active am I really?

Day		Pain or discomfort level	Fatigue
Sunday			
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			
Saturday			
TOTAL			

## Personal Time Audit

**Weekly schedule:**

**Task to do...**

Please fill in the time spent at work/school/other appointments (eg. Children) or regular commitments (e.g., grocery shopping)

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
AM							
PM							

Looking at the chart above:

- a. How much time could you see yourself spending on PA?

---



---

- b. What times would be most suitable for you? Please fill in.

---

**Questions to ask...**

1. How long does it take to get to work/school? \_\_\_\_\_

2. Is there a possibility to do PA during a break? (eg. Gym, park etc)

No

Yes - describe: \_\_\_\_\_



## Quantifying activity 2

### Sample dialogue:

Last session we talked about how much activity you were doing and we decided that it would be a good idea to record how much activity you are doing. I'm really interested in hearing your thoughts on the information that you were able to gather.

"Were you surprised at how active you were in the last week? (elaborate)

What, during the last week helped you be more active?

Were there any activities that you did that resulted in higher levels of activity?

What stopped you being more active?

What is the difference between an active day and a non-active day?

Were you as active as you would like to be?"

If yes: "Do you think there is any benefit relating to increasing your activity levels?"

If no: "How active would you like to be? Are there any activities that are of interest to you?"

"The recommended guidelines for step-related activity are 10,000 steps per day, when you compare this to your current activity levels, what do you think/feel?"

If you were to increase your physical activity, what strategies do you think would be effective?"

### Potential follow-on activities:

The following activities can be completed:

- **Goal setting:** based on the response to the follow up questions, participants may indicate opportunities for increased physical activity participation or strategies they indicate they believe will be effective at increasing their physical activity levels. These strategies can be recorded using the goal setting template.
- **Identify opportunities for increased physical activity:** while evaluating the physical activity levels, the participant may identify peak periods of activity or opportunities to increase their activity. The increase in physical activity can be recorded by completing Stepping Out 2 (this can be modified for participants who wish to self-report their activity). This allows the participant to record, where appropriate, opportunities that they found to be active. When evaluating this activity, the baseline activity levels should be use as a comparison.
- **Leisure diagnostic battery:** this activity can be used to identify physical activities of interest to the participant. This should be used in participants who are unable to self-identify activities that are of interest to them.
- **Importance and Confidence rulers:** any strategy identified by the participant should be reinforced using the importance and confidence rules. This exercise reinforces the importance of- and confidence for- the proposed change. It also identified any barriers that may prevent the adoption of the strategy.
- **Barrier removal:** this involves the participant and Exercise Physiologist discussing and attempting to resolve any identified barriers that may prevent physical activity participation. It is important that the strategy for resolving the barrier is suggested by the participant.

Day		What opportunities did I find?	Pain or discomfort level 0/10	Fatigue 0/10
Sunday				
Monday				
Tuesday				
Wednesday				
Thursday				
Friday				
Saturday				
TOTAL				

## Action Card

### Goal Setting

**Specific:**

Is it clear and well defined?

**Measurable:**

Know if the goal is attainable and how far away completion is.

Know when it has been achieved.

**Achievable:**

Is there a realistic path to achievement?

**Timely**

Enough time to achieve the goal. Is there a time limit?

There is a time pressure which can help you be motivated to achieve the goal.

<b>What is my goal?</b>	
<b>What do I have to do to achieve it?</b>	<b>When do I need to achieve it by?</b>
<b>What do I need to achieve my goal (e.g. resources)</b>	<b>How will I know if I have achieved my goal?</b>
<b>Notes:</b>	





## Identifying Activities of Interest

### Participant characteristics:

This activity is completed with participants who verbalise difficulties with identifying activities that they are interested in or activities that they feel confident completing (e.g., this activity can be used to introduce activity modification and community integration for individuals with neurological conditions). This activity is particularly useful for participants who are in the preparation stage of change. It allows participants to identify activities of interest that will result in increased physical activity levels.

### Sessions goals:

1. Identifying leisure/physical activity interests.
2. Identifying opportunities to be more physically active.
3. Set plans for being physically active.

### Suggested dialogue:

Previously we talked about the different types of physical activity and how physical activity isn't just exercise. Based on this discussion and other discussions we've had about working out what you might be interested in, I have a quick activity today that can help identify activities of interest. In order to complete this activity, I will call out a series of different activities classified as physical activity. What I need you to do is indicate if this is something that interests you or doesn't interest you.

Use the "**Activities classified as physical activity**" to mark the activities that the client is interested/not interest in.

The participant's response can also be used to make a general statement about overall interests of the participant (using the headings of each box) and to check that the activity successfully identified activities of interest eg. "In order for an activity to be interesting to you, it needs to be completed indoors, with an element of creativity and with your friends."

### Upon completion:

1. If the participant has chosen multiple activities of interest, a suggested **plan for the selected activities (figure 1)** can be compiled. This allows the participant to see how the activity would be implemented. This plan can be further divided into short-term vs. long-term strategies, home-based vs. community-based activities or activities implemented independently vs. activities completed with assistance.
2. If the participant is able to identify one or two primary activities of interest, a plan should be set for the participant to self-initiate the tasks. This may include:
  - a. Identifying a call sheet with organisations name and contact details
  - b. Compile a list of questions to be asked during each call
  - c. Setting short-term goals for increasing activity
  - d. Compiling small activity programs that can be completed independently
  - e. Compiling log books or diaries

**Potential follow-on activities:**

The follow-up for this activity should focus on activity adoption and maintenance. This may include:

- Development of short and long term goals
- Development of monitoring materials
- Sourcing of funding for activity maintenance
- Sourcing of sustainable transport options
- Liaising with organisation staff to ensure equitable access/suitability of program

**Activities Classified as Physical Activity**

Outdoor	Sport	Indoor activities
Camping	AFL	Pilates
Canoeing	Archery	Playing a musical instrument
Cycling	Badminton	Playing cards
Fishing	Baseball	Playing pool
Frisbee	Basketball	Yoga
Gardening	Boxing	
Hiking	Darts	
Horse riding	European handball	
Jump rope	Fencing	
Mini golf/putt putt	Golf	
Orienteering	Gymnastics	
Playing with the dog	Ice skating	
Roller skating	Judo	
Rollerblading	Jujitsu	
Sailing	Karate	
Snorkelling	Kickball	
Surfing	Lawn bowls	
Swimming	Martial arts	
Trampoline	Netball	
Water aerobics	Rugby league	
	Rugby union	
	Soccer	
	Softball	

	Squash Table tennis Tae kwon do Ten pin bowling Tennis Totem tennis Track and field Athletics Volleyball Water polo	
<b>Creative</b>	<b>Fitness</b>	<b>General</b>
Arts and craft Ballet Ballroom dancing Dance classes Folk dancing Line dancing Modern dancing Singing lessons Square dancing	Aerobics Lap swimming Rowing machine Running Spinning Stair walking Step machine Walking Boot camp Strength training	Hanging out with friends Housework Part-time work Washing the car

**Figure 1:** Example Activity Plan

**Activities of Interest**

For an activity to be interesting it needs to be: Fun, outdoors (Vitamin D), competitive, have a high level of physical exertion, results in increased strength and helpful and productive.

Activity selected	Chosen strategies
Cycling	<ul style="list-style-type: none"><li>- Begin a home cycling program</li><li>- Set short term goals regarding time, intensity and frequency of activity</li><li>- Source equipment to modify your push bike to allow use in the community</li></ul>
Frisbee	<ul style="list-style-type: none"><li>- Playing Frisbee in the backyard/park with family and friends in order to master skills associated with the game</li></ul>
Mountain climbing	<ul style="list-style-type: none"><li>- Identify mountains (e.g. Castle Hill) in the local area</li><li>- Begin walking up and down hills in local area</li><li>- Set short-term goals regarding time, intensity and frequency of activity</li></ul>
Ten Pin Bowling	<ul style="list-style-type: none"><li>- Set up a modified ten pin bowling game in order to practice the necessary skills</li><li>- Begin bowling with family and friends</li></ul>

Information relating to recreational services can be found at <http://www.sportingwheelies.org.au/our-services/link-up-advisory-services>

## Assessing Importance and Confidence

*“Tip the balance – evoke reasons for change, risks of not changing and strengthens self-efficacy.”*

### Participant characteristics

This activity is beneficial for participants who are in the preparation stage of change. It aims to reinforce self-efficacious statements and change talk. This activity can also be used to evaluate the importance of- and confidence in- achieving goals.

**Purpose:** Elicits change talk (e.g. “I think that I can change as it’s really important to me) and supports self-efficacy (the confidence that they can successfully undertake the desired behavior). It also provides a quick means of determining the primary barriers to change and provides information regarding the strategies would be most helpful in enhancing readiness for change.

### Session goals:

1. Elicits change talk; it is proposed that the Importance Ruler reinforces the importance of change for physical activity. It reiterates the intrinsic motivators for increasing physical activity.
2. Increasing self-efficacy; it is proposed that the Confidence Rulers reinforces the participant’s confidence for completing increased physical activity by eliciting self-efficacious statements.
3. Identifying barriers; by asking the participant to identify why they did not choose a higher number for the Confidence Ruler, the participant identifies tangible barriers to increasing their physical activity.
4. Discussing previous attempts at behavior change; it is proposed that by identifying strategies/activities that the participant previously implemented successfully to change behavior and applying them to physical activity that the participant will perceive a higher likelihood of success (outcome expectations).

### Potential traps/situations to avoid:

Reacting to a small number: The participant may provide a small number regarding the importance of- and confidence for- change which may not reflect the content of previous discussions. The important component of this task is the dialogue behind the number rather than the number selection itself. The questions included in the protocol below aim to facilitate dialogue regarding the number selection.

### Protocol:

### Sample dialogue:

“So far we’ve talked about your thoughts and feelings regarding physical activity. We’ve identified what you like and don’t like about physical activity and we’ve even discussed what the advantages and disadvantages of becoming more physically active are.”

[Provide summary of previous session – benefits/costs of change]

“Today, though, I’d like to know how you feel about the idea of you becoming physically active; whether you think it’s important and how confident you are that you could do it. Sometimes when we are trying to work out how we feel about something, it’s easier to use a number, rather than words to describe our feelings.

I’d like to ask you two questions and get you to answer them for me on a scale of one to ten. One is the worst answer you can give me and 10 is the best. After you answer the question, we’ll discuss why you picked the number that you did.

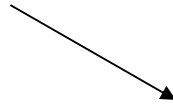
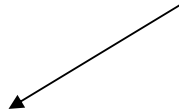
**Importance Ruler:**

One on a scale of 1-10, how important would you say increasing your physical activity is?



Why not a smaller number?

(Reaffirms reasons for the importance of change)



Low score

High score

Last week we talked about the benefits and costs of physical activity (refer to sheet). Which one of these statements (costs of activity) do you think is causing you to choose a low number? Why? Which one of these statements (benefits of activity) do you think would make people pick a high number? Why? Based on this table, do you think you would

Last week we talked about the benefits and costs of physical activity (refer to sheet). I can see from the number that you picked that you feel that being more physically active is important to you. What do you think are the top three reasons for you to

**Confidence Ruler:**

On a scale of 1-10, if you did decide to become more physically active, how confident are you that you would be able to do this?



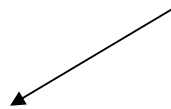
Why not a smaller number? (Elicits positive statements ; increased



Why not a larger number? (Elicits barriers for change)

**Previous attempts at behaviour change**

(“Have you ever attempted to change something about yourself in the past? e.g. biting nails, diet, being more organised, competing physio exercises”)



What worked?



What didn't?



What did you do that helped you make your change? Do you think that this would work with trying to increase your physical activity? How do you think people who are really active stay that way?  
  
**Emphasis – finding strategies participant**



Was there anything that you could have done differently? What strategies did you try that you don't think were successful? If you could try again, what would you do differently? What can you learn from this?

**Follow up enquiries:**

What could we do to get you to a seven? (\*Seven being associated with behaviour change. This question also allows the participant to brainstorm their own ideas regarding how to increase their confidence. The EP may also help with solutions, only when asked). “What would make you more confident about the idea of becoming more active than you are now? Is there anything that you have tried in the past that was successful?”

**Potential follow-on activities:**

- **Identifying activities of interest** - this activity can be used to identify activities to increase physical activities
- **Barrier removal** - this activity aims to identify barriers for moving forward with physical activity. Each barrier identified in the Confidence Ruler is discussed in detail with the participant in order to identify:
  - The source of the barrier;
  - The perceived influence of the barrier on physical activity levels; and
  - Suggested strategies for resolving the barrier
- **Goal setting** - this can be implemented in order to resolve the barriers relating to physical activity participation or coordinating identified activities of interest



# On a scale of 1-10.....

How important?

1 2 3 4 5 6 7 8 9 10

How confident?

1 2 3 4 5 6 7 8 9 10

## Maintenance of Physical Activity Levels/Relapse Prevention

### Participant characteristics:

All participants undertake this activity. This activity has two primary objectives:

**Purpose:** (1) To identify, from the participant's perspective, strategies perceived to be effective at increasing physical activity. These strategies are collated to form a "tool-box" for the participant to utilise in the presence of relapse. (2) To use the identified strategies to develop plans for situations in which relapse is likely. This activity is comprised of two parts:

- Evaluating general situations that are associated with reduced physical activity levels (e.g. weather, illness etc); and
- Evaluating participant-specific situations (derived from the participant) that may reduce physical activity levels (e.g. pain, fatigue, medication change etc).

The activity is usually completed in the participant's last session. This strategy is particularly effective for participants who have begun to complete independent physical activity. If the participant is still in the contemplation phase, this strategy should be completed prospectively identifying strategies (based on previous attempts at behaviour change) that the participant perceives will result in increased physical activity levels.

### Sessions goals:

1. Relapse prevention – it is proposed that identifying and strategising for situations that are likely to negatively influence physical activity levels improves the likelihood of returning to the previous physical activity levels when confronted with the situation.
2. Improving outcome expectations – it is proposed that identifying the successful elements of the intervention will improve the perceived likelihood of success if the strategy is re-implemented during a period of relapse.
3. Strengthening self-efficacy – it is proposed that strategising for situations in which relapse is likely increases the participant's confidence/self-efficacy for continuing their physical activity if the situation does eventuate.
4. Conceptualising continuing activity – allows the participant to begin to think of physical activity beyond the program's duration. This future focus can result in the setting of long-term goals.
5. Goal-setting – setting of both short- and long-term goals (adhering to the principles of SMART goal setting) allows the participant to self-monitor their own behaviour. Goal setting can also resolve any identified barriers moving forward.
6. Social support – development of social networks to promote long-term adherence to activity programs is an important element of relapse prevention.

**Potential traps/situations to avoid:**

**Providing answers.** In order to positively influence an individual's outcome expectations and self-efficacy, it is important that this evaluation comes from the participant's perspective. The perspective of the Exercise Physiologist should only be given if asked for. In this case, the advice provided should be general and the participant should be asked if this applies to them. (e.g. "Which strategy do you think works best?" Rather than stating: "I think that after we identified that your children were important to you, you started doing more activity with them – writing it down also helped initially", try: "In the past, when completing this activity, some of my participants have stated that finding out what was important to them helped them identify activities that they liked and were able to keep us. Did you experience something similar to this at all?" If the participant answers yes, the Exercise Physiologist should encourage reflection of why they felt this worked for them and what strategies it influenced in turn (e.g. writing down the time spent playing with their children).

**Protocol:**

Activity Evaluation - What works, What doesn't?

**Sample dialogue:**

"Right at the start of our time together we discussed the fact that I was interested in hearing about your thoughts and feelings regarding being physically active. I'd be really interested in hearing about how you feel about all of the activities that we've done together, what you think is good, what you think isn't good. This evaluation is important as it allows us to make the program more successful for people who may be completing it after you. This is a good exercise for you as well because it allows you to identify what worked for you regarding being more active."

**Note:** This activity is introduced as a program evaluation in order to allow the participant to honestly evaluate the program elements without fear of offending the Exercise Physiologist.

**COMPLETE WHAT WORKS, WHAT DOESN'T**

**Follow-up questions:**

"Did you feel like this strategy is successful at helping people increase their physical activity levels?"

If yes: "What particular elements do you think helped? Do you think it would help people to maintain their physical activity level? Do you think this happened for you?"

If no: "Why do you feel this strategy wasn't helpful? Do you think there is a way that this strategy could be modified to make it more useful? Would you have done something different in its place? Why do you think this would help?"

Were there any strategies that you think would be helpful at increasing physical activity that weren't included in the program? Why do you think these strategies would be effective?"

**Protocol:**

**Sample dialogue:**

“We’ve made some really great progress with your physical activity. Sometimes though things happen that makes it difficult for us to keep the same level of activity up all the time. Sometimes things happen that make it difficult for us to keep going and we feel like we should give up all together. I find, however, that making a plan for these situations, rather than trying to avoid them, is a good strategy for minimising the impact of these situations when they do occur. For example, sometimes at work I have to work long hours and I’m not able to be active as it’s too dark when I get home. Instead of giving up altogether, I try to find ways indoors that I can be active. I actually have a list of exercises that I can do indoors that I do in order to feel like I’ve accomplished my physical activity for the day. This prevents me feeling bad if I miss a session.

I have a list of situations that are proposed to be negatively associated with physical activity levels. What I was hoping we could do is discuss each of these situations and whether you think that they apply to you and what advice you would give others who are facing a similar situation. In addition, in order to make this strategy more effective, I was hoping that you could give me some information on situations that you think would negatively impact your own physical activity levels and discuss the strategies or advice you would give to prevent this from occurring.?

Note: This activity is introduced as a program evaluation in order to allow the participant to honestly evaluate the program elements without fear of offending the Exercise Physiologist.

**COMPLETE MY PLAN FOR HIGH-RISK SITUATIONS**

**Follow-up questions:**

**General situations:** “Do you think that this situation would impact a person’s ability to complete physical activity?”

If yes: “If you were providing advice to someone in this situation, what would you tell them? Do you think that any of the strategies we have used previously would be effective in managing this situation?”

If no: “Why do you feel this is the case? What strategies or skills would you develop in order to ensure this is not the case?”

**Participant-specific situations:** “What influence do you think this situation would have on your physical activity levels? If you were providing advice to your future self who was in this situation, what would you tell yourself? Are there any strategies that you have undertaken previously that you think would apply to this situation? What do you think you could do to minimise the impact this situation has on your physical activity levels?”

**Follow-up activities:**

Although this activity is completed during the last session of the program, **long-term goal setting** should be undertaken. Participants should be encouraged to conceptualise what their physical activity will look like three, six and 12 months post-program. The goal-setting template can be used to formalise these plans and propose strategies to improve the likelihood of the participant successfully achieving the goal.

# What works? What doesn't?

What did I try?	Works every time/Really helps me be more active.	Works sometimes/Not really important to help me become more active.	Never works/This doesn't help me become more active.

# My plan for high-risk situations

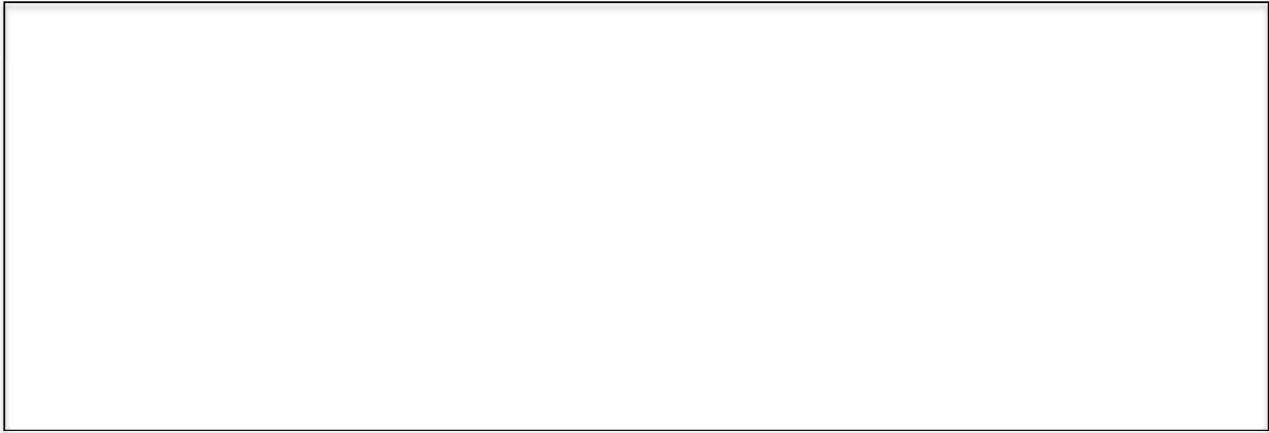
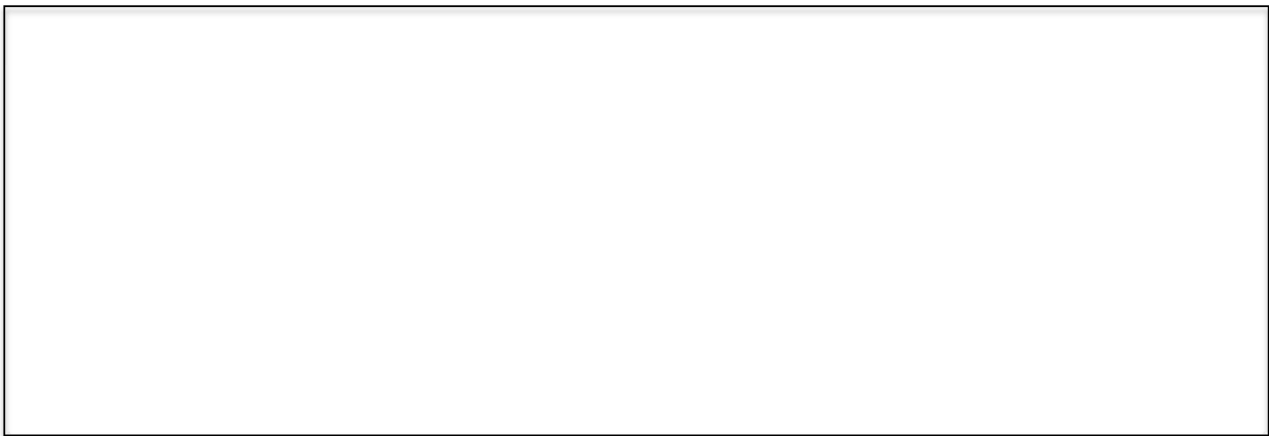
You have just started a new job. This is going to take up a lot of your time that you were previously active in. What do you do now?

You've been sick all week with a rotten cold. The last two days you've spent in bed, however, you are having a hard time getting yourself motivated. What do you do now?

You've previously had your friend or family member help you be physically active but they've decided they don't want to do it anymore. What do you do now?

The weather has been really bad lately and you only like to exercise outdoors. What do you do now?

# My plan for high-risk situations

A large, empty rectangular box with a thin black border, intended for writing a plan for high-risk situations.A second large, empty rectangular box with a thin black border, identical to the one above, for writing a plan for high-risk situations.

# Module 1

<b>Course name:</b>	<b>Aspects of Motivational Interviewing applied in the APAP</b>
<b>Period:</b>	<b>Week 1 or 2 of CRnQ Cycle</b>
<b>Duration:</b>	<b>Two (2) hours</b>
<b>Organisation:</b>	<b>Community Rehab nQ</b>
<b>Administered by:</b>	<b>Accredited Exercise Physiologists at CRnQ</b>
<b>Course coordinator:</b>	<b>Rose Newitt</b>
<b>Course level:</b>	<b>Undergraduate</b>
<b>Campus:</b>	<b>CRnQ, 16 Ryan St, Belgian Gardens</b>
<b>Delivery mode:</b>	<b>Internal and via CRnQ portal</b>
<b>Document last updated:</b>	<b>20 July 2014</b>

## 2.1 Course Description

Students will be required to apply knowledge and skills to activities in sessions of the Adapted Physical Activity Program (APAP). New skills will be developed providing students with the tools required to competently communicate in a collaborative conversation style for strengthening a person's own motivation and commitment to change.

## 2.2 Learning outcomes

By the end of the module, students should be able to:

1. Understand the 'righting reflex' and normal human reactions to the righting reflex.
2. Understand and demonstrate the basic skills in motivational interviewing (OARS):
  - a. Open questions
  - b. Affirmations
  - c. Reflections
  - d. Summarise



## 2.3 Module content

(The following course content has been acquired from a Motivational Interviewing Workshop conducted by William R. Miller in Brisbane in 2012)

### Motivational Interviewing Exercise

*What is motivation?*

*“Motivation can be understood not as something that one has, but as something that one does.*

*It involves recognizing a problem, searching for a way to change, and then beginning and sticking with that change strategy.”*

### 2.4 Practice #1

- Work with one other person
- One will be the speaker
- One will be a helper
- Switch roles when I tell you to reverse

#### Speaker's topic

Something about yourself that you

- want to change
- need to change
- should change
- have been thinking about changing

but you haven't changed yet i.e. – something you're ambivalent about

#### Helper

- Find out what the person wants to change
- Explain why the person should make this change
- Give at least three specific benefits that would result from making the change
- Tell the person how they could make the change
- Emphasise how important it is to change
- Persuade the person to do it.
- If you meet resistance, repeat the above

Switch roles

## 2.5 The Righting Reflex

Healthcare workers have a powerful desire to fix things. Why is this a problem? People have a tendency to resist persuasion, especially when ambivalent. Making people feel bad doesn't help them to change.

Normal human reactions to the righting reflex (teach/direct)		
Invalidated	Resist	Withdraw
Not respected	Arguing	Disengaged
Not understood	Discounting	Disliking
Not heard	Defensive	Inattentive
Angry	Oppositional	Passive
Ashamed	Denying	Avoid/leave
Uncomfortable	Delaying	Not return
Unable to change	Justifying	

## 2.6 Practice #2

### Speaker's topic

Something about yourself that you

- want to change
- need to change
- should change
- have been thinking about changing

but you haven't changed yet i.e. – something you're ambivalent about

### Listener

- Listen carefully with a goal of understanding the dilemma; give no advice
- Ask these four open questions
  - Why would you want to make this change?
  - How might you go about it in order to succeed?
  - What are the three best reasons for you to do it?
  - On a scale from 0 to 10, how important would you say that it is for you to make this change?
    - Follow-up: And why are you at \_\_\_\_\_ and not zero?
  - Give a short summary/reflection of the speaker's motivations for change
  - Then ask: "So what do you think you'll do?"
    - And just listen with interest

Normal human responses to a listen/evoke/empathic style		
Affirmed	Accept	Approach
Understood	Open	Talk more
Accepted	Undefensive	Liking
Respected	Interested	Engaged
Heard	Cooperative	Activated
Comfortable/safe	Listening	Come back
Empowered		
Hopeful/able to change		

### A change of role

- You don't have to make change happen. You can't.
- You don't have to come up with all the answers. You probably don't have the best ones.
- You're not wrestling. You're dancing.

### 2.7 Definition of Motivational Interviewing (MI)

*MI is a collaborative, goal-oriented style of communication with particular attention to the language of change. It is designed to strengthen personal motivation for and commitment to a specific goal by eliciting and exploring the person's own reasons for change within an atmosphere of acceptance and compassion.*

### 2.8 Basic skills in MI - OARS

#### Open questions

#### Affirmations

#### Reflections

#### Summarise

**Open questions** – Open the door, encourage the participant to talk; do not invite a short answer. Example: What is it you like/don't like about physical activity?

Which are open questions:

- What brings you here today?
- Was your family religious?
- Don't you think it's time for a change?
- Is this an open question?

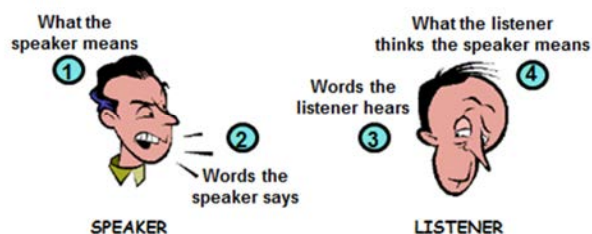
### Some tips:

- Ask fewer questions
- Don't ask three questions in a row
- Ask more open than closed questions
- Offer two reflections per question asked
- Think engagement rather than assessment as your initial task

**Affirmation** - Appreciate a strength or positive action; should be both true and genuine; strengthen working alliance. Example: You're a determined person. I like the way you said that. I appreciate your openness and honesty.

**Reflection** – It makes a guess about what the person means.

### Thomas Gordon's Model of Listening



*Simple reflections* – add little or nothing to what the person has said: repeat or slight rephrase.

*Complex reflections* – make a guess about meaning that has not been directly stated: paraphrase, metaphor, reflection of feeling.

### Summary

- Collect material that has been offered. Example: So far you've told me that....
- Link content with something discussed earlier. Example: That sounds a bit like what you told me about that lonely feeling you get sometimes.
- Transition to a new task by drawing together what has happened. Example: Before I ask you the questions I mentioned earlier, let me summarise what you've told me so far and see if I've missed something important. You came in because you wanted to start being physically active, but you've tried before and....

Offering information and advice

### 2.9 Practice #3

In groups of 3.

#### Speaker

Something you should understand about me is that I am \_\_\_\_\_(adjective).

## Listeners

- Ask: Do you mean that you \_\_\_\_\_?
- The speaker may answer only 'yes' or 'no' (no elaboration)
- When the listeners have asked at least five questions and you have some sense of what the speaker meant, rotate: the next person (to the speaker's right) becomes the speaker.

## 2.10 Practice #3a

### Listeners

- First, *think* (but don't speak) this question:
  - Do you mean that you \_\_\_\_\_?
- Erase the words, "Do you mean that"
- Make it a statement (inflect *down* at the end)
- And you've got a reflection
- It makes a guess about what the person means
- The speaker then replies: essentially 'yes' or 'no' and elaborate a bit what you do mean
- And now the listeners reflect the new information

### Rotate roles:

- When the listeners have offered at least five reflections and have a sense that they understand what the speaker meant
- Then the next person becomes the speaker and you repeat the exercise
- Go around again if needed

## 2.11 Practice #4

(in groups of 3)

### Speaker's topic

- Something that you feel two ways about, for example:
  - Some change that you might make
  - A political party or person
  - A social and/or ethical issue
  - Motivational interviewing
  - A decision that you need to make

### Listener

- Use only OARS
- Offer no opinion or advice – keep out of it
- Make no attempt to influence or 'fix' it
- Seek solely to understand the ambivalence

- Try to keep your balance; don't take sides

### **Observer**

- Count instances of O, A, R and S

Make notes of particularly good examples of each

### Appendix 5 APAP fidelity checklist

Participant Name:

Clinician Name:

PA SOC:

First session date:

Last session date:

3-month follow up date:

	Goal of session	Elements of Intervention	By whom	Adherence		Any Changes? Please state reasons
				Yes	No	
<b>STEP 1: Pre-participation assessment</b>						
<b>Purpose is to determine information about the participant's health condition, impairments, activity limitations, participation restrictions and personal and environmental factors in order to individually tailor the program. All participants undertake the following activities</b>						
New to CRnQ service or APAP con-current with other CRnQ program	Assess all domains of the ICF; inform participant about the APAP & research & invite to participate; develop rapport	Comprehensive Assessment	AEP & I-P Team			
APAP as stand-alone program following other CRnQ program	Inform participant about the APAP & research & invite to participate; ensure participant information up-to-date; develop rapport	Brief Review	AEP			
Consent to participate in research	To ensure participant fully understands what research involves	Information sheet Informed consent	Research Assistant			
Baseline Measures	Obtain baseline measures; elicit change talk	Stage of change questionnaire Decisional balance scale Social support scale Modified MS Self-efficacy scale PA Scale for Individuals with Physical Disabilities Pre-screening for risk factors PA Profile questions 6MWT (distance, HR) Summarise @ end of questionnaires to elicit discussion	AEP			
Information sharing session	Build shared understanding of PA; provide definition of PA; discuss benefits of PA for adults in general and with health conditions	Show video  Follow up questions (Movie Review)	AEP			

	Goal of session	Elements of Intervention	By whom	Adherence Yes      No	Any changes? Please state reasons.
<b>STEP 2a: Individualised behaviour change strategies</b> <b>STEP 2b: Exercise prescription</b> <b>STEP 2c: Community Access/Adaptation</b> <b>Stage Classification: Following the introductory sessions, participants will take part in activities matched to their individual stage of change classification</b>					

**Stage 1 & 2 Activities – Emphasis on developing discrepancy between participant’s current PA behaviour and their broader goals and values, evaluating the benefits and barriers relating to PA participation and eliciting change talk for increasing PA levels.**

Value card sort	ID values & potential intrinsic motivators for change;	Value card sort exercise Value card sort activity sheet completed	AEP			
Decisional balance I & C rulers Time audit Leisure diagnostic battery	Explores ambivalence Elicits change talk IDs barriers for change ID opportunities for change IDs leisure/PA interests Sets goals for increasing PA Discuss current PA levels ID opportunities to be more physically active Fostering social support	Decisional balance sheet Importance & confidence rulers Personal time audit Leisure diagnostic battery	AEP			

**Stage 3 Activities – Emphasis on strategies that directly promote increased PA levels such as goal setting, reward systems and self-monitoring**

Short & long-term goal setting PA monitoring	ID barriers for change ID opportunities for change ID strategies to promote change ID leisure/PA interests Sets goals for increasing PA Discuss current PA levels Look for opportunities to be more physically active Set plans for becoming more active	Leisure diagnostic battery PA monitoring Goal setting Reward systems Social support Evaluation activities (what works, what doesn't)	AEP			
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# ADULT PRE-EXERCISE SCREENING TOOL

This screening tool does not provide advice on a particular matter, nor does it substitute for advice from an appropriately qualified medical professional. No warranty of safety should result from its use. The screening system in no way guarantees against injury or death. No responsibility or liability whatsoever can be accepted by Exercise and Sports Science Australia, Fitness Australia or Sports Medicine Australia for any loss, damage or injury that may arise from any person acting on any statement or information contained in this tool.

Name: \_\_\_\_\_

Date of Birth: \_\_\_\_\_ Male  Female  Date: \_\_\_\_\_

## STAGE 1 (COMPULSORY)

AIM: to identify those individuals with a known disease, or signs or symptoms of disease, who may be at a higher risk of an adverse event during physical activity/exercise. This stage is self administered and self evaluated.

Please circle response

1.	Has your doctor ever told you that you have a heart condition or have you ever suffered a stroke?	Yes	No
2.	Do you ever experience unexplained pains in your chest at rest or during physical activity/exercise?	Yes	No
3.	Do you ever feel faint or have spells of dizziness during physical activity/exercise that causes you to lose balance?	Yes	No
4.	Have you had an asthma attack requiring immediate medical attention at any time over the last 12 months?	Yes	No
5.	If you have diabetes (type I or type II) have you had trouble controlling your blood glucose in the last 3 months?	Yes	No
6.	Do you have any diagnosed muscle, bone or joint problems that you have been told could be made worse by participating in physical activity/exercise?	Yes	No
7.	Do you have any other medical condition(s) that may make it dangerous for you to participate in physical activity/exercise?	Yes	No

**IF YOU ANSWERED 'YES' to any of the 7 questions, please seek guidance from your GP or appropriate allied health professional prior to undertaking physical activity/exercise**

**IF YOU ANSWERED 'NO' to all of the 7 questions, and you have no other concerns about your health, you may proceed to undertake light-moderate intensity physical activity/exercise**

I believe that to the best of my knowledge, all of the information I have supplied within this tool is correct.

Signature \_\_\_\_\_ Date \_\_\_\_\_



## EXERCISE INTENSITY GUIDELINES

INTENSITY CATEGORY	HEART RATE MEASURES	PERCEIVED EXERTION MEASURES	DESCRIPTIVE MEASURES
SEDENTARY	< 40% HRmax	Very, very light RPE# < 1	<ul style="list-style-type: none"> <li>Activities that usually involve sitting or lying and that have little additional movement and a low energy requirement</li> </ul>
LIGHT	40 to <55% HRmax	Very light to light RPE# 1-2	<ul style="list-style-type: none"> <li>An aerobic activity that does not cause a noticeable change in breathing rate</li> <li>An intensity that can be sustained for at least 60 minutes</li> </ul>
MODERATE	55 to <70% HRmax	Moderate to somewhat hard RPE# 3-4	<ul style="list-style-type: none"> <li>An aerobic activity that is able to be conducted whilst maintaining a conversation uninterrupted</li> <li>An intensity that may last between 30 and 60 minutes</li> </ul>
VIGOROUS	70 to <90% HRmax	Hard RPE# 5-6	<ul style="list-style-type: none"> <li>An aerobic activity in which a conversation generally cannot be maintained uninterrupted</li> <li>An intensity that may last up to about 30 minutes</li> </ul>
HIGH	≥ 90% HRmax	Very hard RPE# ≥ 7	<ul style="list-style-type: none"> <li>An intensity that generally cannot be sustained for longer than about 10 minutes</li> </ul>

# = Borg's Rating of Perceived Exertion (RPE) scale, category scale 0-10

# ADULT PRE-EXERCISE SCREENING TOOL

## STAGE 2 (OPTIONAL)

Name: \_\_\_\_\_

Date of Birth: \_\_\_\_\_ Date: \_\_\_\_\_

AIM: To identify those individuals with risk factors or other conditions to assist with appropriate exercise prescription. This stage is to be administered by a qualified exercise professional.

		RISK FACTORS
1.	Age _____ Gender _____	≥ 45yrs Males or ≥ 55yrs Females +1 risk factor
2.	Family history of heart disease (eg: stroke, heart attack) Relative      Age      Relative      Age <input type="checkbox"/> Father      _____ <input type="checkbox"/> Mother      _____ <input type="checkbox"/> Brother      _____ <input type="checkbox"/> Sister      _____ <input type="checkbox"/> Son      _____ <input type="checkbox"/> Daughter      _____	If male < 55yrs = +1 risk factor If female < 65yrs = +1 risk factor Maximum of 1 risk factor for this question
3.	Do you smoke cigarettes on a daily or weekly basis or have you quit smoking in the last 6 months? Yes No If currently smoking, how many per day or week? _____	If yes, (smoke regularly or given up within the past 6 months) = +1 risk factor
4.	Describe your current physical activity/exercise levels: Sedentary      Light      Moderate      Vigorous <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Frequency _____ sessions per week Duration _____ minutes per week	If physical activity level < 150 min/ week = +1 risk factor If physical activity level ≥ 150 min/ week = -1 risk factor (vigorous physical activity/ exercise weighted x 2)
5.	Please state your height (cm) _____ weight (kg) _____	BMI = _____ BMI ≥ 30 kg/m <sup>2</sup> = +1 risk factor
6.	Have you been told that you have high blood pressure? Yes No	If yes, = +1 risk factor
7.	Have you been told that you have high cholesterol? Yes No	If yes, = +1 risk factor
8.	Have you been told that you have high blood sugar? Yes No	If yes, = +1 risk factor

Note: Refer over page for risk stratification.

STAGE 2 Total Risk Factors =



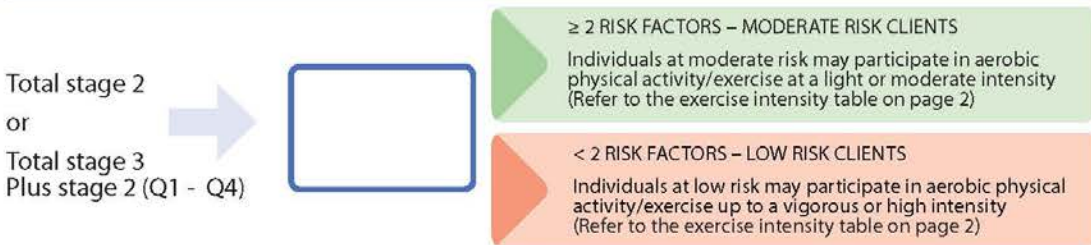
9. Have you spent time in hospital (including day admission) for any medical condition/illness/injury during the last 12 months? Yes No	If yes, provide details
10. Are you currently taking a prescribed medication(s) for any medical conditions(s)? Yes No	If yes, what is the medical condition(s)?
11. Are you pregnant or have you given birth within the last 12 months? Yes No	If yes, provide details. I am _____ months pregnant or postnatal (circle).
12. Do you have any muscle, bone or joint pain or soreness that is made worse by particular types of activity? Yes No	If yes, provide details

## STAGE 3 (OPTIONAL)

**AIM:** To obtain pre-exercise baseline measurements of other recognised cardiovascular and metabolic risk factors. This stage is to be administered by a qualified exercise professional. (Measures 1, 2 & 3 – minimum qualification, Certificate III in Fitness; Measures 4 and 5 minimum level, Exercise Physiologist\*).

	RESULTS		RISK FACTORS
1. BMI (kg/m <sup>2</sup> )		BMI ≥ 30 kg/m <sup>2</sup> = +1 risk factor	
2. Waist girth (cm)		Waist > 94 cm for men and > 80 cm for women = +1 risk factor	
3. Resting BP (mmHg)		SBP ≥ 140 mmHg or DBP ≥ 90 mmHg = +1 risk factor	
4. Fasting lipid profile*		Total cholesterol ≥ 5.20 mmol/L = +1 risk factor	
Total cholesterol		HDL cholesterol > 1.55 mmol/L = -1 risk factor	
HDL		HDL cholesterol < 1.00 mmol/L = +1 risk factor	
Triglycerides		Triglycerides ≥ 1.70 mmol/L = +1 risk factor	
LDL		LDL cholesterol ≥ 3.40 mmol/L = +1 risk factor	
5. Fasting blood glucose*		Fasting glucose ≥ 5.50 mmol = +1 risk factor	
		STAGE 3 Total Risk Factors =	

## RISK STRATIFICATION



Note: If stage 3 is completed, identified risk factors from stage 2 (Q1-4) and stage 3 should be combined to indicate risk. If there are extreme or multiple risk factors, the exercise professional should use professional judgement to decide whether further medical advice is required.

## Appendix 7 Request for medical advice

Dear

Re: Request for medical opinion – commencement of physical activity intervention for (participant name)

(Participant name) has been referred to our Adapted Physical Activity Program (APAP). The main aim of the APAP is to assist people with neurological conditions who are not physically active on a regular basis to find ways to increase their physical activity and thereby improve their health and functioning.

(Participant name's) main aims are to (insert goals). As you would be aware, (participant name) has/had a (condition/injury), therefore, the purpose of this letter is to provide you with an outline of my intended course of action (attached) and ask you to indicate whether you think the plan is medically appropriate, together with any suggestions or recommendations you would have for working with your patient.

I would be grateful if you could complete the section below and give it to (participant name) to return to me, or by e-mail or fax (details above). Thank you so much.

Regards

(Clinician & student name and signature)

I have reviewed the physical activity promotion plan outlined by (clinician/student name) for my patient (participant name), provided for me on (date). I believe the type of activities as well as the intensity, duration and frequency are (check one of the following)

\_\_\_\_\_ Appropriate as described

\_\_\_\_\_ Appropriate, providing the recommendations below are followed

\_\_\_\_\_ Not appropriate and the intervention should not proceed

Name (printed)	Signed	Date

Recommendations (if any)

## Intervention Outline for (participant name)

Prepared by: (Clinician/student name)

Date:

The activities promoted through this intervention will include (then list the following)

- Main types of activities (eg. Exercises, water activities, walking etc)
- Intensity of activities described in two ways
  - Light, moderate, vigorous or very vigorous
  - Where on the Borg RPE scale (1-20 and verbal descriptor)
- Frequency (x/week) and duration (time)
- Whether they will be supervised or unsupervised or, if a mixture, a precise description

## Appendix 8 EP interview guide

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### IMPLEMENTATION

1. *What is your understanding of the goals of the APAP?*

**Prompts:** Were the goals of the APAP clear from the workshop and training? How were you able to apply them to participants during each session? Did you manage them with all participants? What were the challenges? What was good about the program? What would you say are the essential or necessary elements of the APAP? What adaptations, if any, would you make to some of the elements of the APAP?

2. *In relation to the APAP training, what was the learning process for you?*

**Prompts:** What changes would you recommend to the training?

### EFFECTIVENESS

3. *Thinking about the participants you took through the APAP, what outcomes did they achieve?*

**Prompts:** Did they increase the amount of physical activity they do? How did they react to the intervention? Were there any unanticipated outcomes, positive or negative?

### REACH

4. *How well is the APAP reaching the targeted number of participants?*

**Prompts:** For participants at CRnQ who aren't sufficiently physically active, how do you suggest we reach them?

### ADOPTION

5. *How does the APAP contribute to CRnQ's service goals or mission?*

**Prompts:** What capacity, resources or expertise does CRnQ have to enable adoption of the APAP? What are the barriers to adoption of the APAP at CRnQ?

### MAINTENANCE

6. *When the research has finished, what's going to help keep the APAP going?*

**Prompts:** Are there sufficient human resources to maintain the program? Is there an adequate pipeline for participant referrals to the APAP?

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## Appendix 9 CRnQ team interview guide

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### IMPLEMENTATION

1. *What is your understanding of the goals of the APAP?*

**Prompts:** Were the goals of the APAP clear from the workshop and from Rose? What was good about the program? What adaptations, if any, would you make to the APAP?

- 2.

### EFFECTIVENESS

3. *Thinking about some of your participants who did the APAP, what outcomes did they achieve?*

**Prompts:** Did they increase the amount of physical activity they do? How did they react to the intervention? Were there any unanticipated outcomes, positive or negative?

### REACH

4. *How well is the APAP reaching the targeted participants?*

**Prompts:** For participants at CRnQ who aren't sufficiently physically active, how do you suggest we reach them?

### ADOPTION

5. *How does the APAP contribute to CRnQ's service goals or mission?*

**Prompts:** What capacity, resources or expertise does CRnQ have to enable adoption of the APAP? What are the barriers to adoption of the APAP at CRnQ? How do you see the APAP working as a health promotion program?

### MAINTENANCE

6. *When the research has finished, what's going to help keep the APAP going?*

**Prompts:** Are there sufficient human resources to maintain the program? Is there an adequate pipeline for participant referrals to the APAP?

---

**The Physical Activity Scale for Individuals with Physical Disabilities (Was...**

This questionnaire is about your current level of physical activity and exercise. Please remember there are no right or wrong answers. We simply need to assess your current level of activity.

## Leisure Time Activity

This questionnaire is about your current level of physical activity and exercise. Please remember there are no right or wrong answers. We simply need to assess your current level of activity.

**\*5. During the past 7 days , how often did you engage in stationary activities such as reading, watching TV, computer games or doing handcrafts?**

- Never (Go to question #7)
- Seldom (1-2d)
- Sometimes (3-4d)
- Often (5-7d)

What were these activities?

**6. On average, how many hours per day did you spend in these stationary activities?**

- Less than 1hr
- 1 but less than 2hr
- 2-4hr
- More than 4hr

**\*7. During the past 7 days, how often did you walk, wheel, push outside your home other than specifically for exercise, for example, getting to work or class, walking the dog, shopping or other errands?**

- Never (Go to question #9)
- Seldom (1-2d)
- Sometimes (3-4d)
- Often (5-7d)

**8. On average, how many hours per day did you spend wheeling or pushing outside your home?**

- Less than 1hr
- 1 but less than 2hr
- 2-4hr
- More than 4hr

**\*9. During the past 7 days, how often did you engage in light sport or recreational activities such as bowling, golf with a cart, hunting or fishing, darts, billiards or pool, therapeutic exercise (physical or occupational therapy, stretching, use of a standing frame) or other similar activities?**

- Never (Go to question #11)
- Seldom (1-2d)
- Sometimes (3-4d)
- Often (5-7d)

What were these activities?

**10. On average, how many hours per day did you spend in these light sport or recreational activities?**

- Less than 1hr
- 1 but less than 2hr
- 2-4hr
- More than 4hr

**\* 11. During the past 7 days, how often did you engage in moderate sport and recreational activities such as doubles tennis, softball, golf without a cart, ballroom dancing, wheeling or pushing for pleasure or other similar activities?**

- Never (Go to question #13)
- Seldom (1-2d)
- Sometimes (3-4d)
- Often (5-7d)

What were these activities?

**12. On average, how many hours per day did you spend in these moderate sport and recreational activities?**

- Less than 1hr
- 1 but less than 2hr
- 2-4hr
- More than 4hr

**\* 13. During the past 7 days, how often did you engage in strenuous sport and recreational activities such as jogging, wheelchair racing (training), off-road pushing, swimming, aerobic dance, arm cranking, cycling (hand or leg), singles tennis, rugby, basketball, walking with crutches and braces, or other similar activities?**

- Never (Go to question #15)
- Seldom (1-2d)
- Sometimes (3-4d)
- Often (5-7d)

What were these activities?

**14. On average, how many hours per day did you spend in these strenuous sport or recreational activities?**

- Less than 1hr
- 1 but less than 2hr
- 2-4hr
- More than 4hr

**\* 15. During the past 7 days, how often did you do any exercise specifically to increase muscle strength and endurance such as lifting weights, push-ups, pull-ups, dips, or wheelchair push-ups etc?**

- Never (Go to question #17)
- Seldom (1-2d)
- Sometimes (3-4d)
- Often (5-7d)

What were these activities?

**16. On average, how many hours per day did you spend in these exercises to increase muscle strength and endurance?**

- Less than 1hr
- 1 but less than 2hr
- 2-4hr
- More than 4hr

## Household Activity

**\*17. During the past 7 days, how often have you done any light housework, such as dusting, sweeping floors or washing dishes?**

- Never (Go to question #19)
- Seldom (1-2d)
- Sometimes (3-4d)
- Often (5-7d)

**18. On average, how many hours per day did you spend doing light housework?**

- Less than 1hr
- 1 but less than 2hr
- 2-4hr
- More than 4hr

**\*19. During the past 7 days, how often have you done any heavy housework or chores such as vacuuming, scrubbing floors, washing windows, or walls, etc?**

- Never (Go to question #21)
- Seldom (1-2d)
- Sometimes (3-4d)
- Often (5-7d)

**20. On average, how many hours per day did you spend doing heavy housework or chores?**

- Less than 1hr
- 1 but less than 2hr
- 2-4hr
- More than 4hr

**\*21. During the past 7 days, how often have you done home repairs like carpentry, painting, furniture refinishing, electrical work, etc?**

- Never (Go to question #23)
- Seldom (1-2d)
- Sometimes (3-4d)
- Often (5-7d)

**22. On average how many hours per day did you spend doing home repairs?**

- Less than 1hr
- 1 but less than 2hr
- 2-4 hr
- More than 4hr

**\*23. During the past 7 days, how often have you done lawn work or yard care including mowing, leaf or snow removal, tree or bush trimming, or wood chopping, etc?**

- Never (Go to question #25)
- Seldom (1-2d)
- Sometimes (3-4d)
- Often (5-7d)

**24. On average, how many hours per day did you spend doing lawn work?**

- Less than 1hr
- 1 but less than 2hr
- 2-4hr
- More than 4hr

**\*25. During the past 7 days, how often have you done outdoor gardening?**

- Never (Go to question #27)
- Seldom (1-2d)
- Sometimes (3-4d)
- Often (5-7d)

**26. On average, how many hours per day did you spend doing outdoor gardening?**

- Less than 1hr
- 1 but less than 2hr
- 2-4hr
- More than 4hr

**\*27. During the past 7 days, how often did you care for another person, such as children, a dependent spouse, or another adult?**

- Never (Go to question #29)
- Seldom (1-2d)
- Sometimes (3-4d)
- Often (5-7d)



**28. On average, how many hours per day did you spend caring for another person?**

- Less than 1hr
- 1 but less than 2hr
- 2-4hr
- More than 4hr

## Work-related Activity

**\*29. During the past 7 days, how often did you work for pay or as a volunteer?  
(Exclude work that mainly involved sitting with slight arm movement such as light office work, computer work, light assembly line work, driving bus or van, etc.)**

- Never (Go to END)
- Seldom (1-2d)
- Sometimes (3-4d)
- Often (5-7d)

**30. On average, how many hours per day did you spend working for pay or as a volunteer?**

- Less than 1hr
- 1 but less than 4hr
- 5 but less than 8hr
- 8hr or more

**Physical Activity Stage of Change (Marcus, 2003)**

For each of the following questions, please answer Yes or No. Physical activity or exercise in as walking briskly, jogging, bicycling, swimming, or any activity in which the exertion is at least moderate.

**\* 1. I am currently physically active.**

Yes (Go to question 2)

No (Go to question 2)

**\* 2. I intend to become more physically active in the next six (6) months**

Yes (If No to question 1 and Yes to question 2, go to end; If Yes to question 1 & 2, go to question 3)

No ( If No to question 1 & 2, go to end)

For activity to be regular, it must add up to a total of 30 minutes or more per day and be done at least 5 days per week. For example, you could take one 30-minute walk or take three 10-minute walks for a daily total of 30 minutes.

**3. I currently engage in regular physical activity.**

Yes (If Yes to question 3, go to question 4)

No (If No to question 3, go to end)

**4. I have been regularly physically active for the past 6 months.**

Yes

No

**Social Support (Marcus, 2003)**

The following is a list of things people might do or say to someone who is trying to do p  
Please read and answer each question. If you are not physically active, then some of th  
you.

Family Support

**\*31. Please rate how often has anyone living in your household sa  
described during the past three (3) months?**

	None	Rarely	A few times
1. Did physical activities with me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify)	<input type="text"/>		
2. Offered to do physical activities with me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify)	<input type="text"/>		
3. Gave me helpful reminders to be physically active (i.e. Are you going to do your activity tonight?).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify)	<input type="text"/>		
4. Gave me encouragement to stick with my activity program.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify)	<input type="text"/>		
5. Changed their schedule so we could do physical activities together.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify)	<input type="text"/>		
6. Discussed physical activity with me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify)	<input type="text"/>		
7. Complained about the time I spend doing physical activity.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify)	<input type="text"/>		
8. Criticised me or made fun of me for doing physical activity.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify)	<input type="text"/>		
9. Gave me rewards for being physically active (i.e.Gave me something I liked).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify)	<input type="text"/>		
10.Planned for physical activities on recreational outings.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify)	<input type="text"/>		
11.Helped plan events around my physical activities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

12. Asked me for ideas on how they can be more physically active.

Other (please specify)

13. Talked about how much they like to do physical activity.

Other (please specify)

Friend Support

**\*32. Please rate how often your friends, acquaintances or co-workers have said or done what is described during the past three (3) months.**

	None	Rarely	A few times	Often	Very often	Does not apply
1. Did physical activities with me. Other (please specify) <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Offered to do physical activities with me. Other (please specify) <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Gave me helpful reminders to be physically active (i.e. "Are you going to do your activity tonight?"). Other (please specify) <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Gave me encouragement to stick with my activity program. Other (please specify) <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Changed their schedule so we could do physical activities together. Other (please specify) <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Discussed physical activity with me. Other (please specify) <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Complained about the time I spend doing physical activity. Other (please specify) <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. Criticised me or made fun of me for doing physical activity. Other (please specify) <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. Gave me rewards for being physically active (i.e. Gave me something I liked). Other (please specify) <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. Planned for physical activities on recreational outings. Other (please specify) <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. Helped plan events around my physical activities. Other (please specify) <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. Asked me for ideas on how they can be more physically active.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

13. Talked about how much they like to do physical activity.

Other (please specify)



### Decisional Balance (Marcus, 2003)

This questionnaire measures perceived benefits of and barriers to physical activity.

**34. Please rate how important each of these statements is in your decision to be physically active. In each case, think about how you feel RIGHT now you have felt in the past or would like to feel.**

	Not at all important	Slightly important	Modera importa
1. I would have more energy for my family and friends if I were regularly physically active.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify)	<input type="text"/>		
2. Regular physical activity would help me relieve tension.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify)	<input type="text"/>		
3. I think I would be too tired to do my daily work after being physically active.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify)	<input type="text"/>		
4. I would feel more confident if I were regularly physically active.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify)	<input type="text"/>		
5. I would sleep more soundly if I were regularly physically active.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify)	<input type="text"/>		
6. I would feel good about myself if I kept my commitment to being regularly physically active.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify)	<input type="text"/>		
7. I would find it difficult to find a physical activity that I enjoy and that is not affected by bad weather.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify)	<input type="text"/>		
8. I would like my body better if I were regularly physically active.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify)	<input type="text"/>		
9. It would be easier for me to perform routine physical tasks if I were regularly physically active.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify)	<input type="text"/>		
10. I would feel less stressed if I were regularly physically active.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify)	<input type="text"/>		
11. I feel uncomfortable when I am physically active because I get out of breath and my heart beats very fast.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

12. I would feel more comfortable with my body if I were regularly physically active.

Other (please specify)

13. Regular physical activity would take too much of my time.

Other (please specify)

14. Regular physical activity would help me have a more positive outlook on life.

Other (please specify)

15. I would have less time for my family and friends if I were regularly physically active.

Other (please specify)

16. At the end of the day, I am too exhausted to be physically active.

Other (please specify)

## Appendix 14 APAP participant satisfaction questionnaire

Participant:

Interviewer: Rose Newitt

Date:                      Day:                      Time commenced:                      Time completed:

### Protocol

- Explain reason for interview
- Gain permission to record
- Explain that there are no right or wrong answers
- Turn recorder on
- Confirmation that the participant understands the nature of the questions and that they are not obliged to answer any if they do not wish to.
- At conclusion of interview, turn recorder off and ask if there is anything they would like to add now that they are no longer being recorded.

**Q1.** The first question relates to the good parts of the program.

- What were the main benefits of this program for you?
- What was your favourite part?

**Q2.** The second question relates to the negative points of the program.

- What were the disadvantages of being in this program?
- What was your least favourite part?

**Q3.** Did you get what you expected out of the program?

- What were your expectations coming into this?

**Q4.** Do you think you achieved some of your goals by participating in this program?

- Was there anything else that could have been done to help you achieve your goals?

Q5. Do you think this program helped you become more physically active?

- What parts of the program did you find particularly helpful?

Q6. Did you find the activities enjoyable or fun?

- What could have been done to make this more enjoyable?

Q7. If you were trying to help other adults with health conditions become more active, would you recommend they do this program?

- Why/Why not?

**Appendix 15 PASIPD scoring algorithm**

**Scoring: PASIPD**

**Item multipliers**

1. Not scored
2. 2.5
3. 3.0
4. 4.0
5. 8.0
6. 5.5
7. 1.5
8. 4.0
9. 4.0
10. 4.0
11. 4.0
12. 1.5
13. 2.5

**Average Hours Per Day Calculation for Items 2–12**

Category	Reported (hr/d)	Average (hr/d)
Seldom (1–2d)	<1	.11
	1–2	.32
	2–4	.64
	>4	1.07
Sometimes (3–4d)	<1	.25
	1–2	.75
	2–4	1.50
	>4	2.50
Often (5–7d)	<1	.43
	1–2	1.29
	2–4	2.57
	>4	4.29

**Average Hours Per Day Calculation for Item 13**

Category	Reported (hr/d)	Average (hr/d)
Seldom (1–2d)	<1	.12
	1–4	.64
	5–8	1.39
	>8	1.93
Sometimes (3–4d)	<1	.28
	1–4	1.5
	5–8	3.11
	>8	4.5
Often (5–7d)	<1	.49
	1–4	2.57
	5–8	5.57
	>8	7.71

NOTE. PASIPD score = sum of item multiplier × average hours per day over items 2–13.

**APAP explanation for participants**

- Successful physical activity program previously run with people who have had a stroke or traumatic brain injury or cerebral palsy
- The aim of the program is to get you more active in your life to become healthier
- 10 one-on-one sessions over 10-12 weeks
- Sessions can take place in your home and in the community
- Sessions involve activities that explore what really matters to you; improve your motivation toward physical activity and relapse prevention and includes:
  - Watching a short video
  - Filling out forms
  - Chatting
  - Physical activity
- The program works towards helping you to be active independently
- You have two options:
  1. You can participate in the program without participating in the research
  2. You can participate in the program and the research, which will evaluate the program, so we'd be asking you what you think about the program, and this may include:
    - Survey questionnaires
    - Interviews

## Appendix 17 EP scope of service at CRnQ

### Services provided by Exercise Physiologists at Community Rehab nQ

#### Vision:

People with neurological conditions who reside in northern Queensland have a physically active lifestyle within their community.

#### Mission:

Empower people with neurological conditions to improve their functional outcomes, mental health and/or social re-entry by giving them the skills, knowledge and confidence needed to commence and maintain a physically active lifestyle.

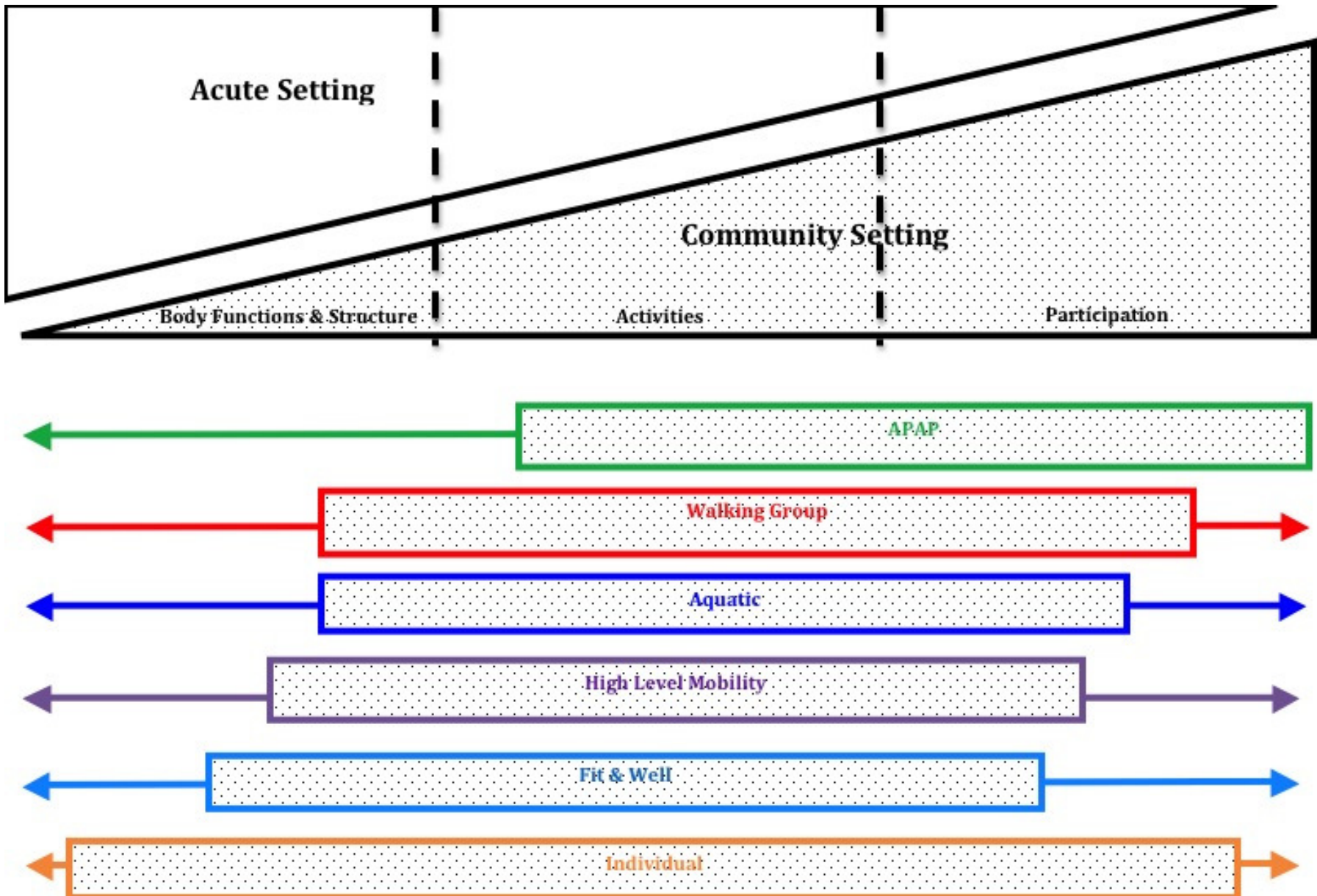
#### Scope of service:

- For individuals with neurological conditions who are participants of Community Rehab nQ.
- For people in the prevention, acute, sub-acute or chronic stage of disability.
- For people with a potentially disabling condition or with a mild, moderate or severe disability.
- Centre-based with visits to home and community to support participation in physical activity.

#### Strategies:

1. Individuals with neurological conditions
  - a. Equip participants with knowledge and skills to become physically active and then remain physically active post-program.
  - b. Assist participants to explore their potential and work out ways to optimize their current health, and prevent sickness and poor health in the future.
  - c. Assist participants to find and access services that promote physical activity (e.g., finding programs, strategies for pool access, joining sports clubs) in *their* community
  - d. Equip participants with the knowledge and skills to create new opportunities and overcome barriers so they can be physically active across their lifespan including:
    - i. Identifying what worked and what didn't (past successes);
    - ii. Planning for high-risk situations;
    - iii. Providing education on physical activity progressions;
    - iv. Finding and accessing new services and facilities; and
    - v. Building support networks eg. Natural support, peer and paid support
2. Community Rehab nQ Service
  - a. Offer a range of individual and group structured programs that focus on each individual participant increasing and sustaining physical activity across the lifespan.
    - i. Adapted Physical Activity Program
    - ii. Walking group
    - iii. Aquatic group
    - iv. High level mobility group
    - v. Fit and well program
    - vi. Individual consultations sessions
  - b. Contribute to other programs at Community Rehab nQ to enhance knowledge and engagement in physical activity
  - c. Link with and strengthen community organisations that are designed to support people with neurological conditions to be physically active e.g. Sporting Wheelies
  - d. Link with and strengthen mainstream organisations and services to support people with neurological conditions to be physically active e.g. PCYC
3. Community of northern Queensland
  - a. Identify opportunities for physical activity within the community e.g. Community Connections Project.
  - b. Strive to minimise physical, attitudinal and social barriers to physical activity in northern Queensland.

Appendix 18 EP delivered programs as per ICF areas of functioning





APAP – focus on participation in a life situation to promote a physically active lifestyle; through modification & adaption of activity; and that leads to improved body functions & structure (e.g. CV health & fitness, strength, flexibility, mood, reduce risk of disease).

Walking Group – focus on participation in a life situation through physical activity in the community (e.g. walking, cycling, wheeling); through skill development, modification & adaption of activity; and leading to improved body functions & structure.

Aquatic – focus on execution of an activity (i.e. swimming) that will enable participation in a life situation in the community; through skill acquisition and / or modification & adaption of activity; leading to improved body functions & structure (e.g. CV health & pain reduction).

High Level Mobility Group – focus on execution of an activity (e.g. running, cycling) that will enable participation in a life situation; through skill acquisition and /or modification & adaptation of activity; and leading to improved body functions and structure.

Fit & Well – focus on improving body functions and structure (e.g. CV health & fitness) by way of physical activity and healthy eating habits; through education and execution of structured exercise (e.g. treadmill, stationary bike) or execution of an activity (e.g. walking, cycling); to enable and encourage participation in a physically active lifestyle.

Individual – complement group programs by focusing on an individual's specific needs and goals with respect to physical activity in order to improve body functions and structures; enhance their ability to execute activities and enable and encourage a physically active lifestyle in the community.