

POWER MOBILITY: MEASURING PARTICIPATION IN EVERYDAY LIFE FOR
CHILDREN BENEFITING FROM POWER MOBILITY USE

by

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A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF

DOCTOR OF PHILOSOPHY

in

THE FACULTY OF GRADUATE AND POSTDOCTORAL STUDIES

(Rehabilitation Sciences)

THE UNIVERSITY OF BRITISH COLUMBIA

(Vancouver)

June 2016

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Abstract

Independent mobility is vital for daily life, with emerging evidence suggesting it is an important foundation for overall development and life-long learning. However, children with mobility limitations are at risk for participation restrictions. Many believe that power mobility (PM) use (typically wheelchairs) makes a difference in children's ability to participate in daily life, but research evidence is limited.

Purpose: To advance understanding of how children (under 18 years) use PM to engage in meaningful life situations and to establish feasible research methods with reliable and valid measurement tools to investigate PM's impact on children's ability to participate.

Methods: A systematic review identified and critically appraised participation tools appropriate for use; a four-round online modified Delphi survey advanced understanding of what participation-related information is important to measure and evaluated suitability of participation tools; and a feasibility study using an interrupted time series design examined process, resources, management and scientific indicators with children using PM.

Results: Twenty potential participation tools were identified. Twenty-one elements describing the 'who, what, where, when and how' of measuring participation for children using PM achieved consensus from 74 parents, therapists and researchers. Then panelists used these elements to rank 13 participation tools, with six demonstrating suitability. Feasibility of conducting longitudinal research was examined with a sample of 32 children, and their everyday

participation was described using three tools. Findings provided reliability and validity evidence, including initial responsiveness of tools for children needing PM. Change in participation was measured over 5 occasions within 4 months for 13/32 children receiving new PM devices.

Conclusion: Employing integrative knowledge exchange, participation elements important to measure for children using PM, along with potential participation tools relating to these elements were identified to explore participation outcomes. Feasibility for larger, multi-site studies was established along with preliminary evidence of three participation tools' measurement properties with children using PM and changes in participation outcomes following receipt of a new PM device. This thesis has provided foundational evidence on how children using PM participate in everyday life, and importantly provided a crucial underpinning for further discussions and investigations relevant to this topic.

Preface

The research for this dissertation was coordinated at the Rehabilitation Research Program at GF Strong Rehabilitation Centre, in collaboration with the Therapy Department at Sunny Hill Health Centre for Children, both in Vancouver, British Columbia (BC). The studies and associated methods that comprise this dissertation were developed by the student (Debra Field (DF)) in consultation with her supervisory committee, including William C. Miller (WCM), supervisor, and committee members Tal Jarus (TJ) and Stephen Ryan (SR). In addition, Lori Roxborough (LR), combined trained occupational and physical therapist, and Roslyn Livingstone (RL), occupational therapist, from Sunny Hill Health Centre for Children were collaborators on studies associated with Chapters 3 through 5 (LR) and Chapters 4 and 5 (RL). Studies associated with Chapters 4 and 5 involved therapists at Sunny Hill Health Centre for Children (coordinated by LR, Professional Practice Leader), and at BC Children's Hospital (coordinated by Susan Garret, occupational therapist and Professional Practice Leader). Studies associated with Chapters 4 and 5 also involved occupational and physical therapists at the Centre for Child Development in Surrey BC (coordinated by Karen Edwards, occupational therapist and Director of Occupational Therapy) and Queen Alexandra Centre for Children's Health in Victoria, BC (coordinated by Sharon Montgomery, occupational therapist and Clinical Leader). Sharon was the primary investigator for the Vancouver Island Health Authority. Formal approval was provided by School District No. 67 (Okanagan Skaha) Superintendent Wendy Hyer and School Board, in Penticton BC, to carry out studies associated with Chapters 4 and 5 within the school district in collaboration with Katy Cox, occupational therapist. Therapists at other child development

centres and school districts around the Lower Mainland, Vancouver Island and Okanagan regions were also involved with recruitment and knowledge dissemination activities.

Ethics approval for Chapter 3 was obtained from the University of British Columbia, Children's and Women's Health Centre of British Columbia Research Ethics Board (UBC C&W REB) (certificate #: CW12-0065 / H12-00375) and Vancouver Coastal Health Research Institute (VCHRI) (certificate #: V12-00375). Additionally ethics approval was obtained from the Centre for Interdisciplinary Research in Rehabilitation of Greater Montreal to gain access to staff and families at the MAB-Mackay Rehabilitation Centre (certificate #: CRIR-746-0712). Ethics for the study associated with chapters 4 and 5 was obtained from UBC C&W REB (certificate #: CW13-0271 / H13-02610) and VCHRI (certificate #: V13-02610). In addition, ethics approval was obtained from Island Health Health Research Ethics Board (certificate #: BC2014-106).

Versions of chapters 2 and 3 have been published in peer-reviewed journals while versions of chapters 4 and 5 will be submitted for review in future. Copyright permissions of previously published works included in this dissertation, including tables and figures, are covered by the Copyright Transfer Agreement.

A version of chapter 2 has been published by Elsevier Inc.: Field DA, Miller WC, Ryan SE, Jarus T, Abundo A. (2016) Measuring participation for children and youth with power mobility needs: a systematic review of potential health measurement tools. Archives of Physical Medicine and Rehabilitation, 97:462-77; first published on-line Sept 10, 2015 [Epub ahead of print]. DOI: 10.1016/j.apmr.2015.08.428.

A version of chapter 3 has been published as two articles. The first article by John Wiley & Sons Inc.: Field DA, Miller WC, Jarus T, Ryan SE, Roxborough L. (2014). Important elements of measuring participation for children who need or use power mobility: a modified Delphi survey. Developmental Medicine and Child Neurology, 57(6): 556-563; first published on-line Dec 15, 2014 [Epub ahead of print]. DOI: 10.1111/dmcn.12645. The second article by Informa Healthcare UK. Ltd.: Field D, Miller WC, Jarus T, Ryan SE, Roxborough L. (2015). Exploring suitable participation tools for children who need or use power mobility: a modified Delphi survey. Developmental Neurorehabilitation, 0, 1-15. First published on-line Mar 31, 2015 [Epub ahead of print] doi:10.3109/17518423.2015.1004763.

DF and WCM conceptualized each of the studies and developed the research designs in consultation with TJ and SR. DF coordinated all aspects of the studies, completed data collection, data analyses, and wrote first drafts and revisions of all chapters and manuscripts. WCM was primary investigator and supervised all research studies, analyzed the data, contributed to interpretation of results, and edited the chapters/manuscripts. TJ and SR were involved in the early stages of thesis development, study formation, review and editing of all chapters and manuscripts. In addition LR, as lead investigator at Sunny Hill Health Centre for Children, was involved in study development and dissemination activities associated with Chapters 4 and 5, as well as review and editing of manuscripts associated with Chapter 3. RL, as the primary knowledge user, was involved in study development and dissemination activities associated with Chapters 4 and 5. Alex Abundo, a 4th year undergraduate workstudy student in the Rehabilitation Research Program at GF Strong Rehabilitation Centre acted as second reviewer for Chapter 2. He also reviewed and edited the manuscript associated with Chapter 2.

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List of Abbreviations

CI ₉₅ :	95% confidence interval
COSMIN:	COnsensus-based Standards for the Selection of health Measurement INstruments
Cronbach's α :	Cronbach's alpha, an estimate of internal consistency
GT:	Generalizability theory
ICC _(2,1) :	Intraclass correlation coefficient estimate using a 2-way random effects model with absolute agreement
ICF:	International Classification of Functioning Disability and Health
IRT:	Item Response Theory methods
MDD:	Minimal Detectable Difference
PM:	Power mobility
PRISMA:	Preferred Reporting Items for Systematic reviews and Meta-Analyses statement
OMRF:	McMaster Outcome Measures Rating Form
T(number):	Time (1 to 5) referring to research session number
r:	Pearson product-moment correlation coefficient
r _s :	Spearman's rank correlation coefficient
SD:	standard deviation
SEM:	standard error of measurement
$\geq, <$:	equal to or greater than, less than

Glossary

Activities:	execution of an act or task by an individual
Assistive technologies:	equipment used to improve an individual's functional capabilities
Barriers:	external obstacles that limit involvement
Body structures:	anatomical structures of body systems
Body functions:	physiological functions of body systems
Capacity:	what the individual is capable of doing in a standardized setting
Child self report:	providing the child's own point of view
Children:	individuals aged 0-17 years
Community life:	involvement outside of the home
Cronbach's alpha:	an estimate of internal consistency
Delphi Survey technique:	structured process of sequential rounds, developed to build consensus
Elements of participation:	the 'who, what, where and how' participation should be measured
Engagement:	active or attentive interacting with someone or something
Enjoyment:	experiencing a positive emotion
Environment:	physical, social and attitudinal milieu in which people live
Facilitator:	people or objects that support and encourage involvement
Family participation:	involvement in meaningful situations of family members
Importance:	of great value or significance
Independent mobility:	self-generated movement through space
Internal consistency:	interrelatedness within a set of test items
Intrarater reliability:	variability in scores by one rater on multiple occasions

Interrater reliability: variability between two or more raters when rating the same variable

International Classification of Functioning Disability and Health (ICF): a biopsychosocial model of health that provides a standard language and theoretical framework for the description of health and health-related states

Life habits: habits that ensure survival and personal development throughout the lifespan

Manual wheelchair: type of mobility device for personal transport that requires human power

Measurement properties: evidence of reliability and validity for use with a specific population

Measurement tool: an instrument used to evaluate quantitative data

Mobility limitation: difficulty walking and moving about

Minimal Detectable Difference: the smallest amount of change considered above the threshold of measurement error in a group of individuals who were expected to be stable

Objective: that which can be observed

Occupational performance: dynamic experience engaging in daily occupations within environments

Outcome measurement: evaluation of therapeutic interventions designed to effect a change

Participation: involvement in life situations

Performance: what an individual actually does in everyday life

Personal factors: characteristics unique to an individual

Power mobility: related to use of electrically powered wheeled devices to enhance personal mobility such as power wheelchairs, ride-on toy cars, standers or scooters

Power mobility interventions: assessment, prescription, provision, training and monitoring of power mobility device use

Power wheelchair: electrically powered wheeled mobility device for personal transport

Reliability: evidence that supports reproducibility of test scores

Responsiveness: ability to detect change when change is truly occurring

Satisfaction: the state of being pleased or satisfied

Standard Error of Measurement: a statistic that quantifies a score's precision within a sample

Subjective: meaning attached to a particular situation

Systematic review: a structured critical assessment and evaluation process including all research studies addressing a specific topic

Test-retest reliability: degree of stability of scores based on repeated administrations to the same individuals over a specific time interval

Toolkit: a set of measurement tools used as a resource for a particular purpose

Type I error: rejecting a null hypothesis incorrectly (resulting in a false positive)

Type II error: failure to reject a null hypothesis (resulting in a false negative)

Unidimensionality: referring to all items assessing a single common construct

Validity: degree that evidence supports the interpretation of scores for a measurement tool's intended purpose. It may include examination of content, relationship with other variables, internal structure, response processes, responsiveness, or consequences of use

Wheelchair use: for this dissertation, refers to active use of a power wheelchair or other power mobility device for mobility purposes or to engage in chosen activities

Wheeled mobility: related to use of manual or power mobility devices

Acknowledgements

First, I would like to express my deepest appreciation and gratitude to the participants who volunteered for the studies on which this dissertation is based. The dedication and energy that families engage in to support their children's participation in meaningful life opportunities to their fullest potential is inspiring. So too is the commitment that professionals make to enhancing children's and their family's health and well-being. As for the children and youth who are the focus of this dissertation, their positivity, determination and enthusiasm are impressive. I thank everyone for sharing their time and wisdom with me. I've learned much from their experiences and opinions, and it has contributed significantly to this work. Thanks also to everyone who helped spread the word about the studies and encouraged others to participate. I would especially like to thank my colleagues Roslyn Livingstone, Kathie Marina and Lori Roxborough, who along with many others, too numerous to mention, supported this work and engaged in thought-provoking dialogue about the benefits and challenges of power mobility clinical practice and research and that helped create the impetus for this dissertation. The ongoing support, friendship, and expertise from colleagues at Sunny Hill Health Centre for Children, Access Community Therapists Ltd, around the province, nationally and internationally is heartwarming.

I feel privileged to have been mentored and supported by such a distinguished group of researchers and educators including my supervisor Dr. Bill Miller, and PhD committee members Dr. Steve Ryan and Dr. Tal Jarus. Thank you for your invaluable guidance throughout my academic journey. Your insights and challenges have contributed immeasurably to my learning and skill development as a researcher, and I look forward to continued collaborations. Many

others assisted me, most importantly Kate Keetch and before her, Elmira Chan, along with Jenn Zelmer, Kristen Eng, Nathalie Manuel, Linh Huynh, Rei Ahn, Alex Abundo and other talented research assistants at the Rehabilitation Research Program at GF Strong Rehab Centre. Thanks so much for all of your assistance, and especially your ‘can do’ attitudes.

I have been fortunate to work with many individuals who provided scholarly dialogue and friendship, including Krista Best, Bitra Imam, Ed Giesbrecht, Ada Tang, Brodi Sakakibara, Jeremy Noble, Dominik Zbogor, Paula Rushton, Ben Mortenson, Caryne Torkia, Lisa Simpson, Emma Smith, Megan MacGillivray, Stephanie Glegg and others associated with the Rehabilitation Research Program and the Graduate Programs in Rehabilitation Sciences at the University of British Columbia.

I would like to recognize the personal financial support that the Canadian Institutes of Health Research Fellowship Award and the Canadian Occupational Therapy Foundation Blake Medical Distribution Scholarship Award have provided me while carrying out this research for which I am truly grateful. I would also like to extend my sincere appreciation to the University of British Columbia and International Collaboration On Repair Discoveries for travel grants enabling me to disseminate my work internationally.

Dedication

This has been an incredible journey. I am indebted to my family for their unwavering support and encouragement as we have ventured together over the years. Gerry, Nikki, Christian, Benjamin, Jeremy, Mom and Dad this accomplishment is one for us all to share.

Much love, Debbie

Chapter 1: Introduction

1.1 Impetus for this Research

For children and youth who have difficulty walking and keeping up with their family and peers, participating in everyday life situations can be challenging.¹ Participation in everyday life situations, such as taking care of oneself, learning, contributing to family life, or playing with friends is crucial for healthy development and well-being.²⁻⁴ However, children and youth with physical disabilities have more participation restrictions than those who are typically developing, which may intensify their disability and bring about a decreased quality of life.⁵ For those with limited mobility, power mobility (PM) devices, such as power wheelchairs, ride-on toy cars, standers or scooters, may be recommended by occupational therapists or physical therapists to enable independent mobility. PM interventions (involving assessment, prescription, provision, training and monitoring of PM device use) are considered for children as young as 7 months of age⁶ who may be unable to walk or self-propel a manual wheelchair, keep up with their friends and family when they do self-propel, or lack the strength and endurance to travel needed distances to participate in desired activities.^{7,8} Frequently, enabling independent mobility is expected to improve their participation in daily life and thereby influence participation of their families. While PM interventions involve a significant commitment of health care resources, limited empirical research evidence supports the effectiveness of PM in increasing children's and youth's participation in age-expected life situations.⁹⁻¹¹

The population of interest for this dissertation is children and youth under 18 years of age with mobility limitations who may benefit from PM interventions. For ease of reading, they will be referred to as children using PM, with the understanding that this includes those currently using PM along with those who may benefit from its use but who do not yet have such equipment.

Occupational therapists and physical therapists (referred to as ‘therapists’ hereafter) use outcome measurement tools to prioritize treatment goals, monitor progress, evaluate success, and justify funding for interventions, including provision of assistive technologies.^{12, 13} However, few therapists use such tools when making PM decisions.^{8, 14} Perhaps this is because of the limited understanding of what factors influence participation in everyday life when children use a PM device or because specific impacts of PM on participation are unclear. Additionally, questions remain about how best to measure participation in everyday life when children use a PM device. Determining participation-related outcomes of importance for these children and their families in order to describe their participation needs and evaluate PM intervention effectiveness is needed. Although a number of paediatric participation tools are available, how suitable these are for children using PM is unclear and signals a need to identify measurement tools with acceptable levels of reliability and validity with this population. Determining suitable measurement tools is a necessary step towards understanding PM’s impact on children and their family’s participation in everyday life.

1.2 Power Mobility Use with Children

1.2.1 Prevalence and Need

An estimated 25,000 children under 15 years of age in Canada have mobility limitations,¹⁵ although the prevalence of those using PM is unknown. Nearly half of Canadian children with mobility limitations have difficulty with everyday activities; 20.5% of these children experience such high levels of difficulty with their daily activities that they are completely prevented from participating.¹⁶ Therapists often assist children and their families to overcome participation restrictions by recommending mobility options, including PM.^{14,17} In the United States, an estimated 136,000 children with mobility limitations use wheeled mobility (typically manual or power wheelchairs).¹⁸ Power wheelchairs and other electrically powered assistive equipment (referred to as PM devices) enhance personal mobility by providing a means to change location in space.¹⁹ PM has the potential to provide independent mobility and facilitate participation in everyday life activities^{9,10} such as playing with friends, learning at school, helping out at home or attending community events.

PM is often recommended as one of a range of options for those with mobility limitations²⁰ due to a variety of medical conditions and diagnoses.^{21,22} While some use PM as their only means of independent mobility, others use PM for specific activities or in specific environments, using other mobility-related assistive technologies such as walking aids or manual wheelchairs in other situations.^{23,24} Some children (e.g., those with cerebral palsy (CP), spinal muscular atrophy (SMA) or osteogenesis imperfecta) may not achieve typical motor milestones for standing, crawling and walking due to significant developmental delays or motor impairments

early in life and as a result may experience delayed independent mobility or remain dependent on others.^{21, 25} Others achieve these motor milestones early in life, but then lose independent mobility because of trauma (e.g., brain or spinal cord injury) or degenerative medical conditions (e.g., Duchenne muscular dystrophy).^{8, 21} For some, PM is used for a (relatively) short period of time (e.g., during rehabilitation), while for others, PM is used throughout their lifespan. For many, use of assistive technologies for communication, learning, leisure and/or environmental control necessitates consideration of how these technologies can be integrated with their PM devices, both in terms of how to mount the equipment on the PM device and access methods (e.g., should the input for the PM device be used for other technology, and if so are additional components or skills required?) Specific participation restrictions encountered by these children, as well as the effectiveness of therapeutic strategies to assist them are not well understood.

1.2.2 Power Mobility Provision and Costs

PM interventions involve a commitment of substantial healthcare resources, both for assistive technology equipment and specially trained personnel. Healthcare provision and funding opportunities for PM devices vary by province,^{26, 27} with most government funding based on medical need. Families are often on their own to find funds for PM components that optimize their children's participation in daily activities and improve their quality of life. In some jurisdictions, funding is left to charitable organizations, or individual fund-raising efforts.^{14, 22, 28} Few published studies illustrate the overall costs of PM,¹¹ however PM devices are expensive. Clinical experience suggests purchase costs in British Columbia (BC) range from \$5,000 to \$40,000. These figures are for product only, and do not include therapists' or vendors' time, or families' lost wages while they take time (and travel) to assess, trial and fit PM equipment.

Equipment costs are dependent on wheelchair features and components that impact performance (e.g., drive type, electronics, input and output devices, seating functions). Further costs arise as PM modifications or replacements are needed as children grow, experience health changes, or transition to new roles.¹¹

1.2.3 Finding the ‘Just Right’ Match

Professionals with clinical and technical PM expertise work collaboratively with children and families, using a child and family-centred approach,²⁹ to make the ‘just right’ match between their individualized needs and the multitude of equipment choices. Professionals promote participation in everyday life by optimizing the match between PM user’s abilities, equipment features, activity demands and environmental considerations to facilitate what they want or need to do.^{14, 30, 31} Staying abreast of technological and clinical advances can be challenging because of rapid development and innovations. This increases decision-making complexity around PM provision and highlights the need for evidence-informed decision-makers.

While choosing the ‘right’ PM device is most desired, profound implications exist if the equipment does not meet the individual’s needs adequately, including: (i) potentially higher financial costs to the healthcare system for additional personnel time and equipment purchases; (ii) greater societal costs associated with higher caregiver burden and burnout and (iii) increased personal costs for individuals and families unable to participate fully in everyday life.^{11, 32} Risk of device abandonment is intensified with an ill-fitting match between their abilities, activity demands and device features.^{31, 32} Given limited health resources, decisions regarding PM provision should be made using best evidence.¹¹

1.3 Participation in Everyday Life

1.3.1 The International Classification of Functioning, Disability and Health (ICF)^{33,34}

The World Health Organization's International Classification of Functioning, Disability, and Health (ICF)³³ and its child and youth version (ICF-CY)³⁴ propose that health is influenced by interactions between individuals' 'health condition,' their 'body structures and functions,' as well as their 'activities,' 'participation,' and the 'contextual factors' affecting them.'^{33,34} Many paediatric rehabilitation professionals have adopted the ICF-CY³⁴ framework because it addresses developmental and maturational needs of children and youth.³⁵ This biopsychosocial conceptual framework strives to improve our understanding of functioning and disability by providing a universal language, through its taxonomy, to improve communication across disciplines and countries.^{33,34}

The ICF framework is divided into two parts, each having two components: Part 1 describes 'body structures and functions,' (defined as the body's anatomy and physiology) as well as 'activities' (defined as 'execution of specific tasks') and 'participation' (defined as 'involvement in life situations'). 'Activities' and 'participation' can be qualified either as capacity (what the individual is capable of doing in a standardized setting) or performance (what the individual actually does in everyday life).^{33,34} Part 2 consists of 'contextual factors;' either 'personal factors' (specific to the individual) or 'environmental factors' (including surrounding physical, social and attitudinal environments). These environmental factors can be qualified either as facilitators or barriers.^{33,34} Although the ICF defines 'activities' and 'participation' separately

recognizing each as a component of health, within its taxonomy ‘activities’ and ‘participation’ are combined, leaving others to differentiate between them based on their situation.^{33, 34} In the taxonomy, nine chapters detail ‘activities and participation’ including learning and applying knowledge, general tasks and demands, communication, mobility, self-care, domestic life, interpersonal interactions and relationships, major life areas, and community, social and civic life. For this dissertation, ‘participation’ is operationalized to include ICF Chapters 6 through 9 relating to domestic life, interpersonal interactions and relationships, major life areas, community, and social and civic life.^{33, 34} Figure 1.1 illustrates the ICF^{33, 34} framework in reference to those who use PM, suggesting variables to consider when exploring children’s participation in everyday life. Note that PM devices, as well as services and supports associated with their provision are classified under environmental factors.^{33, 34}

1.3.2 Children With and Without Physical Disabilities

Building on the ICF definition,^{33, 34} Coster and Khetani defined life situations as ‘sets of organized sequences of activities directed toward a personally or socially meaningful goal’,^{35(p.643)} while Adolfsson and colleagues further expanded it to ‘frequently occurring routines or other activities that are complex, include sequences of actions suitable in societal contexts, involve engagement, and are directed towards meaningful goals’.^{36(p. 1231)} Participation-focused research has expanded since introduction of the ICF,^{37, 38} examining participation in typically developing children, as well as children with disabilities.³⁹⁻⁴² For all children, participation in meaningful life situations leads to increased self-confidence, satisfaction, competence, development of functional abilities and social skills.^{3, 4, 13} Ultimately, this promotes growth and

independence in preparation for adulthood,^{43,44} and contributes to well-being and quality of life.^{5, 42, 45, 46}

Disability, according to the ICF,^{33,34} can be experienced across one or more impairments in body structure or functioning, activity limitations or participation restrictions.^{33, 34} Improving participation in everyday life is an important rehabilitation goal, and one of the most common, yet most meaningful rehabilitation outcomes for children with physical disabilities and their families.^{3, 35} Research suggests children with physical disabilities, including those with limited mobility, participate in life situations that are less diverse, more indoor, home-based, and less physically active when compared to typically-developing peers or those with other types of disabilities.^{37, 39-41, 45-49} Children with physical disabilities also spend more time alone or with family rather than with friends or classmates,^{37, 46, 50, 51} potentially impacting their overall quality of life.⁵ Differences in age, sex and ability levels influence children's engagement, intensity, and enjoyment as well as the support needed, when participating in both school and out-of-school activities.^{5, 13, 37, 38, 40, 51-54}

Studies have investigated participation for children with a range of disabilities^{40, 51, 55, 56} as well as children with specific diagnoses such as spina bifida,⁵⁴ muscular dystrophy,⁵³ acquired brain injury (ABI),^{37, 38, 57, 58} spinal cord injury (SCI),^{37, 59-61} and, most commonly, children with CP.^{46, 48, 62, 63} Although these diagnoses may result in mobility limitations, and the studies may have included participants who use PM, we cannot draw conclusions specific to those using PM because the authors did not explicitly identify PM use. What is known is an association between lower gross motor function and lower levels of participation in out-of-school leisure pursuits.^{48,}

^{58, 61, 63, 64} Additionally, a systematic review of children with various diagnoses of physical ability found gross motor function, manual ability, cognitive ability, communicative skills, age and gender to be important determinants of frequency of leisure participation. ⁴⁶ These findings are particularly relevant, as children who use PM typically have more restricted motor and functional abilities than their peers. ^{24, 65} Our clinical experience suggests children who use PM have more challenges related to physical, cognitive, sensory or environmental demands than other children with disabilities who can walk or use a manual wheelchair, and therefore may have different participation needs. Conducting research to explore participation in everyday life of children who use PM fits with the direction suggested for further advancement of pediatric rehabilitation: exploring the nature, variability and consequences of participation for those with severe disabilities. ⁶⁶

1.3.3 Children Who Benefit from Power Mobility

PM interventions aim to minimize disability and improve participation in everyday life. Research evidence related to paediatric PM is developing, ^{10, 20} but has primarily focused on justification as a therapeutic intervention for young children, ⁶⁷⁻⁷² outcomes related to independent mobility, cognitive and psychosocial development; ^{25, 73-75} as well as considerations for assessment and training. ⁷⁶⁻⁷⁹ Descriptive studies suggest PM use has a positive influence on children's participation in everyday life, however a lack of empirical research that demonstrates causation is lacking. ^{9-11, 80} Moreover, little is known about everyday life situations children engage in when they use PM. ²⁰

Several literature reviews, utilizing different methodologies (i.e. systematic review, qualitative synthesis) have summarized evidence regarding children's use of PM.^{9-11, 80-82} Table 1.1 summarizes PM-related publications described in these reviews that address participation-related outcomes. Reviews were identified while carrying out a systematic review of published studies from 1980 to February 2014.^{10, 80} Two of the six reviews rated quality of study conduct using structured and well-accepted evaluation tools: one¹¹ used the Critical Appraisal Skills Programme (CASP)⁸³ and the Centre for Evidence Based Management (CEBMA)⁸⁴ tools, while the other¹⁰ used the Academy of Cerebral Palsy and Developmental Medicine (AACPDMD) methodology for group and single subject designs.⁸⁵ All three rating systems evaluated study conduct and strength of evidence but used somewhat different definitions and criteria for different study designs.⁸³⁻⁸⁵ Using the AACPDMD methodology,⁸⁵ the highest level of evidence supporting PM's positive impact on children's participation was level IV (case series, cohort studies without concurrent control group, case-control study, non-randomized controlled single subject research design with at least three phases).^{10, 21, 85} Evidence included one single subject ABAB research design with two participants aged 5 years with CP,⁷⁴ and one study using a cohort design without a control group, with 23 parents and children 18 to 72 months (13 with CP and 10 with other diagnoses).^{86, 87} Remaining studies included qualitative interviews, cross-sectional designs, and case studies.^{9-11, 80-82} Authors of the reviews stated generalizations were difficult to make because of the studies' heterogeneity, but concluded that most studies provided lower levels of evidence.^{9-11, 80-82} These reviews suggested potential for PM to have an impact on children's participation but studies with stronger levels of evidence and higher quality ratings for study conduct and reporting are needed.⁹⁻¹¹ Table 1.1 also includes three recent case-reports and

one case series reporting on participation-related outcomes published after the reviews were completed.⁸⁸⁻⁹¹

1.4 Measuring Participation in Everyday Life of Children Needing Power Mobility

1.4.1 Paediatric Power Mobility Literature and Clinical Practice

Within the paediatric PM literature, few standardized measurement tools have been used to measure participation-related outcomes, as the publications in Table 1.1 illustrate.^{1, 7, 25, 67, 70, 86-92}

Of the 12 paediatric PM publications that used standardized measurement tools, only the Life Habits Assessment (LIFE-H),⁹³ Pediatric Evaluation of Disability Inventory (PEDI),^{94, 95} and Canadian Occupational Performance Measure (COPM)⁹⁶ had items focused on ICF ‘activities and participation’ categories.^{33, 34, 36} The LIFE-H⁹³ and PEDI^{94, 95} had pre-determined items, while the client-centred COPM⁹⁶ had individualized items most important to children and/or parents. The other seven standardized measurement tools were generalized assessments measuring different aspects of functioning,⁹⁷⁻¹⁰³ with most⁹³⁻¹⁰³ developed prior to the ICF.^{33, 34} With the current emphasis on evaluating participation-related outcomes in paediatric rehabilitation^{13, 66} and mobility-related assistive technology provision,^{22, 104} it is essential that appropriate participation measurement tools suitable for children using PM be identified. In Chapter 2 we report on a systematic review conducted to identify potential paediatric participation tools that may be suitable for our population.

Similar to PM research, few therapists in clinical practice use standardized measurement tools to evaluate participation in everyday life and inform PM decisions.^{8, 14} When selecting a

measurement tool, the choice of options can be confusing, especially if therapists are less knowledgeable about measurement issues (such as the importance of reliability and validity evidence), the differences between tools, or their conceptual underpinnings. In fact, lack of knowledge regarding available tools and their usage was one identified barrier to using outcome measures in clinical practice.¹⁰⁵ Our lack of knowledge about children's participation while using PM is compounded by studies that employ health measurement tools with limited measurement properties. In Chapter 2 we critically appraise the measurement properties supporting the use of participation tools included in our systematic review.

1.4.2 Importance of Measurement Properties

Three purposes for measurement in healthcare are: (i) to discriminate between individuals or populations (e.g., to make a diagnosis); (ii) to predict future occurrence based on present circumstance (e.g., for prognosis or to facilitate treatment planning); or (iii) to evaluate change (e.g., to determine effectiveness of an intervention).¹⁰⁶ It is essential that measurement tools have demonstrated evidence of reliability and validity with a particular population to provide meaningful interpretations of the test scores for the anticipated purpose.^{106, 107} For PM, measurement is valuable when assessing children's participation needs, facilitating the 'just right' match for equipment recommendations, discriminating who needs (additional) interventions, determining intervention effectiveness and improving service delivery.^{11, 31}

Reliability refers to the consistency or reproducibility of scores when measurement tools are used repeatedly, whereas validity refers to the extent that a measurement tool measures what it is intended to measure.^{108, 109} Several approaches for evaluating these measurement properties have

evolved over time. Classical test theory, an earlier approach to explaining reliability, states that an observed score reflects the true score plus an error score, where the variability in scores upon repetition are attributed to measurement error (but this error is undifferentiated).¹¹⁰

Generalizability theory (GT), a more recent development, states reliability is influenced by multiple sources of error, related to specific testing conditions. Further, depending on the testing context, different sources of measurement error may be appropriate for analysis, with some sources of error randomly generated and other sources occurring more systematically. GT stipulates that estimates of reliability can be generalized only to the context in which the measurement tool is tested, and therefore is not a characteristic specific to the tool. Different methods of reliability testing have been developed to reflect these theoretical assumptions; the most familiar being internal consistency, test-retest reliability, interrater reliability and intrarater reliability.^{106, 110} Internal consistency is defined as the degree of interrelatedness within a set of test items,^{110, 111} while test-retest reliability is defined as the degree of score stability based on repeated administrations to the same individuals over a specific time interval where change is not expected.^{110, 112} Degree of score agreement when evaluating the same variable between two or more raters is known as interrater reliability, in comparison to intrarater reliability defined as the degree of score agreement by one rater on multiple occasions.¹¹⁰

Our understanding of validity has also evolved over time. Earlier approaches describe separate types of validity, most commonly known as content (and face) validity, criterion-related validity and construct validity.¹¹² More recently, construct validity is viewed as a unified concept that seeks validity evidence from different sources.^{107, 110} Validity evidence may include examination of content, relationship with other variables, internal structure, response processes

and consequences of tool use.^{107, 113, 114} Content-related evidence examines item and response wording and format, fit with the construct being measured, as well as administration and scoring procedures. Evidence supporting the association between two or more variables may include convergent, discriminant, concurrent or predictive validity evidence, while internal structure evidence evaluates how items relate to one another and the construct being measured. Response processes evidence involves asking respondents how they interpret the items and responses, while consequential evidence refers to the use and misuse of measurement tools with different populations and within different contexts.^{107, 113, 114} Other validity-related issues may include identification of construct underrepresentation or construct-irrelevant components.^{107, 113, 114} Validity, in this newer conceptualization, is no longer viewed as a characteristic of the measurement tool, but rather the amount of support for the interpretation of scores and the subsequent actions taken based on those scores. When investigating validity evidence using measurement tools to evaluate change, one important strategy is to provide evidence of responsiveness.^{112, 115, 116} Much like measuring participation in everyday life, considerable debate over how to define and measure responsiveness exists.^{115, 117-119} We chose the definition of responsiveness ‘the ability of an instrument to detect change,’ put forward by de Bruin and colleagues^{120 (p529)} and adopted by Beaton and co-authors in their responsiveness taxonomy,¹¹⁷ because of its broad definition.

1.4.3 Applying Knowledge of Measurement Properties

Like reliability, generalization of validity evidence can only be applied to the context in which the measurement tool was evaluated.^{107, 110} However, finding a measurement tool that has sufficient measurement properties for the intended purpose and population can sometimes be

frustrating as evidence supporting reliability and validity may be widely variable or non-existent.^{38, 109, 121, 122} To complicate matters, evidence supporting measurement properties continues to draw on a multitude of theoretical approaches.

Outcome measurement, the evaluation of therapeutic interventions designed to effect a change, is valued by a variety of stakeholders - including therapists, administrators, policy makers, equipment suppliers, funders and families.^{12, 105} Therapists often use outcome measurement tools to prioritize treatment goals, monitor progress and evaluate success of an intervention.^{12, 38} Using well-developed outcome measurement tools, appropriate for the population under investigation with evidence supporting detection of meaningful change following intervention, is critical.^{12, 112} Demonstration of a measurement tool's clinical usefulness is another important characteristic.^{108, 123} Clinical usefulness (or utility as its sometimes referred to) may encompass meaningfulness of scores and their interpretations, administration and scoring ease, length of time and acceptability (known as assessor and respondent burden), evaluation format, instruction availability and clarity, as well as required assessor training;^{108, 123} all considerations when selecting a measurement tool. Several quality-rating tools for outcome measures may be valuable when evaluating measurement tools and studies reporting their development.^{124, 125} In current paediatric PM clinical practice, what dimensions of participation in everyday life are important to measure, what tools are available, and what measurement properties are for those tools with children using PM are yet unknown. In Chapter 3 we report on an online Delphi survey conducted to achieve expert consensus on participation outcomes important to measure for children needing PM and to determine suitability of paediatric participation tools.

1.5 More on Conceptual Frameworks and Theory

1.5.1 Limitations to the ICF^{33, 34}

Conceptual frameworks and theory often guide choice of outcomes and indicators to explore, measurement tools to use and relationships to be tested. Although using the ICF^{33, 34} has advantages, limitations have been acknowledged. For example although subjective dimensions of participation and personal contextual factors are recognized as being important in the conceptual framework, detailed descriptions within its classification taxonomy are lacking.^{35, 126, 127}

Similarly, importance of quality of life and temporal changes across the lifespan are discussed but not detailed in the current ICF^{33, 34} conceptual framework.¹²⁶ Another limitation is the lack of differentiation between ‘activities’ and ‘participation’ within the taxonomy, despite each construct being specifically defined.^{122, 128} The ICF^{33, 34} suggests four different ways to differentiate between ‘activities’ and ‘participation’ but leaves it to the user to define based on what makes most sense for the situation. The four suggested ways include (i) designating some domains as ‘activities’ and others as ‘participation’ without overlap, (ii) allowing partial overlap between designated domains of ‘activities’ and ‘participation’, (iii) designating broad category headings as ‘participation’ while designating the more detailed domains as ‘activities’, or (iv) considering all domains as both ‘activities’ and ‘participation.’^{33, 34} As a result, no agreement exists on what constitutes ‘participation,’ or how to differentiate it from ‘activities.’^{122, 128}

Measurement of the participation construct then becomes especially challenging because it is difficult to operationally define and quantify.^{35, 122} We chose to adopt strategy (i).

1.5.2 Paediatric Participation Conceptual Models

Given the complexity of participation,^{37, 48, 61} several models have been generated to clarify our understanding of children's participation and guide research efforts. King and colleagues proposed a multi-dimensional conceptual model of paediatric recreation and leisure participation based on review of childhood disability, risk and resilience, leisure and recreation, and physical activity and exercise bodies of literature.³ This model described predictive factors within the child, their family and their community environment and relationships between these factors believed to influence, either directly or indirectly, a child's participation in recreation and leisure.³ More recently, Palisano and colleagues presented a conceptual model of determinants of intensity of participation in recreation and leisure for children with CP, formulated through an iterative process involving literature searches, appraisal of theory and research, team discussions, and structural equation modeling testing.⁶³ It too reflects the complex and multi-dimensional nature of children's participation, influenced by characteristics within the child, their family, and educational, healthcare, and community services that serve them.⁶³ Another proposed conceptual model of optimal participation in children with physical disabilities expanded understanding of participation in recreation and leisure.^{2, 13} Researchers suggested that the child's objective and subjective experiences inform their participation through physical, social and self-engagement, and that factors within the child, their family and their environment dynamically affect the child's health, well-being and quality of life.^{2, 13} All of these models address participation in terms of recreation and leisure participation, one important aspect of childhood. Models incorporating other aspects of participation may evolve as investigations become more discerning (e.g., home, school, community, social, or physical activity participation).^{66, 126} Refinement of participation measurement has however fueled debate about meanings and

definitions attributed to participation.^{35,66} Determining relevant aspects of participation in everyday life for children using PM, as reported on in Chapter 3, will help guide research efforts and clinical practice.

1.5.3 Conceptual Models Specific to Those Using Power Mobility

Within the wheeled mobility literature, conceptual models hypothesize the influence that wheeled mobility has on participation in everyday life. Routhier and colleagues developed ‘The Relational Model of Wheelchair Mobility’ to explain the relationship between an individual’s wheeled mobility performance, their occupation and social participation.¹⁹ This model suggests bidirectional relationships between five influencing factors (user profile; environment; daily activities and social roles; assessment and training [processes]; and wheelchair characteristics) as well as bidirectional relationships between each of the five factors and wheeled mobility performance.¹⁹ Rousseau-Harrison and Rochette discussed the relevance of another model, ‘The Disability Creation Process (DCP) Model,’⁹³ to their systematic review on activity and participation of children using wheeled mobility.⁹ They suggested the DCP Model’s two-way causal links between social participation, personal factors, and the child’s immediate social environments⁹³ may help explain differences between children without mobility limitations and those using mobility-related assistive technologies.⁹ Specific to PM, Hardy discussed how ‘The Occupational Performance Model (Australia),’¹²⁹ may be used to guide PM assessment and training considerations.⁸ She described unidirectional associations between wheelchair features, physical, sensory, social, and cultural environments, and performance components relating to biomechanical, sensory–motor, cognitive, intrapersonal and interpersonal characteristics. She

stressed the importance of time in relation to efficiency of mobility, access method, and fit between personal characteristics and wheelchair features.⁸

Livingstone and Field in their synthesis of the qualitative paediatric PM literature, acknowledged these three models share a number of similar constructs, despite using slightly different terminology.⁸⁰ Their synthesis included three over-arching themes from 21 peer-reviewed journal articles, suggesting that PM experience (i) promotes developmental change and independent mobility, (ii) enhances social relationships and engagement in meaningful life experiences and (iii) is influenced by factors in the physical, social and attitudinal environments. Their findings support the multifactorial nature of the three models described above, along with the interconnectedness of influencing factors.⁸⁰ In Chapters 4 and 5 of this dissertation we explore children's participation in everyday life more systematically to gain a greater understanding of how children who use PM engage in meaningful life experiences. This will contribute further evidence supporting (or refuting) these models.

Questions specific to participation in everyday life of children using PM have been minimally addressed in paediatric rehabilitation and wheeled mobility literature. Research questions for children with PM needs (who may be more limited in their abilities and activities than their peers), include: What does their participation in everyday life look like? Do they have unique considerations because of their PM use? and How do changes in their PM use affect their participation in everyday life? Given the importance of understanding the nature, variability, and consequences of children's participation,^{2, 13, 35, 122} especially for less accessible populations,⁶⁶ further investigation of participation-related outcomes for those using PM is warranted.^{20, 104, 130,}

¹³¹ Before evaluating effectiveness of PM interventions on children’s participation in everyday life, we first need to be confident that methods and measurement tools are suitable for use with our population. Moreover, because few participation tools are used clinically or in research with this population, identifying suitable measurement tools, and generating evidence supporting their reliability and validity with children using PM before moving forward with larger, more expensive studies is important. ^{132, 133} Chapters 4 and 5 present findings of a feasibility study that investigated process, resources, management, and scientific indicators related to conducting research with our population. Table 1.2 lists common feasibility indicators ^{132, 133} that guided our investigations. Given the scope of this material, we chose to present our findings as two chapters with Chapter 4 focusing on estimating measurement properties of selected participation tools to explore their suitability for use with our population ¹³² and Chapter 5 examining other feasibility indicators including a preliminary investigation of treatment effect with provision of a new PM device on participation in everyday life. ^{133, 134}

1.6 Dissertation Purpose

The purpose of this dissertation is to advance understanding of how children using PM participate in everyday life situations, and to establish feasible research methods with reliable and valid measurement tools to investigate the impact that PM has on participation in everyday life. Research findings are presented in Chapters 2 to 5, with each chapter outlined below:

Chapter 2: Measuring Participation in Everyday Life of Children Using Power Mobility: A Systematic Review of Potential Measurement Tools.

Purpose: To identify and critically appraise participation measurement tools available for potential use with children with PM needs. This information provides background information for Chapter 3.

Chapter 3: Reaching Expert Consensus on Participation Outcomes Important to Measure for Children Using Power Mobility and Determining Suitable Measurement Tools.

Purpose: To advance understanding of what participation-related information is important to measure for children using PM, and to determine measurement tools that may be suitable for this population.

Chapter 4: Establishing Measurement Properties of Participation Tools for Children Using Power Mobility.

Purpose: To evaluate the measurement properties (i.e., reliability and validity) of three paediatric participation tools with children using PM.

Chapter 5: Determining Feasibility of Conducting Participation-Related Research with Children Using Power Mobility.

Purpose: (a) To examine feasibility related to process, resources, management and scientific indicators when conducting research with children using PM and their families; and, (b) to describe changes in participation in everyday life situations for children using PM after provision of a new power wheelchair.

Figure 1.1 International Classification of Functioning, Disability and Health Framework ^{33, 34}

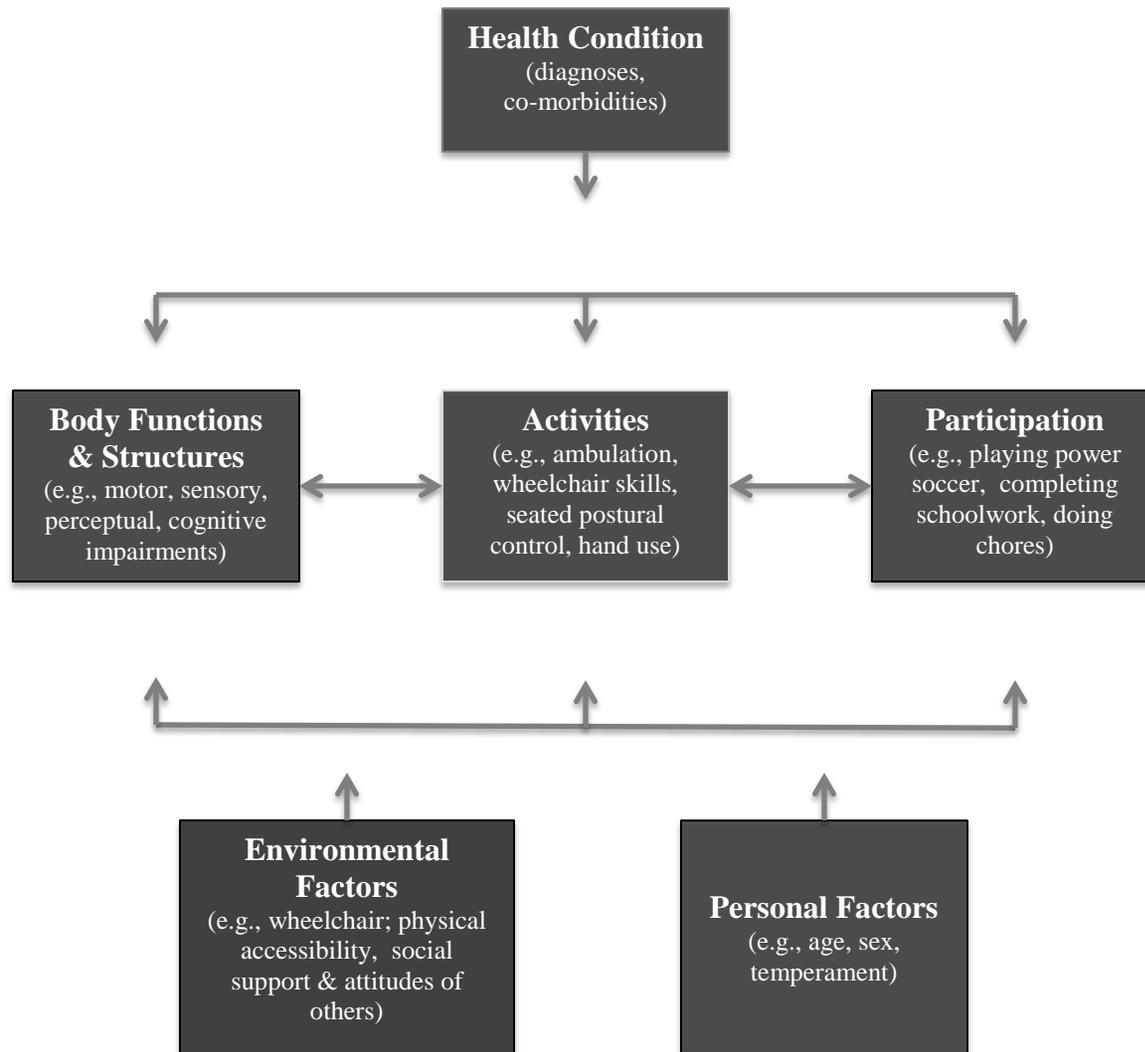


Table 1.1 Power Mobility-Related Studies Addressing Participation Outcomes and Measurement Tools Used

(Organized From Highest To Lowest Evidence Level Ratings Assigned By Review Authors And Date Of Publication)

Study	Design	Participants Sample Size Age Diagnoses	PM Device & Duration Of PM Use Evaluated	Evaluation Method & Results	Evidence Level Rating Assigned By Review Authors	Participation-Related Outcomes Identified By Review Authors
Deitz et al. 2002 ⁷⁴	SSRD ABA(B)* (*only 1 child completed second intervention phase)	2 children 5 yrs with CP	ride-on toy car Baseline min. 7 weeks, intervention min. 3 weeks; post- intervention min. 1 week	10 minute video recording during school gym sessions or recess Frequency count of 'initiation of contact' behavior recorded every 15 seconds from video: i) by target child directed to adults or peers ii) from others directed to target child, (by adult or peers) Reliability of coding evaluated Descriptive statistics provided	Livingstone & Field, 2014 ¹⁰ AACPDM ⁸⁵ Level IV Henderson et al. 2008 ⁸¹	Social interaction ¹⁰ Interacting with others ⁸¹
Guerette et al. 2013 ⁸⁷	Cohort without control (same children as below)	23 children 18 to 72 mos 13 with CP (to 72 mos) 10 other dx (to 42 mos)	power wheelchair 4 mos	12 minute observation of behaviour during indoor & outdoor play using study specific data form: statistically significant increased number of mobility play activities engaged in from pre to post tests. Adaptive Social Behavior Inventory ⁹⁹ statistically significant increased 'prosocial' component scores between pre and post tests	Livingstone & Field, 2014 ¹⁰ AACPDM ⁸⁵ Level IV	Play skills ¹⁰ Social skills & interaction ¹⁰
Tefft et al. 2011 ⁸⁶	Cohort without control (same children as above)	Parents of 23 children 18 to 72 mos 13 with CP 10 other dx	power wheelchair 2 pre-tests (wheelchair specification T1 & delivery T2) + 1 post- test (T3 4 to 6 mos post delivery)	Matching Assistive Technology & Child (MATCH) survey ⁹⁷ statistically significant change in Item- 'parents' satisfaction with child's social & play skills' score from pre to post test (T1,T2+T3) Survey of Technology Use ⁹⁷ statistically significant change in item 'Interactions with family' between pretest scores (T1+T2)	Livingstone & Field, 2014 ¹⁰ AACPDM ⁸⁵ Level IV Bray et al. 2014 ¹¹ 8/12 score on CEBMA Questionnaire Survey Appraisal Outcomes Tool ⁸⁴	Social interaction ¹⁰ Social & play skills ¹¹

Study	Design	Participants Sample Size Age Diagnoses	PM Device & Duration Of PM Use Evaluated	Evaluation Method & Results	Evidence Level Rating Assigned By Review Authors	Participation-Related Outcomes Identified By Review Authors
					Rousseau-Harrison & Rochette, 2013 ⁹	Play & interpersonal relationships ⁹
Ragonesi et al. 2011 ⁷⁵	Case study (same child as below)	1 child 3 yrs with CP (+ 1 TD peer comparison)	UD2 Baseline 10 days with mobility & socialization training vs 7 days post (no) training	Daily 2 hour video recording of free play. Most active 30 minutes of video coded & analyzed for frequency count of behavior in preschool class: number of minutes in solitary vs parallel play/awareness; interacting with teachers & peer interaction. Reliability of coding evaluated. Descriptive statistics provided increased interaction with teachers and peers during training & decreased during post-training	Livingstone & Field, 2014 ¹⁰ AACPDM ⁸⁵ Level V	Play skills ¹⁰ Peer participation ¹⁰
Ragonesi et al. 2010 ¹³⁵	Case study (same child as above)	1 child 3 yrs with CP (+ 2 TD peer comparison)	UD2 Baseline of 10 days without UD2 vs intervention of 13 days with UD2	Daily 2 hour video recording of free play. Most active 30 minutes of video coded & analyzed for frequency count of behaviour in preschool classroom. Number of minutes in solitary vs parallel play/awareness; interacting with teachers & interacting with peers. Reliability of coding evaluated. Descriptive statistics; increased interaction with peers in intervention	Livingstone & Field, 2014 ¹⁰ AACPDM ⁸⁵ Level V	Play skills ¹⁰ Peer participation ¹⁰
Home & Ham 2003 ²⁸	Cross-sectional postal survey	61 parents 2 to 7 yrs with CP & with SMA	power wheelchair Duration not stated	Study specific survey on perceived effects of PM Items: 'integration with others'; 'participation in games and activities'; 'increased participation in family life' Descriptive statistics provided	Livingstone & Field, 2014 ¹⁰ AACPDM ⁸⁵ Level V Bray et al. 2014 ¹¹ 5/12 score on CEBMa Questionnaire	Peer & social interaction ¹⁰ Able to socialise more ¹¹

Study	Design	Participants Sample Size Age Diagnoses	PM Device & Duration Of PM Use Evaluated	Evaluation Method & Results	Evidence Level Rating Assigned By Review Authors	Participation-Related Outcomes Identified By Review Authors
					Survey Appraisal Outcomes Tool ⁸⁴	
					Livingstone & Field, 2014 ⁸⁰	Enhance ability to play ⁸⁰ Increase participation ⁸⁰
Wuart et al. 2003 ¹⁷	Cross- sectional phone interviews	66 PM users receiving power wheelchair before 18 yrs 52 with parent proxy PM users 4.5 to 27.5 yrs with CP, SB, SCI, OI	power wheelchair Duration not stated	22 closed ended questions & 4 open-ended questions Descriptive statistics provided	Livingstone & Field, 2014 ¹⁰ AACPD ⁸⁵ Level V Bray et al. 2014 ¹¹ 5/12 score on CEBMA Questionnaire Survey Appraisal Outcomes Tool ⁸⁴ Livingstone & Field, 2014 ⁸⁰	Peer participation ¹⁰ Able to socialise more ¹¹ Enhance ability to play ⁸⁰ Increase participation ⁸⁰ Enhance peer relationships ⁸⁰
Nisbet et al. 2002 ¹³⁶	Case studies	3 girls 10, 10, 5 yrs with CP	SMART wheelchair 6 mos	Narrative of observations and experiences reported by caregivers to professional, as well as professional's observations	Livingstone & Field, 2014 ¹⁰ AACPD ⁸⁵ Level V Livingstone & Field, 2014 ⁸⁰	Peer participation ¹⁰ Increase participation ⁸⁰
Le Page et al. 1998 ¹	Cross- sectional evaluation	96 children including 12 PM users 5 to 17 yrs with CP	power wheelchair Duration not stated	Assessment of Life Habits (LIFE-H) ⁹³ administered in 1 session ANOVA & Tukey post hoc test differences in Life- H ⁹³ scores between children who used a power wheelchair and those who: used a manual wheelchair, used a	Livingstone & Field, 2014 ¹⁰ AACPD ⁸⁵ Level V	Social roles ¹⁰ Education ¹⁰ Responsibility ¹⁰ Interpersonal relationships ¹⁰

Study	Design	Participants Sample Size Age Diagnoses	PM Device & Duration Of PM Use Evaluated	Evaluation Method & Results	Evidence Level Rating Assigned By Review Authors	Participation-Related Outcomes Identified By Review Authors
				walking aid & who did not use any aids	Rousseau-Harrison & Rochette, 2013 ⁹	The higher level of locomotion the better the participation in life habits ⁹
Nisbet et al. 1996 ¹³⁷	Case studies	3 boys 8, 8.5, 10 yrs with CP	SMART wheelchair 15 mos	Narrative of observations and experiences reported by caregivers to professional, as well as professional's observations	Livingstone & Field, 2014 ¹⁰ AAPDM ⁸⁵ Level V Livingstone & Field, 2014 ⁸⁰	Peer participation ¹⁰ Enhance ability to play ⁸⁰ Increase participation ⁸⁰
Everard 1984 ¹³⁸	Case study	1 child 22 mos with SMA	power wheelchair 6 weeks	Narrative of observations and experiences reported from mother's perspective	Livingstone & Field, 2014 ¹⁰ AAPDM ⁸⁵ Level V Livingstone & Field, 2014 ⁸⁰	Peer participation ¹⁰ Enhance ability to play ⁸⁰ Increase participation ⁸⁰ Enhance peer relationships ⁸⁰
Jones et al. 2012 ²⁵	Randomized controlled trial	28 children 14 to 30 mos 18 with CP 10 other dx	Power wheelchair Pretest prior to wheelchair delivery Post-test 1 yr post delivery	Battelle Developmental Inventory ¹⁰⁰ Pediatric Evaluation of Disability Inventory (PEDI) ⁹⁴ Early Coping Inventory ¹⁰¹ (reactive behavior scale & self-initiated behavior scale). Reliability of scoring evaluated	Livingstone & Field, 2014 ¹⁰	Findings did not demonstrate statistically significant differences between groups on participation-related items
Gudgeon & Kirk 2013 ¹³⁹	Semi-structured interviews	9 EPIOC users 7 to 16 yrs with MD, CP, SMA, brain tumour	EPIOC	Topic guide developed Interpretative Phenomenological Analysis	Livingstone & Field, 2014 ⁸⁰	Enhance ability to play ⁸⁰ Increase participation ⁸⁰

Study	Design	Participants Sample Size Age Diagnoses	PM Device & Duration Of PM Use Evaluated	Evaluation Method & Results	Evidence Level Rating Assigned By Review Authors	Participation-Related Outcomes Identified By Review Authors
McGarry et al. 2012 ⁷³	Observation Semi-structured interviews	Parents of 4 children 5 to 13 yrs with CP	SMART wheelchair 8 x 1 hour session/week	Multiple case study design using mixed methods 5 open-ended questions topic guide; Inductive analysis	Livingstone & Field, 2014 ⁸⁰ Livingstone & Field, 2014 ¹⁰	Enhance ability to play ⁸⁰ Participation outcomes not reported
May & Rugg 2010 ⁷	Pre-post assessment Semi-structured interviews (for 6 users)	20 EPIOC users 11 to 92 yrs interviewed 1 child 11yrs with SMA	EPIOC	Canadian Occupational Performance Measure (COPM) ⁹⁶ administered pre and 4-12 weeks post wheelchair delivery Statistically significant improvements in occupational performance & satisfaction scores-items not specified 6 participants completed post-provision interviews; Interpretative phenomenological analysis	Livingstone & Field, 2014 ⁸⁰	Increase participation ⁸⁰
Huang et al. 2009 ¹⁴⁰	Semi-structured face to face interviews	15 children 8 to 15 yrs with CP one 8-yr-old PM user 15 mothers 14 teachers	power wheelchair	Descriptive statistics provided thematic qualitative analysis	Livingstone & Field, 2014 ⁸⁰	Enhance ability to play ⁸⁰ Increase participation ⁸⁰ Enhance peer relationships ⁸⁰
Evans et al. 2007 ¹⁴¹	Telephone interviews	18 adolescents 10 to 18 yrs 13 with parental assistance 10 with MD 5 with CP 3 other dx	electric powered indoor – outdoor chair (EPIOC)	Closed-ended & open-ended questions Descriptive statistics provided Qualitative conceptual framework	Bray et al. 2014 ¹¹ 7/10 score on CASP Qualitative Study appraisal tool ⁸³ Livingstone & Field, 2014 ⁸⁰	Able to socialise more ¹¹ Increase participation ⁸⁰
Wuart et al. 2004 ¹⁴²	Semi-structured interviews	5 mothers of children 10 to 18 yrs	power wheelchair	Open-ended questions Phenomenological data analysis	Bray et al. 2014 ¹¹ 8/10 score on CASP Qualitative	Able to socialise more ¹¹

Study	Design	Participants Sample Size Age Diagnoses	PM Device & Duration Of PM Use Evaluated	Evaluation Method & Results	Evidence Level Rating Assigned By Review Authors	Participation-Related Outcomes Identified By Review Authors
		4 with CP 1 with SB			Study appraisal tool ⁸³ Livingstone & Field, 2014 ⁸⁰ Henderson et al. 2008 ⁸¹	Increase participation ⁸⁰ Meaningful activities ⁸¹
Jones et al. 2003 ⁷⁰	Case study assessments at baseline, 3 & 6 mos wheelchair provided at 4 mos	1 child 20 mos with SMA	power wheelchair 6 mos	Battelle Developmental Inventory ¹⁰⁰ Personal-social skills increased PEDI ⁹⁴ positive trend observed, scores not provided nor if change statistically significant Parent interview pre & post provision	Rousseau- Harrison & Rochette, 2013 ⁹ Livingstone & Field, 2014 ¹⁰	Improved social functioning ⁹ Participation-related outcomes not reported in detail, unable to make conclusions
Skar 2002 ¹⁴³	Semi- structured interviews	8 children 6 to 11 yrs with CP, SB, other dx one PM user	power wheelchair	Open-ended questions, topic guide Grounded Theory constant comparative method	Livingstone & Field, 2014 ⁸⁰ Rousseau- Harrison & Rochette, 2013 ⁹	Enhance ability to play ⁸⁰ Increase participation ⁸⁰ Not obstacle to play-part of self ⁹
Bottos et al. 2001 ⁶⁷	Case history survey design Semi- structured interviews	Parents and 25 children 3 to 8yrs with CP	power wheelchair baseline (T1) + 6 to 8 mos pre-test (T2); 6 to 8 mos post-test (T3)	COPM ⁹⁶ measured change in activities of daily life; significant difference in performance & satisfaction between T2 & T3 Impact of Childhood Illness Scale ¹⁴⁴ measured change in social participation Descriptive statistics provided	Henderson et al. 2008 ⁸¹ Livingstone & Field, 2014 ¹⁰	Quality of life ⁸¹ No statistically significant change reported in social participation
Benedict et al. 1999 ⁹²	Caregiver Semi- structured interviews Telephone	13 families 2 to 4 yrs 11 with CP 2 with metabolic	power wheelchair	Record review (n = 21) Telephone survey (n = 13) PEDI ⁹⁴ Interview with 4 open-ended questions thematic qualitative analysis	Livingstone & Field, 2014 ⁸⁰ Livingstone & Field, 2014 ¹⁰	Increase participation ⁸⁰ Participation outcomes not reported

Study	Design	Participants Sample Size Age Diagnoses	PM Device & Duration Of PM Use Evaluated	Evaluation Method & Results	Evidence Level Rating Assigned By Review Authors	Participation-Related Outcomes Identified By Review Authors
	survey	disorders 4 families interviewed one PM user		Descriptive statistics provided		
Berry et al. 1996 ¹⁴⁵	Semi- structured interviews	36 caregivers of 34 children 5 to 17 yrs + 2 18 to 23yrs 29 with CP 4 with SB 3 other dx	power wheelchair Duration not stated	Reliability of frequency data and coding of qualitative data evaluated closed ended & open-ended questions 31 interviewed by phone 5 interviewed at home Descriptive statistics provided thematic qualitative analysis	Livingstone & Field, 2014 ⁸⁰	Enhance ability to play ⁸⁰ Increase participation ⁸⁰
Douglas & Ryan 1987 ¹⁴⁶	Case study	1 child 4 yrs with SCI	power wheelchair 2 years	Narrative of observations and experiences reported by professional	Livingstone & Field, 2014 ⁸⁰ Henderson et al. 2008 ⁸¹	Increase participation ⁸⁰ Group activities ⁸¹ Responsibilities ⁸¹
Articles not rated, published after reviews						
Kenyon et al. 2016 ⁸⁸	Case series	3 children 17 mos to 3.5 yrs with CP	power wheelchair trainer 1/hour/week /12 weeks	Narrative of observations & experiences reported Pediatric Evaluation of Disability Inventory- Computer Adaptive Test (PEDI-CAT) ⁹⁵ & Dimensions of Mastery Questionnaire (social persistence subscale) ¹⁰² Descriptive statistics provided	Not rated Published after reviews	
Kenyon et al. 2015 ⁸⁹	Case study	1 young adult 18 yrs with CP + CVI	power wheelchair trainer 1 hour/2x week/12weeks	Narrative of observations & experiences reported & Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD) ¹⁰³ Descriptive statistics provided	Not rated Published after reviews	
Logan et al. 2014 ⁹⁰	Case study	1 child 13 mos with Down	ride-on toy car; 3 mos baseline,	20 minute video recording: 10 minutes natural play + 10 minutes of ride-on toy car play. Socialization measured	Not rated Published after reviews	

Study	Design	Participants Sample Size Age Diagnoses	PM Device & Duration Of PM Use Evaluated	Evaluation Method & Results	Evidence Level Rating Assigned By Review Authors	Participation-Related Outcomes Identified By Review Authors
		syndrome	3 mos intervention, 1 mos post- intervention	counting reaching for toy & facial expressions from video. Coding reliability evaluated. Daily activity log and questionnaires Descriptive statistics provided Narrative of observations & experiences reported PEDI ⁹⁴ scores suggested changes in mobility & socialization		
Huang et al. 2014 ⁹¹	Case report	1 child 21 mos with CP	ride-on toy car; 1 week baseline, 12 week intervention, 2 week post- intervention, min.ride-on toy play 20 minutes/day/5 days/week during intervention	20 minute video recording: 10 minutes natural play + 10 minutes of ride-on toy car play. Socialization measured counting reaching for toy/adult, facial expressions & vocalizations from video. Also coded natural family interaction for 10 minute period. Daily activity log and questionnaires Descriptive statistics provided PEDI ⁹⁴ suggested increase in functional mobility and socialization	Not rated Published after reviews	

Legend: AACPDM = American Academy of Cerebral Palsy and Developmental Medicine level of evidence scale;⁸⁵ ANOVA = analysis of variance; CP = cerebral palsy; CASP = Critical Appraisal Skills Programme Qualitative Study appraisal tool;⁸³ CEBMa = Centre for Evidence Based Management Questionnaire Survey Appraisal Outcomes Tool;⁸⁴ CVI = cortical visual impairment; dx = diagnosis; et al. = and colleagues; MD = muscular dystrophy; min. = minimum; mos = months; n= = sample size; OI = osteogenesis imperfect; PM = power mobility; SB = spina bifida; SCI = spinal cord injury; SMA = spinal muscular atrophy; SSRD ABA(B) = single subject research design with two conditions A is without intervention, B is with intervention; TD = typically developing; T() = time (session number); UD2 custom power mobility device for infants; vs = versus; yrs = years; & = and; x = times; / = out of; + = plus.

Table 1.2 Summary of Feasibility Indicators ^{132, 133}

Process indicators	Resource indicators	Management indicators	Scientific indicators
Recruitment rate	Recruitment effort	Participant processing	Treatment effect
Consent rate	Community access	Protocol administration	Measurement intervals
	Participant and Assessor burden	Equipment performance	Suitability of measurement tools
	Completion time & rate		Treatment safety
	Retention rate		Perceived benefit

Chapter 2: Measuring Participation in Everyday Life of Children Using Power Mobility: A Systematic Review of Potential Measurement Tools

2.1 Introduction

In the last chapter we learned that participation in everyday life situations is important for children's growth and development and contributes to their quality of life, and although the body of literature describing participation of children with disabilities is expanding, little information is known about the participation in everyday life of children using PM. This is concerning because they may be at greater risk for participation restrictions and decreased quality of life because of their mobility limitations.¹⁴⁷ To address this knowledge gap, appropriate measurement tools are necessary to describe their participation needs, develop intervention strategies, and evaluate outcomes. Measuring participation in everyday life will inform clinical decision-making with children using PM, and justify provision of PM-related therapy services and equipment to policymakers and funding agencies.

Challenges to measuring participation in everyday life for children include: operationally defining participation; distinguishing 'participation' from 'activities' (within the ICF framework);^{33, 34} addressing objective dimensions (e.g., number or type of life situation, frequency) versus subjective dimensions (e.g., enjoyment, satisfaction, importance, preference) of participation; incorporating environmental contexts and cultural influences and evaluating participation over time.^{35, 109, 122, 148} Objective tools designed to capture information that can be observed³⁵ often measure performance against normative comparisons,¹²⁸ while subjective tools

measure perspectives of participation¹²⁸ that reflect personal meaning.³⁵ Other challenges intensifying the complexity of measuring children's participation include how best to account for: developmental changes; the child's participation within their family context; differences in perspectives (i.e., parent versus child); and changing abilities, autonomy and roles as children grow.^{38, 48, 109, 122} Although a number of participation tools are available, each tool addresses these challenges differently.^{35, 38, 109, 121, 122, 148} Nevertheless, the scope of each tool, how they compare to each other, and how useful they are for children using PM needs to be determined.

Within the last ten years, literature reviews have synthesized information about various participation measurement tools,^{36, 122, 149-151} with some reviews targeting specific populations such as those with CP or ABI.^{38, 109, 121, 148, 151-156} Given that children using PM have a range of diagnoses,²¹ questions arise regarding relevance of these reviews' findings for those with diagnoses other than those investigated.³⁸ While these reviews are valuable, the literature does not expressly describe wheelchair use, even though tool development and evaluation may have included children using wheelchairs. This raises questions about the measurement tools' validity for children using PM (without further testing).^{123, 157} Given the small number of children within a single diagnostic population, reviewing evidence supporting participation tools based on functional ability rather than diagnoses only⁴⁷ is valuable for those with PM needs.

While a body of evidence supports PM's influence on activity-level outcomes, demonstration of PM's impact on participation is particularly important because an assumption exists that independent mobility leads to greater participation in life situations and thereby facilitates child well-being and development.^{10, 11, 80} To verify this assumption, measurement

tools that specifically evaluate the participation construct for PM applications are required. Many published reviews explore measurement tools for ICF^{33, 34} ‘activities’ and ‘participation’ domains together^{109, 122, 148, 151, 152} making it difficult to isolate tools measuring ‘participation’ only. The task of identifying ‘participation’ tools becomes more complex because these reviews often consider ‘activities’ and ‘participation’ from different perspectives,^{36, 109, 121, 122, 148, 150-153} reflecting debate over how to define ‘participation’ and differentiate it from ‘activities.’^{33-35, 66,}¹²² Although some reviews address measurement properties, others focus on linking content to the ICF^{33, 34} for clarity on what is measured,^{36, 122, 150-152} or examine information about the tools’ clinical usefulness.^{109, 121}

Choosing a suitable tool to measure participation in everyday life is challenging given the number of measurement tools available, the dimensions of participation evaluated by these tools,^{35, 122} and the unique needs of children who use PM. Some tools include items that are not relevant, requiring gross motor or fine motor skills beyond abilities of children using PM (e.g., climbing on playground equipment),^{1, 24} possibly limiting the tools’ ability to detect functional change for this group of children. Scoring may be punitive against assistive technology use, putting those using PM at a disadvantage.^{123, 157, 158} A systematic review of participation measurement tools (evaluating both measurement properties and clinical usefulness) provides a comprehensive overview and critical appraisal of available evidence for children using PM.^{159,}¹⁶⁰ More importantly, it can serve as a valuable source of synthesized information for clinicians, researchers and other interested stakeholders (i.e. clients, families, policymakers and funders) as they strive to implement evidence-informed practice and decision-making.^{159, 160}

2.1.1 Purpose

The purpose of this systematic review was to identify and critically appraise participation measurement tools appropriate for potential use with children under 18 years of age with PM needs. Framing the systematic review in this way may advance our understanding of what tools might be suitable for describing children's participation in everyday life for those using PM or investigating PM's impact on children's participation in everyday life. Our primary clinical question was 'For children under 18 years of age with mobility limitations who may benefit from PM interventions, what measurement tools may be used to assess participation in everyday life situations?' Secondary questions included 'What aspects of participation do these tools address?' 'What are the reported measurement properties of these tools?' and 'What information supports the tools' clinical usefulness?'

2.2 Method

The National Center for the Dissemination of Disability Research Comprehensive guidelines¹⁵⁹ along with the Preferred Reporting Items for Systematic reviews and Meta-Analyses statement (PRISMA) statement¹⁶¹ were used to structure this systematic review.

2.2.1 Search Strategy

An electronic database search, conducted by two reviewers identified primary peer-reviewed studies and systematic reviews published from database inception to January 2015. The nine databases were CINAHL; EBM Reviews (e.g. Cochrane Central Register of Controlled Trials, Cochrane Database of Systematic Reviews, Health Technology Assessment); EMBASE; ERIC;

Health and Psychosocial Instruments; Medline OVID SP; OT Seeker; Physiotherapy Evidence Database (PEDro) and PsycINFO. A multipurpose, keyword search strategy included word stem descriptors of children with mobility limitations, participation and measurement tools. Terms included child, adolescent, movement, motor, musculoskeletal, neuromuscular, (neuro)developmental, neuromotor or physical disease, disability or impairment, participation, everyday, life, situation, activity or involvement, assess, measure, question, interview, survey or tool. Two health librarians experienced in systematic reviews were consulted in search planning and documentation. Appendix A has a complete listing of keywords and search terms for each database while Appendix B provides a sample search strategy. Terms were used as keywords and where relevant for the database, mapped to subject headings. Manually searched bibliographies of electronically retrieved full text articles meeting inclusion criteria, along with targeted electronic tool and author searches also identified relevant additional publications.

2.2.2 Study and Tool Selection

Two reviewers independently reviewed titles, then abstracts and if the abstract appeared relevant to inclusion criteria, the full-text was obtained. Given that development and testing of participation tools was not always the primary focus of publication, a two-step selection process was taken. Reviewers independently determined if full-text articles first met study inclusion criteria, and gathered referenced information once potential tools were identified. They then independently determined if tools met specific tool inclusion criteria, after all related publications on the identified tools' development and testing were sought. They met after each step to reach consensus, with a third person identified in case consensus was not achieved.

Inclusion and exclusion criteria listed in Table 2.1 were set *a priori*. Participation was defined in reference to the ICF-CY Chapters 6 to 9.³⁴

2.2.3 Data Extraction

The reviewers, independently and using a common form, extracted data that documented evidence source, measurement properties, conduct and rigour of reported measurement tool development. Evidence source information included author, name of measurement tool(s), study design and population characteristics. Descriptive information included participation aspects assessed, type and number of items and responses, targeted rater(s)/responder(s), population with which the tool was validated for use with and clinical usefulness information such as administration and scoring time, and environmental needs.^{35, 122, 148} The tools' measurement properties included reliability and validity evidence¹⁰⁸ organized using terminology and structure of two quality assessments.^{124, 125} Responsiveness, or the ability to detect change when change was truly occurring, was listed separately because of its importance for evaluative purposes.^{108, 112} Criterion-related validity was not assessed because no 'Gold Standard' for paediatric participation measurement exists.^{35, 66, 122} Cross-cultural validity was also not included due to limited available information, given that the search was restricted to English-language.

2.2.4 Quality Assessment

The two raters independently rated the evidence using two quality assessments, before meeting to reach consensus. The COnsensus-based Standards for the Selection of health Measurement INstruments (COSMIN) checklist,¹²⁴ developed by international consensus, provided a method for rating the methodological quality of studies on measurement properties of health status

measurement tools for use in systematic reviews, while the McMaster Outcome Measures Rating Form (OMRF) ¹²⁵ provided a rating of reliability and validity results. These two rating scales have been used in other reviews, ^{38, 121, 149} and complement rather than duplicate one another's ratings to provide a more comprehensive understanding of the evidence.

2.3 Results

Figure 2.1 illustrates the PRISMA flowchart ¹⁶¹ outlining the process and number of identified articles and measurement tools. From full-text review, 138 articles met *study inclusion* criteria. These articles described 50 tools, of which, 20 met *tool inclusion* criteria. These 20 tools were described in 85 of the 138 articles. Table 2.2 identifies the number and reasons for exclusion of full text articles, and measurement tools. The remaining 30 tools were excluded primarily because of their population, the tool's measurement properties and/or clinical usefulness lacked description, or other constructs were assessed along with participation-related items. Initial agreement between reviewers was 83% for identification of eligible articles, and 88% for eligible tools. At all stages, consensus was achieved with discussion between the primary reviewers, without involvement of a third reviewer.

2.3.1 Study and Measurement Tool Characteristics

Of the 85 articles that described the included measurement tools, 30 focused on tool development and evaluation of measurement properties, while 12 were review articles of participation tools for children with physical disabilities. The remaining 43 articles were primarily intervention studies that provided measurement properties of a participation-related

measurement tool. Table 2.3 describes the 20 included measurement tools.^{45, 93, 96, 162-184} Validity evidence included children of various ages, diagnoses and abilities with the majority involving school-aged children, six included those in early childhood^{93, 162, 167, 170, 176, 180} and another three were for youth only.^{177, 179, 182} Thirteen tools were parent report,^{45, 93, 162, 163, 167, 168, 170-172, 174, 176, 178, 180, 183} 10 were child report^{93, 96, 166, 169, 173, 176, 177, 179, 182, 183} and four tools were to be completed by educators and/or health professionals.^{93, 164, 176, 184} Five of these tools included multiple respondents.^{93, 96, 168, 169, 172, 176, 183} As for settings in which participation was evaluated, five measured participation in just one setting (home,¹⁷¹ school,^{164, 184} or community),^{167, 177} four tools evaluated home and community participation,^{162, 163, 166, 170} while the remainder evaluated home, school and community participation.^{45, 93, 96, 168, 169, 172-176, 178-183} Objective dimensions of participation (e.g., number of life situations, frequency)^{35, 122} were evaluated in 14 tools,^{45, 93, 162, 164-171, 174, 178-180, 182, 183} while subjective dimensions (e.g. satisfaction, importance, enjoyment)^{35, 122} were evaluated in 12 tools.^{93, 96, 164, 166, 170-173, 178-180, 183, 184} The most commonly assessed objective dimension was frequency,^{45, 162, 164-170, 174, 178, 179, 182, 183} while involvement was the most commonly assessed subjective dimension.^{164, 165, 178, 180, 184} Two tools evaluated desire for change in participation,^{178, 182} four tools reported on degree of problem,^{93, 176, 177, 183} and 11 tools assessed contextual factors that influence participation, such as where, with whom, amount of assistance required, barriers or facilitators.^{93, 163, 166, 168-171, 175, 176, 178-181, 184} Two^{93, 176} of the four tools documenting use of assistive devices,^{93, 168, 169, 176, 184} downgraded scores if assistive devices (such as PM) were used. Clinical usefulness documentation was limited although administration times were reported to be 10 to 40 minutes.

2.3.2 Measurement Properties

2.3.2.1 Reliability Evidence

Appendix C(i,ii) summarizes evidence on the reliability testing results for the 20 measurement tools.^{45, 93, 96, 162-207} For 11 tools, only the developers generated evidence of measurement properties,^{45, 163, 167, 170, 171, 173, 174, 177, 178, 180, 182, 183} whereas other researchers contributed evidence for the remainder of the tools. Literature provided evidence supporting internal consistency (n=18)^{45, 93, 162-173, 177-179, 182-184} test retest reliability (n=12),^{93, 96, 166, 168, 170, 171, 176, 178-180, 183, 184} inter-rater reliability (n=5)^{93, 166, 176, 180, 184} and intra-rater reliability (n=1).⁹³ Measurement error calculations were reported for two tools, Child Engagement in Daily Life (CEDL)^{170, 206} and Children Helping Out: Responsibilities Expectations and Supports (CHORES).^{171, 192}

2.3.2.2 Validity Evidence

Appendix D(i,ii) summarizes details on the validity testing results for the 20 measurement tools.^{1, 45, 93, 96, 162-225} All tools had reported evidence of face and/or content validity while many had evidence of construct validity. Construct validity was demonstrated primarily using the known groups method¹¹² to distinguish participation between two or more groups. Ten tools had evidence of convergent and/or discriminant validity, evaluated by comparing scores with other measurement tools,^{45, 162, 163, 168, 171, 172, 177, 202, 207, 223} 11 examined structural validity^{163, 164, 166-171, 173, 181, 183, 184, 187, 190, 197, 213, 222, 226} and seven reported on hypotheses generated *a priori*.^{1, 162, 163, 166, 191, 204, 206, 207, 223} Eleven tools^{163-171, 173, 180, 183, 184} had dimensionality evaluation evidence.¹²⁴ Only two tools had evidence of responsiveness: the Child Engagement in Daily Life (CEDL)²⁰⁶ and the Canadian Occupational Performance Measure (COPM).^{211, 212}

2.3.3 Quality Ratings

2.3.3.1 Reliability Ratings

Table 2.4 summarizes quality ratings of reliability evidence presented in Appendix E. Three measurement tools, Preference for Activities of Children (PAC),¹⁶⁶ Child and Adolescent Scale of Participation (CASP) youth version¹⁶⁹ and Questionnaire of Young People's Participation (QYPP)¹⁸³ achieved excellent ratings using the COSMIN checklist¹²⁴ but only for internal consistency. Half of the tools rated poor for internal consistency because they lacked unidimensionality testing, or did not report an internal consistency statistic for each subscale, or a goodness of fit statistic at a global level (if appropriate). COSMIN¹²⁴ downgraded quality ratings for relative reliability and measurement error because of small sample sizes, unknown study conditions or no description of how missing items were handled.

Three measurement tools achieved excellent overall reliability ratings using the OMRF¹²⁵ with supporting evidence from more than two studies. Tools rating excellent for internal consistency evidence included Assessment of Preschool Children's Participation (APCP),^{162, 185, 186} CASP parent version^{168, 169, 190} and Pediatric Interest Profile (ALIP).^{179, 202} The ALIP also rated excellent on supporting evidence for test-retest reliability.^{179, 202} The remaining tools achieved adequate overall reliability ratings. Despite three tools having more than two publications,^{171, 173, 184, 191, 192, 197, 198, 203-205} they had an overall rating of adequate because evidence came from only one or two studies. In contrast, rating reliability coefficients within individual studies yielded excellent ratings for seven tools on internal consistency,^{163, 164, 170-172, 177, 184, 187, 191, 192, 205} four tools on test-retest reliability^{168, 171, 180, 181, 183} and two tools on inter-rater reliability.^{176, 180, 181} The 'R' designation referenced measurement properties from

administration manuals or unpublished manuscripts, not peer-reviewed sources.^{38, 93, 96, 109, 148, 166, 172, 184, 188, 189, 193, 199, 203, 204} Most COPM^{96, 193, 196} and MayoPortland Adaptability Index (MPAI)¹⁷⁵ reliability evidence were adult-generated and beyond the scope of this review. However, articles describing evidence for COPM⁹⁶ parent proxy¹⁷² and MPAI¹⁷⁵ paediatric use¹⁷⁶ were rated.

2.3.3.2 Validity Ratings

Table 2.5 summarizes quality ratings of validity evidence presented in Appendix F. All except four measurement tools^{45, 174-176, 179, 184} rated excellent for content validity using the COSMIN checklist.¹²⁴ Most tools rated fair or poor for structural validity and hypothesis testing because they lacked description of how missing items were handled, had little description of study conditions, or had small sample sizes. The PAC¹⁶⁶ and the APCP¹⁶² were the exception with good ratings for structural validity¹⁶⁶ and hypothesis testing.^{162, 166} Two studies rated excellent for structural validity^{169, 231} but those same tools also had studies with lower ratings.^{168, 173, 190, 197} Similarly for hypothesis testing, two studies rated good^{166, 207} but other studies for those same tools rated lower.^{1, 93, 209, 216, 227} The two studies with responsiveness evidence rated fair^{206, 211, 212} because of sample size and lack of description regarding hypotheses, study conditions, and/or how missing items were handled.

All but three measurement tools^{45, 174, 176, 184} rated excellent on OMRF¹²⁵ individual study ratings of content validity. Discrete OMRF¹²⁵ rating criteria for individual study's construct or responsiveness evidence was not present, however, overall OMRF¹²⁵ ratings resulted in excellent construct validity evidence for six tools.^{93, 166, 168, 172, 180, 184} All remaining tools rated

adequate overall for validity evidence, however one tool^{45, 174} had items adapted from another tool⁹³ without report of further testing. Despite referencing more than two publications, four tools^{45, 171, 173, 174, 178} rated adequate overall because data were derived from no more than two studies. Similarly, the two tools with responsiveness evidence came from one or two studies.^{206, 211, 212}

2.4 Discussion

This systematic review was undertaken to answer our primary question (i) ‘For children with PM needs, what measurement tools are potentially available to assess participation in everyday life situations?’ and our secondary questions (ii) ‘What aspects of participation do these tools address?’ (iii) ‘What are the reported measurement properties of these tools’ and (iv) ‘What information supports the clinical usefulness of these measurement tools?’ Eighty-five of 138 studies identified in this review yielded 50 potential measurement tools, with 20 meeting tool inclusion criteria.^{45, 93, 96, 162-184} Included tools differed in their evaluation of settings, dimensions of participation, response formats, and intended respondents. Most tools had evidence of at least adequate levels of reliability and validity, while few tools commented on clinical usefulness. The challenge then becomes selecting measurement tools that best meet the intended purpose.

2.4.1 Participation Tools

When determining what tool best fits the intended purpose, practitioners and researchers would be wise to solicit what is important to children and their families, as participation may mean different things to different people.⁶⁶ Most identified tools were parent and/or child self-report,

thereby obtaining participation information reflective of their everyday lives.^{13, 35, 122} The COPM⁹⁶ uniquely relies on the child and/or parent to identify important participation concerns to be evaluated, while other tools evaluated a predetermined list of daily life situations. Tools that allow input from both parents and children^{93, 96, 168, 169, 172, 175, 176, 183} may be valuable considering children's and parents' views of participation may differ.⁶⁶ Tools evaluating the child's participation within the context of the family's participation may also be beneficial,^{35, 66} especially for children needing PM with cognitive or complex disabilities.^{9, 10, 80} A number of qualitative paediatric PM studies describe children's and parents' perspectives and the importance they place on participation in daily life.⁸⁰ Having participation tools that document their experience using PM more systematically will facilitate research efforts.^{9, 10, 80}

2.4.2 Quality Ratings, Measurement Properties and Clinical Usefulness

Despite having a range of tools to choose from, many reviewed measurement tools had limited reliability and validity evidence supporting their use. This was not surprising given the number of tools developed recently in response to the ICF framework's^{33, 34} inclusion of participation. More tools achieved excellent ratings using the OMRF¹²⁵ compared to using the COSMIN checklist.¹²⁴ Rating reliability and validity information (as done using the OMRF¹²⁵) is a more familiar investigation method than rating study conduct (as done using the COSMIN checklist¹²⁴). However, both evaluations are useful when selecting suitable measurement tools. Studies were strongest for content validity and internal consistency, as one might expect, since these two measurement properties are often addressed in initial tool development.¹¹² None achieved excellent ratings for other forms of reliability and validity suggesting that further empirical evidence is needed. Several researchers provided initial reliability and validity

evidence yet acknowledged that tool development and evaluation was on-going.^{162, 163, 170, 177, 178,}
¹⁸³ Interestingly, more established tools^{93, 96, 166, 184} referenced measurement properties from non-peer reviewed sources. This suggests that standards for tool development, evaluation and reporting have changed over the years, and that perhaps tools developed more recently are better situated to meet newer standards.¹²⁴ If we use our quality rating tools^{124, 125} as guides, then the Assessment of Preschool Children's Participation (APCP),¹⁶² Preferences for Activities of Children (PAC),¹⁶⁶ Child and Adolescent Scale of Participation (CASP),^{168, 169} Child Engagement in Daily Life (CEDL),^{170, 206} Canadian Occupational Performance Measure (COPM),⁹⁶ Questionnaire of Young People's Participation (QYPP)¹⁸³ measurement tools had higher quality reliability and validity evidence than other tools. Several researchers used Item Response Theory (IRT) approaches to inform tool development.^{163, 168, 170, 171, 173, 181, 226} IRT methods typically use larger sample sizes, with more robust analyses and interpretations,¹¹² but assumptions that (i) the scale measures one underlying latent trait (or dimension) and (ii) a hierarchical structure to questions and responses exists, must be met.^{35, 108} This raises thought-provoking questions when thinking about how best to measure participation: is participation unidimensional? and does it follow a hierarchical structure? Conceptual models proposed by some researchers^{2, 3, 13} and some developers' rationale for tool development^{183, 200} suggest otherwise.

Methods used to validate score interpretations should fit the theoretical rationale chosen when developing the measurement tool, and should be suitable for the hypotheses tested.¹¹² Although few tools had evidence of hypothesis testing, some tools^{93, 96, 168, 173, 200} were grounded in a theoretical framework. Several tools, based on different conceptual models,^{93, 96, 167, 184} were

developed prior to the introduction of the ICF, ^{33, 34} yet remain relevant with a body of empirical evidence supporting their use. ^{109, 121, 122, 148, 155} Other tools ^{162, 166, 168, 174, 178, 180, 197} developed more recently, use current definitions of participation. ^{33, 34}

2.4.3 Application to Paediatric Power Mobility

Some of the earlier theoretical models referenced in several participation tools' development, have been discussed in the paediatric PM literature, introduced in Chapter 1. ^{9, 80} These models facilitate understanding of concepts we are attempting to measure and provide rationale for inclusion of specific items. Two tools ^{93, 96} identified in this systematic review have also appeared in paediatric PM literature. The COPM ⁹⁶ was used to detect change in occupational performance and satisfaction following PM provision in two studies, ^{7, 67} while the Assessment of Life Habits (LIFE-H) ⁹³ was used in a cross-sectional study to evaluate life habits among groups of children using different types of mobility devices (PM being one type). ¹ Although it is encouraging to see occupational performance and life habits being evaluated in paediatric PM research, these three studies offered little description or insight into children's use of PM or the role PM played in enabling children to participate in desired in life situations. To make meaningful interpretations of the scores and advance our understanding of participation in everyday life for children using PM, more in-depth accounts describing children's participation when using PM are needed along with changes in scores of participation tools. Additionally, establishing the tools' responsiveness with this population is critical before judgments are made about PM's impact on children's participation in everyday life.

As discussed in Chapter 1, choice of measurement tool may be influenced by the depth and complexity of desired participation information as well as the tools' clinical usefulness.^{35, 122} Although acceptability of tool questions and format were evaluated for some tools within the context of content validity, other aspects (e.g., who can administer the tool, training required, availability, cost, and score interpretability) were reported on less consistently. Administration time varied, from very brief¹⁷⁷ to comprehensive participation coverage.^{93, 166} Administration time is a key consideration with PM interventions because participation in everyday life is just one of many areas assessed.^{9, 10, 80} How measurement tools address use of assistive devices is another important consideration for those using PM.^{123, 157} Two of four tools addressing assistive device use^{168, 184} acknowledged use without affecting scores, yet two tools downgraded scores.^{93, 175, 176} Downgrading scores is punitive^{123, 157} and counterintuitive, given that PM goals are often to enhance independent mobility and participation in everyday life.^{20, 22} Knowing this information will help guide selection of potential participation tools for those using PM.

2.4.4 Limitations

Several limitations may affect generalizability of our review's findings. Other relevant evidence might have been overlooked because of chosen search terms, and electronic databases; or restrictive inclusion and exclusion criteria limiting consideration of potential tools (e.g. English language, and peer-reviewed journals). However, we mitigated this concern by reviewing our search strategy with experienced health sciences librarians and including two reviewers who independently screened articles following clear eligibility criteria. Additionally, a publication bias with selective reporting may have limited exposure to meaningful tool information. Our findings may have been influenced by criteria used within the chosen quality rating tools, and as

our quality ratings suggest, reporting standards and terminology may have changed over the timespan in which the studies occurred, with study designs, sample sizes, statistical methods and rudimentary analyses once considered high quality at their time of publication, not readily meeting contemporary expectations. For some tools,^{162, 166, 171, 203} additional non-English language information about measurement properties were not included in this review. Finally, the Young Children's Participation and Environment Measure (YC-PEM),^{219, 228} a recently developed English-language tool, may have potential, however we were unable to obtain detailed information about the items used to evaluate participation, so excluded it from our review.

2.5 Conclusion

This systematic review advances our knowledge about available participation tools, and sets a foundation from which evidence-based decisions can be made. In this chapter, 20 measurement tools meeting inclusion criteria were identified and critically appraised. Given the current evidence, no single participation tool stood out as being most appropriate for children using PM, although several tools demonstrated potential. Moreover, each tool was developed for different ages of children, used different respondents and evaluated different dimensions of participation. To further guide tool selection for children using PM, the following chapter investigates what dimensions of participation are important to measure for our population and examines suitability of available measurement tools.

Table 2.1 Inclusion and Exclusion Criteria

Study Inclusion	Tool Inclusion
<ul style="list-style-type: none"> • English language, peer-reviewed, primary articles, systematic reviews or meta-analyses • focused on children aged 18 months to 17 years • included participants with motor impairments or movement disorders due to neurological, neuromotor, neuromuscular or musculoskeletal condition • participant characteristics were described in sufficient detail to determine that some might benefit from PM (e.g. Gross Motor Function Classification System (GMFCS)²²⁹ levels III-V for children with CP). They may be non-ambulatory, ambulate for short distances and/or use walking aids • tool description used in the evaluation of participation included reference to measurement properties and clinical utility 	<ul style="list-style-type: none"> • detailed description of scale items and responses enabled judgement about tool content • scale or subscale items represented ≥ 2 dimensions of participation as defined in ICF-CY³⁴ Chapters 6-9 • 85 percent (%) or more of scale or subscale items related to some aspect of participation (including barriers or facilitators) • evidence of English language version's measurement properties and clinical utility included children under 18 years with a motor impairment or movement disorder affecting independent mobility • detailed evidence of measurement properties included reliability, validity, responsiveness and/or clinical utility
Study Exclusion	Tool Exclusion
<ul style="list-style-type: none"> • individuals younger than 18 years were included along with adults, however the younger group comprised less than 15% of the sample • age of participants were not identified 	<ul style="list-style-type: none"> • evaluated burden of care; quality of life or health related quality of life • evaluated environmental considerations in isolation of participation • individualized, goal-setting tools for intervention did not specifically address participation outcomes

Figure 2.1 PRISMA¹⁶¹ Flowchart of Search Results

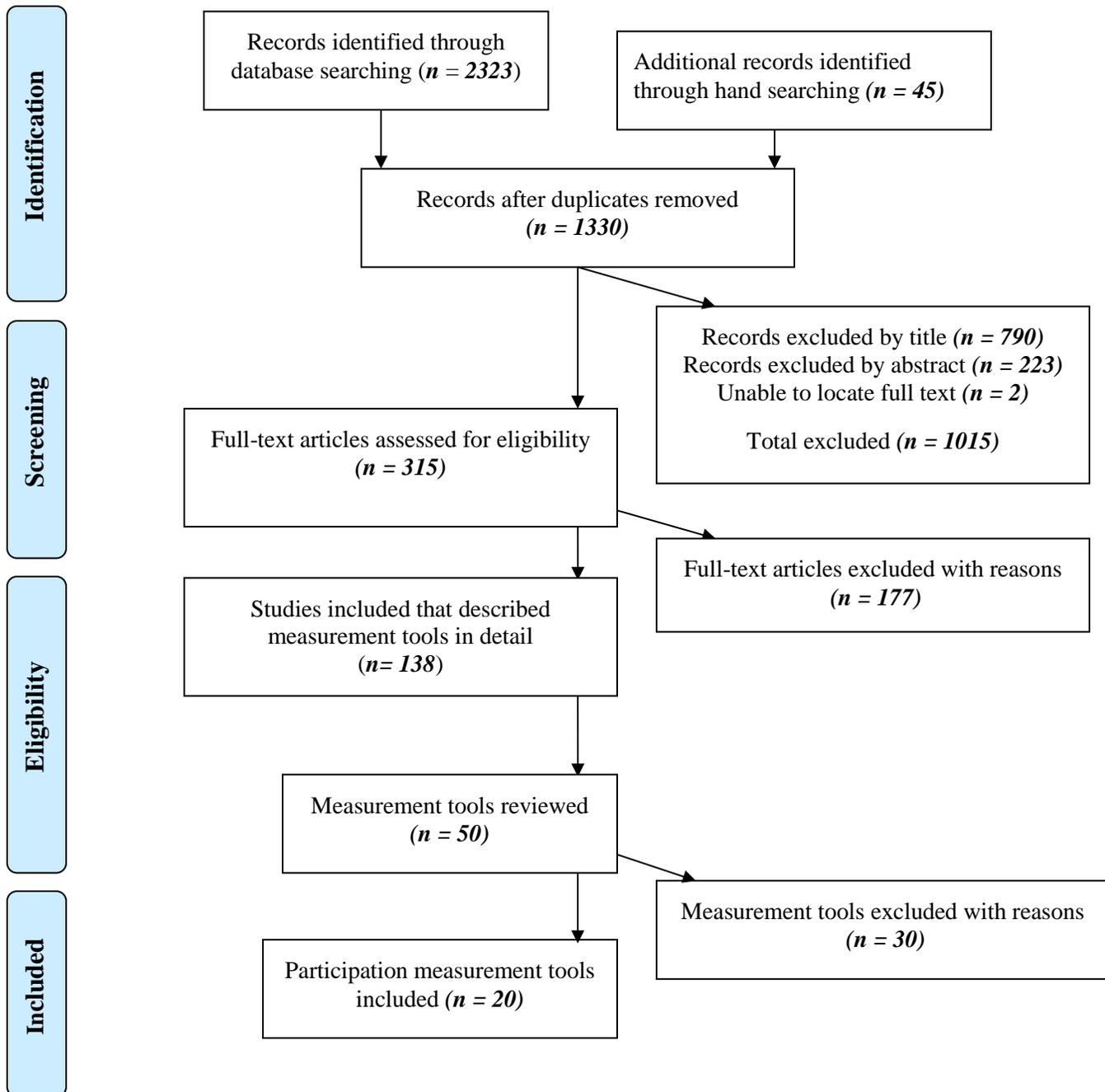


Table 2.2 Excluded Full Text Articles and Measurement Tools

Full-Text Articles Excluded (n = 177)	Measurement Tools Excluded (n = 30)
Child participation measured, but inclusion criteria not met n=72 Not focused on participation n=54 Adult participation tool n=26 Descriptive information only about participation n=12 Qualitative study design n=12 Full text not found n=1	<85% of items related to participation n=22 No evidence of measurement properties for children n=7 No evidence of validation for children with motor impairment n=7 Only 1 dimension of participation (i.e. play) n=4 Tool developed and tested in language other than English n=3 Unable to locate details of tool n=1

Table 2.3 Description of Paediatric Participation Tools

Tool	Population	Dimensions	Items	Response Format and Scoring
Assessment of Preschool Children's Participation (APCP) ¹⁶²	preschool children aged 2 years to 5 years 11 months	<ul style="list-style-type: none"> • diversity • frequency • intensity <p>Evaluates participation in home and community</p>	<p>45 items across 4 subscales:</p> <ul style="list-style-type: none"> • Play- 9 items • Skill Development- 15 items • Active Physical Recreation- 10 items • Social Activities- 11 items 	<ul style="list-style-type: none"> • Parent/caregiver report • For each item: Yes or no indicated if child did activity during previous 4 months, (Diversity) & if yes, how frequently using 7-point ordinal scale (Frequency Intensity) • Scores generated: For Total & each of 4 subscales Diversity- sum of items answered yes Frequency- sum of frequency /actual # participated in Intensity- sum of frequency /total # items listed
Assistance to Participate Scale (APS) ¹⁶³	children 5 to 18 years with a disability	<ul style="list-style-type: none"> • extent of assistance provided to child during play and leisure <p>Evaluates participation in home and community</p>	<p>8 items across 2 subscales:</p> <ul style="list-style-type: none"> • Home Alone- 4 items • Community Social- 4 items 	<ul style="list-style-type: none"> • Parent/caregiver report • For each item: Degree of assistance rated using 5-point scale • Scores generated: Total & subscale scores
Availability and Participation Scale (AvailabilityPS) ^{164, 165}	school-aged children with a disability	<ul style="list-style-type: none"> • degree of activity availability • degree of child's participation in activity <p>Evaluates participation in school</p>	English version: 27 items across 6 factors (social, recreational, communal, creative, civic & academic)	<ul style="list-style-type: none"> • Teacher report¹⁶⁴ • For each item: Degree of availability & Degree of participation scored using 4- point ordinal scales • Scores generated: Availability & Participation Total scores¹⁶⁵

Tool	Population	Dimensions	Items	Response Format and Scoring
				<ul style="list-style-type: none"> Aggregate Participation Score calculated¹⁶⁴ converted to standardized Z scores to allow comparison across students
Children's Assessment of Participation and Enjoyment (CAPE) ¹⁶⁶ and accompanying Preference for Activities of Children (PAC) ¹⁶⁶	young people aged 6 to 21 years	<ul style="list-style-type: none"> diversity intensity location with whom enjoyment <p>Evaluates participation in home and community</p> <p>[preference assessed by Preference for Activities of Children¹⁶⁶]</p>	<p>55 items across 2 domains & 5 activity type subscales:</p> <p>Domains:</p> <ul style="list-style-type: none"> Informal- 40 items Formal- 15 items (i.e., structured with rules & instructors) <p>Activity types:</p> <ul style="list-style-type: none"> Recreational- 12 items Social- 10 items Active-physical- 13 items Skill-based- 10 items Self-improvement- 10 items 	<ul style="list-style-type: none"> Child self report (with parent/caregiver assistance as needed) Interviewer-administered vs printed booklet For each item: yes or no indicated if child did activity during previous 4 months, if yes, rate intensity using 7-point ordinal scale Where using 6-point scale Whom using 5-point scale Enjoyment using 5-point scale Scores generated: Dimension scores calculated for overall participation, domain &/or activity type subscales
Community Activities Questionnaire (CAQ) ¹⁶⁷	preschool children aged to 2 to 5 years	<ul style="list-style-type: none"> frequency <p>Evaluates participation in community</p>	18 items related to community activities	<ul style="list-style-type: none"> Parent/caregiver report For each item: Estimate number of times child has engaged in item in past week, month or 6 months
Child and Adolescent Scale of Participation (CASP) ^{168, 169}	children aged 5 to 18 years	<ul style="list-style-type: none"> participation as compared to other children of same age <p>Evaluates participation in</p>	<p>20 items across 4 subsections:</p> <ul style="list-style-type: none"> Home- 6 items Community- 4 items School- 5 items Home & Community Living 	<ul style="list-style-type: none"> Parent/caregiver report for children 5 years & older¹⁶⁸ Youth self report for children 11 to 17 years¹⁶⁹

Tool	Population	Dimensions	Items	Response Format and Scoring
		home, school and community	Activities- 5 items	<ul style="list-style-type: none"> • Interviewer-administered for face to face or phone • Printed booklet for face to face or mail survey • For each item: rated using 4-point scale or not applicable • Additionally 4 open-ended questions asking about barriers & facilitators to participation • Scores generated: Summed, averaged & converted to 100-point scale for overall participation vs subsections
Child Engagement in Daily Life Measure ¹⁷⁰	preschool children aged 18 to 60 months	<ul style="list-style-type: none"> • frequency (Part I) • enjoyment (Part I) • (performance/degree of assistance- Part II) <p>Evaluates participation in home and community</p>	<p>18 items across 2 parts:</p> <p>Part I Participation in Family and Recreational Activities- 11 items</p> <p>Part II Participation in Self Care- 7 items</p>	<ul style="list-style-type: none"> • Parent/caregiver report • For each item in Part I: Frequency & Perception of child's enjoyment rated using 5-point scales • For each item in Part II: Performance/Degree of assistance rated using 5-point scale • Scores generated: Sum of raw scores converted to scaled score for each of Part I & II
Children Helping Out: Responsibilities Expectations and Supports (CHORES) ¹⁷¹	children aged 6 to 14 years	<ul style="list-style-type: none"> • performance • degree of assistance <p>Evaluates participation in home</p>	<p>34 items across 2 subscales</p> <ul style="list-style-type: none"> • Self Care- 13 items (managing own needs and belongings) • Family Care- 21 items (ability to take care of other's) 	<ul style="list-style-type: none"> • Parent/caregiver report • For each item: Performance indicated by yes or no if child did activity Degree of assistance rated using 6-point scale

Tool	Population	Dimensions	Items	Response Format and Scoring
			needs and belongings)	<ul style="list-style-type: none"> • Additionally, two attitudinal questions, one Importance & one Satisfaction, rated using • 6-point scale, each with open-ended comments • Scores generated: Performance- sum of yes responses Assistance- summed, averaged & converted to 100-point scale for total participation vs subscales
Canadian Occupational Performance Measure (COPM) ⁹⁶	individuals of all ages	<ul style="list-style-type: none"> • importance • performance • satisfaction <p>May evaluate participation in home, school and community, dependent on individual's selected (productivity and/or leisure) goals</p>	<p>up to 5 items (goals) selected based on importance related to:</p> <ul style="list-style-type: none"> • self-care (personal care, community & mobility activities) • productivity (home & school activities) • leisure (play & recreation) 	<ul style="list-style-type: none"> • Semi-structured interview with child (if 8 years or older)⁹⁶ parent/caregiver (if under 8 years)¹⁷² • For each item: rate Importance to identify up to 5 goals. Performance & Satisfaction rated on 10-point scales • Scores generated: Performance & Satisfaction scores summed & averaged over number of goals selected. Change scores determined on re-administration
Child Occupational Self Assessment (COSA) ¹⁹⁷	children aged 6 to 17 years with a disability	<ul style="list-style-type: none"> • competence • importance <p>Evaluates participation in</p>	25 items related to participation at home, school and community	<ul style="list-style-type: none"> • Child self-report • Administered in three formats: <ol style="list-style-type: none"> i. print with visual cues ii. card sort version iii. summary form without cues

Tool	Population	Dimensions	Items	Response Format and Scoring
		home, school and community		<ul style="list-style-type: none"> • For each item: Perceived Importance (value) & Competence rated using 4-point scales. * Can use 2-point scale for younger children or those with intellectual disabilities • Additionally 3 open-ended questions invite children to share information about strengths, challenges and activities of importance. • Scores generated: normative or criterion referenced scores not generated but rather ratings determine gaps & areas to focus on in therapy
Frequency of Participation Questionnaire (FPQ) ^{45, 174}	children aged 8 to 12 years	<ul style="list-style-type: none"> • frequency Evaluates participation in home, school and community	14 items related to participation at home, school and community	<ul style="list-style-type: none"> • Parent/caregiver report • For each item: Frequency rated using 6-point scale • Scores generated: Total score
Assessment of Life Habits (LIFE-H) ⁹³	individuals of all ages different versions dependent on age, respondent, length & format currently available: children aged 14 years & older (including adults): General Version 3.113	<ul style="list-style-type: none"> • accomplishment of life habit • amount of assistance • respondent's satisfaction Evaluates participation in home, school and community	Number of items vary depending on length, but all represent 11 (or 12 for children 5 years and older) life habit categories across 2 domains Daily Activities domain: <ul style="list-style-type: none"> • communication • personal care • housing • mobility 	<ul style="list-style-type: none"> • Child self-report (not 0-4 years version) • Parent/Caregiver Report • Professional Evaluation • Interviewer-administered • print vs electronic format • For each item: Accomplishment Level score using 10-point scale generated from combination of Accomplishment using 5-point

Tool	Population	Dimensions	Items	Response Format and Scoring
	<p>children aged 5 to 13 years: LIFE-H Child 5–13 Version 1.08</p> <p>children aged 0 to 4 years: LIFE-H for Children 0-4</p>		<ul style="list-style-type: none"> • nutrition • fitness <p>Social Roles domain:</p> <ul style="list-style-type: none"> • recreation • responsibility • education • community life • interpersonal relationships • (work/employment) <p>LIFE-H General Version 3.113</p> <ul style="list-style-type: none"> • <i>Short form</i>- 77 items • <i>Brief form</i>- 16 items • <i>Long form</i>- 242 items <p>LIFE-H Child 5–13 Version 1.08</p> <ul style="list-style-type: none"> • <i>Short form</i>- 64 items • <i>Long form</i>- 198 items <p>LIFE-H for Children 0-4</p> <ul style="list-style-type: none"> • <i>Long form</i>- 71 items 	<p>rating of Degree of difficulty & 4-point rating of amount of Assistance (+ not applicable) Respondent's Satisfaction rated using 5-point scale</p> <ul style="list-style-type: none"> • Scores generated: Weighted Total score, Domain & category scores
<p>MayoPortland Adaptability Index (MPAI)^{175, 176}</p>	<p>children aged 1 to 18 years (as well as adults) with acquired brain injury (ABI)</p>	<ul style="list-style-type: none"> • problems affecting daily life after ABI • for some items, rating addresses assistance needed <p>Evaluates participation in home, school and community</p>	<p>8 items in Participation Index</p> <ul style="list-style-type: none"> • Initiation • Social contact • Leisure/recreational activities • Self-care • Residence • Transportation • Work/school • Money management <p>29 items in total for MPAI-4 12 items in Ability Index 12 items in Adjustment Index (3 items same for Participation & Adjustment Indexes)</p>	<ul style="list-style-type: none"> • Child self-report • Parent/caregiver report • Professional evaluation- individual or group consensus • For each item: Degree of problem affecting daily life rated using 5-point scale • Scores generated: Participation Index score [as well as Total score, Ability & Adjustment Index scores]

Tool	Population	Dimensions	Items	Response Format and Scoring
Pediatric Community Participation Questionnaire (PCPQ) ¹⁷⁷	young people aged 8 to 20 years	<ul style="list-style-type: none"> • degree of difficulty participating <p>Evaluates participation in community</p>	19 items related to community activities	<ul style="list-style-type: none"> • Child self-report • Interviewer-administered for face to face or phone • For each item: degree of Difficulty participating rated using 6-point scale, can indicate don't know or not appropriate • Scores generated: Total score
Participation and Environment Measure for Children and Youth (PEM-CY) ¹⁷⁸	children aged 5 to 17 years	<ul style="list-style-type: none"> • frequency • involvement • desire for change • facilitators • barriers • strategies to promote participation <p>Evaluates participation in home, school and community</p>	25 items across 3 settings: <ul style="list-style-type: none"> • Home- 10 items • School- 5 items • Community- 10 items Facilitators & Barriers: <ul style="list-style-type: none"> • Home- 8 items + 4 items • School- 12 items + 4 items • Community- 13 items + 4 items 	<ul style="list-style-type: none"> • Parent/caregiver report • For each item: Frequency in last 4 months rated using 8-point scale, Involvement rated using 5-point scale, Desire for change indicated using 6 options Supports & barriers rated using either 3- or 4-point scales. Space provided to comment on 3 strategies used to support participation • Scores generated: Summary scores for Frequency, Involvement, Desire for Change, Environmental scores
Paediatric Interest Profiles (PIP) Adolescent Leisure Interest Profile (ALIP) ¹⁷⁹	youth aged 12 to 21 years	<ul style="list-style-type: none"> • frequency • enjoyment • with whom • competency • interest & why 	83 items + 5 items child/ youth identified Categories: Sports activities Outside activities Creative activities	<ul style="list-style-type: none"> • Child Self-Report • For each item: Enjoyment, with whom and competency rated using 3-point scale Interest rated using 5-point scale

Tool	Population	Dimensions	Items	Response Format and Scoring
		Evaluates participation in home, school and community	Socializing Exercise activities- ALIP Relaxation activities- ALIP Intellectual activities- ALIP Club/Community Organizations- ALIP	<ul style="list-style-type: none"> • Scores generated: Total score and category scores for each dimension
Preschool Activity Card Sort (Preschool ACS) ¹⁸⁰	children aged 3 to 6 years	<ul style="list-style-type: none"> • participation • involvement <p>discussion of importance, frequency, barriers & facilitators as well as parent's satisfaction of child's participation</p> <p>Evaluates participation in home, preschool and community</p>	<p>85 items across 7 domains:</p> <ul style="list-style-type: none"> • self-care- 15 items • social interaction- 12 items • domestic chores- 11 items • education- 10 items • sedentary leisure- 11 items • vigorous leisure- 10 items • community mobility- 16 items <p>Version 2¹⁸¹ revisions involve additions of 6 education, 1 sedentary leisure and 2 vigorous leisure items and removal of 3 domestic chores</p>	<ul style="list-style-type: none"> • Semi-structured interview with parents using cards with photos of specific activities • For each item: Participation rated using 6-point scale that describes involvement • Scores generated: Domain scores
Quality of Social Functioning Scale /Index (QOSF) ¹⁸²	youth aged 12 to 18 years	<ul style="list-style-type: none"> • frequency • desired frequency <p>Evaluates participation in home, school and community</p>	<p>11 items with two parts/item</p> <ul style="list-style-type: none"> • Part A- frequency of doing the item during a month • Part B- how often would like to do item during a month 	<ul style="list-style-type: none"> • Child self-report • Interviewer-administered for face to face or phone • For each item: Part A and Part B each rated using 6-point scale • Scores generated: Index score calculated by subtracting Part A from Part B for each item, then sum differences of each item/total # items

Tool	Population	Dimensions	Items	Response Format and Scoring
Questionnaire of Young People's Participation (QYPP) ¹⁸³	young people aged 14 to 21 years	<ul style="list-style-type: none"> • frequency <p>Evaluates participation in home, school and community</p>	<p>45 items across 7 domains:</p> <ul style="list-style-type: none"> • Getting on with others- 8 items • Autonomy- 4 items • Recreation- 14 items • Home life- 5 items • Education- 5 items • Work/finances- 4 items • Preparing for future- 5 items 	<ul style="list-style-type: none"> • Child self-report • Proxy (parent/caregiver) report • For each item: Degree of difficulty participating rated using response scales with up to 7 choices • Scores generated: Total and domain scores
School Function Assessment (SFA) ¹⁸⁴ Participation section (Part I) only	elementary school aged children 5 to 14 years with a disability	<ul style="list-style-type: none"> • degree of participation across school settings <p>Evaluates participation in school</p>	<p>6 items in Part I Participation</p> <ul style="list-style-type: none"> • classroom (regular or specialized) • playground/recess • transportation • bathroom/toileting • transitions • mealtime/snack time <p>SFA consists of 3 sections: Part I Participation Part II Task Supports [21 items rated on assistance & adaptations using 4-point scales] Part III Activity Performance (265 items) [21 activity performance sections rated using 4-point scales]</p>	<ul style="list-style-type: none"> • Teacher or other school personnel report • For each item: Degree of participation scored using 6-point ordinal scale • Scores generated: Items summed, and converted to 100-point criterion Participation score. A score of 100 represents a criterion of full grade-appropriate functioning

Legend: '&' = and; '/' = divided by; '#' = number.

Table 2.4 Summary of Reliability Evidence Quality Ratings

Measurement Tool	COSMIN rating ¹²⁴ Lowest rating as specified in COSMIN guidelines ¹²⁴ E = excellent, G = good, F= fair, P = poor			OMRF rigour of studies' reliability evidence ¹²⁵ Lowest rating as specified in OMRF guidelines ¹²⁵ E = more than 2 studies supporting evidence A = 1 to 2 studies supporting evidence			
	Internal Consistency	Reliability	Measurement Error	Internal Consistency	Test-retest	Inter-rater	Intra-rater
Assessment of Preschool Children's Participation (APCP) ^{162, 185, 186}	P			E			
Assistance to Participate Scale (APS) ^{163, 187}	F			A			
Availability and Participation Scale (AvailabilityPS) ^{164, 165}	P			A			
Children's Assessment of Participation and Enjoyment (CAPE) ^{166, 186, 188, 189} and Preference for Activities of Children (PAC) ^{166, 186, 188, 189}	P CAPE E PAC	<i>test-retest</i> R F <i>inter-rater</i> R F		A CAPE & PAC	A CAPE	A CAPE	
Community Activities Questionnaire (CAQ) ¹⁶⁷	P			A			
Child and Adolescent Scale of Participation (CASP) ^{168, 169, 190}	P Parent version E Youth version	<i>test-retest</i> F		E Parent version A Youth version	A Parent version		
Child Engagement in Daily Life Measure (CEDL) ^{170, 206}	F	<i>test-retest</i> P	P	A	A		
Children Helping Out: Responsibilities Expectations and Supports (CHORES) ^{171, 191, 192}	P	<i>test-retest</i> P	P	A	A		
Canadian Occupational Performance Measure (COPM) ^{172, 193, 230}	F Parent proxy version	<i>test-retest</i> R P <i>inter-rater</i> P		A Parent proxy version	R A	A Parent proxy version	
Child Occupational Self Assessment (COSA) ^{173, 197, 198, 231}	F			A			
Frequency of Participation Questionnaire (FPQ) ⁴⁵	P			A			

Measurement Tool	COSMIN rating ¹²⁴ Lowest rating as specified in COSMIN guidelines ¹²⁴ E = excellent, G = good, F = fair, P = poor			OMRF rigour of studies' reliability evidence ¹²⁵ Lowest rating as specified in OMRF guidelines ¹²⁵ E = more than 2 studies supporting evidence A = 1 to 2 studies supporting evidence			
	Internal Consistency	Reliability	Measurement Error	Internal Consistency	Test-retest	Inter-rater	Intra-rater
Assessment of Life Habits (LIFE-H) ^{93, 109, 148, 207,}	R P	P		R A	A	A	A
MayoPortland Adaptability Index (MPAI) ^{175, 176}		<i>test-retest</i> F <i>inter-rater</i> P			A	A	
Pediatric Community Participation Questionnaire (PCPQ) ¹⁷⁷	P			A			
Participation and Environment Measure for Children and Youth (PEM-CY) ^{178, 201}	G	P		A	A		
Pediatric Interest Profile - Adolescent Leisure Interest Profile (ALIP) ^{179, 202}	P	<i>test-retest</i> G (PD) P (TD)		E	E		
Preschool Activity Card Sort (Preschool ACS) ^{180, 181}	P	<i>test-retest</i> P <i>inter-rater</i> P		A	A	A	
Quality of Social Functioning Scale and Index (QOSF) ¹⁸²	P			A			
Questionnaire of Young People's Participation (QYPP) ¹⁸³	E	<i>test-retest</i> F		A	A		
School Function Assessment (SFA) ^{184, 204, 205, 226}	F	<i>test-retest</i> P <i>inter-rater</i> P		A	A	A	

Legend: A = adequate; COSMIN = COnsensus-based Standards for the Selection of health Measurement Instruments;¹²⁴ E = excellent; F = fair; G = good; OMRF = McMaster Outcome Measure Rating Form;¹²⁵ P = poor; R = referenced from other source: unable to locate original, or not peer-reviewed source; PD = those with physical disabilities; TD = those who are typically developing; & = and.

Table 2.5 Summary of Validity Evidence Quality Ratings

Measurement Tool	COSMIN Rating ¹²⁴ Lowest rating as specified in COSMIN guidelines ¹²⁴ E = excellent, G = good, F= fair, P = poor				OMRF rigour of studies' validity evidence ¹²⁵ Lowest rating as specified in OMRF guidelines ¹²⁵ E = more than 2 studies supporting evidence A = 1 to 2 studies supporting evidence		
	Content Validity	Structural Validity	Hypotheses Testing	Responsiveness	Content Validity	Construct Validity	Responsiveness
Assessment of Preschool Children's Participation (APCP) ¹⁶²	E		G		A	A	
Assistance to Participate Scale (APS) ^{163, 187, 208}	E	F	F		A	A	
Availability and Participation Scale (AvailabilityPS) ^{164, 165}	E	F	F		A		
Children's Assessment of Participation and Enjoyment (CAPE) and Preference for Activities of Children (PAC) ^{166, 186, 188, 189}	CAPE & PAC E	PAC G	CAPE F PAC G		A	E	
Community Activities Questionnaire (CAQ) ¹⁶⁷	E	F	F		A	A	
Child and Adolescent Scale of Participation (CASP) ^{168, 169, 190}	E	P	F		A	E	
Child Engagement in Daily Life Measure (CEDL) ^{170, 206}	E	F	F	F	A	A	A
Children Helping Out: Responsibilities Expectations and Supports (CHORES) ^{171, 191, 192}	E	P	F		A	A	
Canadian Occupational Performance Measure (COPM) ^{172, 193, 230}	E		F Parent proxy	F Parent proxy	A Parent proxy	E Parent proxy	A Parent proxy
Child Occupational Self Assessment (COSA) ^{173, 197, 198, 214, 231}	E	P	F		A	A	
Frequency of Participation Questionnaire (FPQ) ⁴⁵	F		F		A	A	

Measurement Tool	COSMIN Rating ¹²⁴ Lowest rating as specified in COSMIN guidelines ¹²⁴ E = excellent, G = good, F= fair, P = poor				OMRF rigour of studies' validity evidence ¹²⁵ Lowest rating as specified in OMRF guidelines ¹²⁵ E = more than 2 studies supporting evidence A = 1 to 2 studies supporting evidence		
	Content Validity	Structural Validity	Hypotheses Testing	Responsiveness	Content Validity	Construct Validity	Responsiveness
Assessment of Life Habits (LIFE-H) ^{93, 109, 148, 207}	E		P		A	E	
MayoPortland Adaptability Index (MPAI) ^{175, 176}	F		P		A	A	
Pediatric Community Participation Questionnaire (PCPQ) ¹⁷⁷	E		F		A	A	
Participation and Environment Measure for Children and Youth (PEM-CY) ^{178, 201}	E		F		A	A	
Pediatric Interest Profile - Adolescent Leisure Interest Profile (ALIP) ^{179, 202}	F		F		A	A	
Preschool Activity Card Sort (Preschool ACS) ^{180, 181}	E	P	F		A	E	
Quality of Social Functioning Scale and Index (QOSF) ¹⁸²	E		P		A	A	
Questionnaire of Young People's Participation (QYPP) ^{183, 222}	E	P	F		A	A	
School Function Assessment (SFA) ^{184, 204, 205, 226}	G	P	F		A	E	

Legend: A = adequate; COSMIN = COnsensus-based Standards for the Selection of health Measurement Instruments;¹²⁴ E = excellent; F = fair; G = good; OMRF = McMaster Outcome Measure Rating Form;¹²⁵ P = poor; & = and.

Chapter 3: Reaching Expert Consensus on Participation Outcomes Important to Measure for Children Using Power Mobility and Determining Suitable Measurement Tools

3.1 Introduction

The systematic review in Chapter 2 advances knowledge about available participation tools, and informs evidence-based decisions, yet questions remain about how best to use this information for children using PM. In the last chapter we learned that numerous tools are available that *might* work for children with varying degrees of mobility limitation. Critical appraisal of the included tools found a broad range of evidence supporting measurement properties and clinical usefulness, as well as considerable variation in quality ratings. Findings suggest both positive and negative consequences. On the positive side, having such choice provides an opportunity to select tools that may fit better with a specific client's situation. On the negative side, this choice can be confusing and overwhelming, leaving professionals with a sense of bewilderment not knowing which tool to pick, given participation is a complex construct and quality of measurement properties vary.^{2, 3, 35}

Recognizing that participation in everyday life for those using PM may be different from those who walk or use manual mobility devices,¹ determining what elements of participation are most important to measure for children using PM is a needed to assist stakeholders in their decision-making, given that different tools address different dimensions of participation, and capture different perspectives (e.g. therapist vs. parent vs. child) using different response formats.^{66, 122, 148} Rather than adopting existing measurement tools with children using PM on an

ad-hoc basis, a more systematic approach is warranted. We define ‘elements of participation’ to encompass the ‘who, what, where and how’ of participation measurement. These elements incorporate who should be the focus of the evaluation, whose views should be sought as respondents, what kinds of participation, how and where participation in everyday life should be measured (objective, subjective and contextual dimensions).^{2, 3, 35} Measurement tools can then be compared based on elements of importance, to identify what tools are most suitable for a particular situation. Given the variation in participation tools and the broad age-span and abilities of PM users, it may be unrealistic to expect one tool to address the range of life situations important for young people using PM. One option might be to develop a measurement toolkit, offering choice of tools dependent upon measurement purpose, age, functional abilities, and environmental contexts being considered for evaluation.²³²

Calls for consensus have been raised in wheeled mobility^{104, 233} and paediatric rehabilitation¹⁵⁵ to better understand and determine how best to measure participation for specific client groups, understand their rehabilitation needs, identify relevant tools and develop more effective interventions.^{128, 234} The Delphi survey technique is an iterative survey method²³⁵ consisting of a structured process of sequential rounds, developed to build consensus when uncertainty or lack of empirical evidence exists.²³⁶ Consensus-building using this technique has been demonstrated in clinical guideline development,²³⁵ outcome determination for measurement in clinical trials,²³⁷ and various problem identification and planning initiatives for research, education and service delivery.²³⁸ Priority setting developed using this formal consensus method minimizes bias and strengthens scientific credibility and methodological transparency^{235, 237} while drawing on the best available evidence from collective knowledge and experiences of participants.^{236, 239}

Stakeholders' information goals are key guiding factors for measurement tool development and selection.¹⁴⁸ As such, it is extremely valuable to have stakeholder input into identifying and prioritizing participation elements important for children using PM. Those with practical knowledge of how children use PM may know best what outcomes are important for participation in everyday life.^{13, 240} Clinicians and researchers specializing in paediatric participation-focused PM interventions have firsthand knowledge and a vested interest in identifying clinically important and meaningful elements of participation. Likewise, parents of children using PM have a unique and ecologically valid expertise in dealing with their children's day to day challenges and strategies for promoting participation at home, at school and out in the community.^{13, 35, 80} Although children may provide the best insight into their own participation, developmental or disability-related challenges may prevent them from providing reliable information.^{66, 241} Seeking input from stakeholders who will be using this information and engaging them from the start is valuable, both for informing research and carrying out integrated knowledge translation activities.^{148, 237}

3.1.1 Purpose

The purpose of this study was to (a) advance understanding of what participation-related information is important to measure for children using PM and, (b) determine how best to measure these elements of participation.

Specific objectives were to:

1. Identify and reach consensus on elements of participation in everyday life important to measure for children using PM.
2. Prioritize important content and features to be included in participation-focused measurement tools.
3. Map these elements to existing participation measurement tools.
4. Use the identified important elements to distinguish suitable tools for measuring participation in children who use PM to
 - (a) evaluate participation-related information of value when assessing PM, and
 - (b) evaluate change in participation after provision of PM interventions.
5. Identify tools to be considered for inclusion in a measurement toolkit for clinical and research applications (aptly named the POWER (Paediatric Participation Outcomes for Wheelchair Evaluation in Rehabilitation) Mobility toolkit)
6. Identify a network of therapists and researchers involved in this area of investigation for knowledge exchange and future collaborations.

3.2 Method

3.2.1 Design

We employed an online modified Delphi survey technique²³⁶ (Figure 3.1) to engage key stakeholders and advance participation measurement.^{128, 234, 240} This method afforded ‘quasi-anonymity’ (i.e. unknown to each other, but known to the researcher);²³⁶ participants never interacted directly, allowing for non-biased disclosure while lessening the effect of group

pressure and inter-personal dynamics.²³⁷ The Delphi technique was selected because of its cost-effectiveness in communicating with a geographically-diverse panel, overcoming issues with meeting in real-time over multiple time zones.^{236, 238} It also gave participants time to reflect and answer questions thoughtfully, on their own time.^{238, 239} To maximize efficiency, a modified Delphi technique was chosen, incorporating a more structured first round, with content based on a literature review rather than open-ended questioning.^{236, 238} The iterative nature of the Delphi technique fit with our objective of integrating knowledge exchange from the study outset.

3.2.2 Participants

Participants were a purposive sample of parents, therapists and researchers with expertise in paediatric PM and participation in everyday life. Careful consideration of who to include as participants was one strategy taken to reduce dropout rates as individuals more familiar with the topic under investigation were expected to have more passion about the topic, and be more likely to stay committed throughout the process.^{236, 239} Figure 3.2 specifies inclusion and exclusion criteria set to identify those with significant experience living or working with children using PM or with expertise in measuring participation for children who have physical disabilities. We chose to restrict the ages of children from 18 months to 12 years to focus our investigation, given that participation looks very different across developmental stages from infants to young adulthood. Recognizing that sample sizes for Delphi surveys vary considerably (ranging from 15 participants to more than 50),^{236, 238} we sought a total sample size of 60 participants, with 20 participants each for parents, therapists and researchers. We wanted adequate stakeholder subgroup representation given their different perspectives, to ensure the panel represented a diverse group, but over-sampled to allow for attrition.^{236, 239}

3.2.3 Sampling Procedure

Parents of children using PM and therapists were recruited in North America by posting recruitment information in various physical and electronic locations, including clinics, conferences, e-newsletters and magazines. Additionally, therapists and researchers (from within North America and beyond) potentially meeting inclusion criteria were emailed invitations directly. Purposive sampling was thought to be a more appropriate and efficient recruitment strategy for targeting key informants given that paediatric PM and the measurement of participation are very specialized areas of practice and research.²³⁶ Snowball sampling was also used to expand recruitment to colleagues within individuals' networks who may meet inclusion criteria.

Study information was provided at least one week prior to survey commencement. After individuals initiated contact, a copy of the consent form describing the study was sent via email. Details of the study included objectives, an explanation of the Delphi survey process, privacy and confidentiality information, rights and expectations as participants (what was required of them, amount of time needed, timeline, and types of information collected). Participants were informed that consent would be indicated by activation of the initial survey link, but that they were free to withdraw at any time without consequence. To encourage retention, an honorarium, offsetting their time and expenses, was provided for participants (\$25/survey round completed). The Clinical Research Ethics Board at the University of British Columbia provided ethical approval before recruitment commenced.

3.2.4 Data Collection

A personalized survey link and instructions for completion were emailed on day one of each round. Participants were instructed to contact the team if questions or technical difficulties arose. Each round, designed to take less than one hour to complete, was available online, 24 hours a day for a minimum of three weeks. Participants were instructed to consider and provide responses for two age groups: early childhood (18 months-5 years) and school-age (6-12 years) as these are often ages when PM is introduced.^{21,22} The 18 month lower limit was chosen to reflect the age that children have demonstrated ability to achieve basic wheelchair driving skills (such as moving forward, turning or stopping intentionally),¹⁰ while middle and upper ages are associated with typical developmental and school transitions. Each round's questions were organized similarly for both age groups to facilitate understanding of important elements for measuring participation, helping target appropriate measurement of participation and guiding measurement tool selection.

The computer-based online Delphi survey was developed and managed using software by FluidSurvey©.²⁴² In keeping with privacy laws, FluidSurvey, a Canadian company with servers located in Canada, uses Secure Sockets Layer (SSL) 128 bit for encryption, ensuring secure and confidential data collection and storage.²⁴² All questions and statements for each round were pilot tested by a minimum of three of a five-member advisory committee (representative of the sample), and revised based on their feedback.

Given the iterative nature of the Delphi survey, data were analyzed immediately after each round with results informing next round development.²³⁶ Each subsequent round included a

summary of the previous round's results, thereby promoting an integrative form of knowledge translation and contributing to new knowledge generation as participants reflected on their answers individually and collectively.²³⁶ In addition to survey questions, each round included relevant information to assist participants with their decision-making. To encourage completion, reminders were emailed one week prior to, as well as one and two weeks following round commencement.

For our purpose, consensus was set *a priori* at 80% or greater agreement^{236, 239, 240} for the total group and each of the three subgroups, to remove bias of uneven subgroups. Delphi surveys typically end with consensus, when response rates drop off, or when no new information is gained.²³⁸ Although four surveys were planned, the number of rounds was left open to adjustment (plus or minus 1 round) dependent on survey results, in effort to reduce participant attrition (i.e. if consensus was not reached as planned or alternately, if response rates [greater than 20%] dropped off significantly).^{236, 237, 239}

Round One: Socio-demographic information described the sample and confirmed eligibility. Appendix G lists the 46 statements generated to operationalize 14 questions about elements of participation important to measure for children using PM. Questions and statements evolved from a literature review of participation measurement, tools, and ICF^{33, 34} taxonomy. Both single option and combination option statements were intentionally included, enabling a variety of responses to decrease frustration and avoid attrition. Background information included a brief summary of considerations. Survey questions were primarily closed-ended, with participants indicating their agreement with each statement being a critical element to measure participation

for children using PM. The response format of each question consisted of a 5-point Likert scale (i.e., 1= strongly agree to 5= strongly disagree).²³⁹ Open-ended questions with text boxes for comments provided opportunity for response elaboration or specifying additional elements of importance.

Round Two: A summary of Round One results presented feedback both of the group's responses (Appendix H) as well as each individual's responses. This feedback informed participants of the range of responses and gave them opportunity to reflect on their answers.²³⁹ Given that the second round's aim was to provide opportunity for reflection and confirmation of respondent's selection, elements from Round One with 75-79% agreement were deemed close enough to threshold to be included so as not to lose important information. The same Likert scale as Round One was used for confirmation. Two additional questions were included in Round Two for respondents to indicate their agreement with two elements (child's engagement and autonomy) suggested by respondents in Round One.

Round Three: A summary of Round Two results provided feedback on elements that reached at least 80% consensus for the total group and each of the subgroups (Appendix I). Participants were instructed to rank the importance of elements in each age group that reached consensus in Round Two, with no duplications (i.e. 1= most important, 2= 2nd most important, 3= 3rd most important, etc). Participants were asked to rank only the top 10 if more than 10 elements were presented. Rankings in Round Three were assigned a weighted score where weight was indicated by the number of elements reaching consensus (#1 was assigned the highest weighted score (e.g. 10, if 10 elements presented), #2 was assigned the second highest weighted score

(e.g. nine if 10 elements presented, etc.). The summed weighted score for the total group determined final ranking of elements (i.e., element with highest sum of weighted scores was first priority).

Round Four: Those who completed at least two of the three earlier rounds were invited to complete the fourth online survey. Summary of Round Three results included feedback on top ranked elements for each age group that were reached by the total group (Appendix J). Appendix K(i-vii) presents supporting documents included in Round Four. In preparation for the fourth round, a systematic review of participation tools in the paediatric rehabilitation literature (to January 2013) was conducted with 22 tools identified for consideration. Tools were excluded from consideration if they addressed elements not identified as third-round priorities. We chose to focus on measures that demonstrated high concordance with the important elements (selected by consensus through the previous Delphi rounds) and reduce respondent burden.²⁴³

Descriptive information about each tool under consideration was provided to participants including: name of tool; intended ages for use; intended respondent(s); settings evaluated; number and examples of items; objective and/or subjective dimensions evaluated (number, frequency, satisfaction, importance); supports and barriers to participation; brief description of scoring and reported administration time; and how the tool aligned with the top-ranked consensus elements for each age group established previously. Charts enabled comparison of all tools under consideration for each age group using the top-ranked participation elements (Appendix Ki-iv). In addition, charts included ratings of measurement properties using the McMaster Outcome Measure Rating Form.¹²⁵ To be transparent with decision-making, a third

chart listed tools that were excluded from consideration along with a brief explanation of reasons for exclusion (Appendix Kv). A reference list for all tools was provided to enable those interested to seek further information (Appendix Kvi, vii).

Participants were instructed to indicate their degree of familiarity with each of the tools under consideration along with their degree of agreement that the tool be included in a participation measurement toolkit. Response options for indicating familiarity included a four-point ordinal scale ranging from 1 (very familiar, used several times) to 4 (not heard of it until now). The response options for indicating agreement again used a five-point Likert scale ranging from 1 (strongly agree) to 5 (strongly disagree). Text boxes allowed participants the opportunity to provide comments on tools presented, the selection process and additional tools to consider with their rationale for inclusion. Participants had opportunity to comment on content, suitability and process of the Delphi survey overall after completion of the final round, providing feedback for end-of-study knowledge translation.

3.2.5 Data Analyses

Descriptive statistics included frequencies and percentages (for nominal and categorical data), along with measures of central tendency (mean, median and mode) and levels of dispersion (standard deviation and inter-quartile range) for continuous data. Raw data, entered and coded for analyses in Microsoft Excel,²⁴⁴ described socio-demographic characteristics of participants, response rate for each round and each item response. Thematic analysis of participants' responses was used for open-ended questions. Elements for measuring participation and measurement tools common to both age groups were identified, as well as those unique to each

age group. Summaries provided to participants after each round included graphic displays and text summaries for the total group and each of the two age groups as appropriate.

3.3 Results

Seventy-six participants initially agreed to participate. One parent activated the survey link but did not complete any questions after realizing that she no longer met eligibility criteria. One therapist activated the survey link but did not respond due to personal reasons, resulting in a total sample of 74 for Round One (14 parents, 40 therapists, and 20 researchers. Table 3.1 describes the socio-demographic characteristics of Round One participants. Therapists, females and those 40 to 49 years of age were most predominant. Figure 3.3 summarizes recruitment contacts and responses. Of the 74 stakeholders who participated in the initial Delphi round, 70 completed Round Two, 67 completed Round Three, and 70 completed Round Four (Table 3.2). The response rate remained 90% and above across the four rounds over a ten month period.

3.3.1 Round One

Table 3.3 presents the important elements of measuring participation that reached consensus in Round One. In Round One, 14 of 46 elements reached consensus for school-aged children for the total group plus all three stakeholder subgroups, unlike the early childhood group, where no element reached consensus for the total group plus all three stakeholder subgroups (although 13 of 46 elements obtained >80 % for total group only). Panelists identified two additional elements for consideration in both age groups in Round Two: the child's engagement and autonomy.

3.3.2 Round Two

Table 3.3 presents Round Two elements reaching consensus ($\geq 80\%$ agreement) for the total group plus all three stakeholder subgroups (including 18 of 48 elements in total for the older group and eight of 48 elements for the younger group). Overall, 21 elements were identified, with five in common across both age groups. Elements reaching consensus described whose point of view should be sought (parent and/or child), who should be the focus (child and family), what types of participation (objective and/or subjective dimensions), where participation takes place (home, school and/or community), and how participation should be evaluated (comparison with self over time, include barriers and facilitators). Table 3.4 presents the elements not achieving consensus in Round Two.

3.3.3 Round Three

Table 3.5 presents the top five ranked priorities for elements that reached consensus for each age group in Round Three. For the younger group, a ranking of #1 (most important) was given a weighted score of eight as there were eight elements ranked. For the older group, a ranking of #1 was given a weighted score of 10 as 10 out of 18 elements were ranked. Of the five elements that reached consensus across both age groups, four ranked within the top five. Measuring participation in a combination of settings was the highest priority for both age groups.

3.3.4 Round Four

From the 22 tools identified in the literature, no single tool addressed all elements deemed important to measure for each age group (i.e., priorities from third-round). Thirteen tools met the highest-ranked element of participation (evaluating participation in a combination of settings)

and addressed at least two of the remaining highest ranked elements for each age group (five elements in total for the younger age group and seven elements in total for the older group). Appendix K(i-iv) presents the information presented to participants for the 13 tools under consideration.^{45, 49, 93, 96, 162, 166, 171, 177-180, 184, 197} Appendix K(i) provides a comparison of the five most promising tools under consideration for those in early childhood,^{49, 96, 162, 178, 180} while Appendix K(ii) Parts I and II provide a comparison of the five most promising tools under consideration for those of school age.^{96, 166, 178, 180, 197} Several additional tools were presented to participants for consideration because they evaluated a particular aspect of participation identified by participants as important. Appendix K(iii) presents the additional tools under consideration for those in early childhood,^{93, 245} while Appendix K(iv) Parts I and II present the additional tools under consideration for those of school age.^{45, 93, 171, 177, 179, 184} Appendix K(v) summarizes the nine tools not selected for consideration.^{94, 166, 168, 246-251}

Figure 3.4 summarizes the total group's familiarity with the 13 tools under consideration while Figures 3.5 to 3.7 summarize the three subgroups' familiarity. For the total group, amalgamating scores for somewhat familiar and very familiar ratings, our panelists found the Canadian Occupational Performance Measure (COPM)⁹⁶ most familiar for both the younger age group (68%) and older age group (67%). The School Functional Assessment (SFA)²⁴⁵ was second most familiar (36%), while the Children's Assessment of Participation and Enjoyment (CAPE)¹⁶⁶ was third most familiar (27%).

Figure 3.8 presents the total groups' degree of agreement for each tool being considered for inclusion in the proposed toolkit, while Figures 3.9 to 3.11 summarize the three subgroups'

degree of agreement. Given our requirement that consensus be at least 80% agreement for the total group and all subgroups, none of the tools reached consensus for being included in the toolkit for the younger group and only the Participation and Environment Measure for Children and Youth (PEM-CY)¹⁷⁸ reached consensus for school-aged children. For the total group, amalgamating scores for strongly agree and agree ratings, the three tools with the highest level of agreement in the early childhood group were Preschool Activity Card Sort (PACS)¹⁸⁰ (70%), COPM⁹⁶ (65%) and PEM-CY¹⁷⁸ (60%). The three tools with the highest level of agreement in the school-age group were PEM-CY¹⁷⁸ (88%), COPM⁹⁶ (77%), and CAPE¹⁶⁶ (62%). The PEM-CY¹⁷⁸ and COPM⁹⁶ were in the top three across both age groups for agreement for potential toolkit inclusion.

3.4 Discussion

Consensus building, recognized for synthesizing and strengthening evidence inherent in clinical practice,^{158, 240} is recommended for advancing participation measurement.²³⁴ This study reached consensus on 21 important elements for measuring participation of children using PM by way of a modified Delphi survey. Panelists, including parents, therapists and researchers, achieved $\geq 80\%$ agreement on eight elements for those in early childhood and 18 elements for those of school-age. Five elements were common across both groups. Panelists also nominated suitable tools for measuring key elements of participation in children who use PM. The selection of tools was based on how each matched important elements for measuring participation, as determined in earlier Delphi rounds. Of the 22 tools identified in a literature review of participation tools for children with mobility limitations, 13 tools matched elements of participation deemed important

to measure by the panel. No single tool met all elements deemed important to measure, however, four tools addressed at least three of the most important elements for the early childhood group, whereas, five tools addressed at least three of the most important elements for the school age group. Although no tools reached consensus for inclusion in a participation toolkit for the younger group, one tool -- the PEM-CY ¹⁷⁸ -- achieved over 80% consensus for inclusion in a toolkit for school-aged children.

Although a developmental aspect may exist in terms of which elements reached consensus for each age group, the disparity in number reaching consensus between groups could be influenced by several factors. Adults may have a greater awareness of school-aged children's needs as they have more life experiences and speak more for themselves. It may be reflective of greater research evidence describing participation for the older age group, ¹²⁷ with which some participants might be familiar. Alternatively, this evidence may have inadvertently biased questions and responses in survey development. It could also reflect differences in geographical clinical practices whereby PM provision to preschoolers is not as common, ¹⁰ with school-aged children having more opportunity for PM use. Given the difference in numbers of elements that reached consensus, it is noteworthy that four of the top five elements were similar for both age groups.

3.4.1 Elements of Participation

The importance of understanding the nature, variability and consequences of participation has been acknowledged, especially for less accessible populations, ⁶⁶ such as those using PM. The elements that reached consensus provide guidance as to what is meaningful to measure for our

population, and should facilitate selection or development of participation tools.^{36, 252} The highest priority -- measuring participation in a combination of settings -- reflects the importance of where participation occurs,^{35, 66} as participation and the environment are intimately linked.^{2,}
²⁰⁰ For children using PM, environmental factors have a tremendous influence on successful implementation of PM interventions^{9, 10} and they participate differently depending on setting.^{20,}
21, 158

Other elements common across both age groups included ‘the child’s engagement in participation,’ and ‘the child’s enjoyment of participation,’ as well as evaluating a ‘combination of family participation and child participation,’ and ‘including barriers and facilitators when measuring participation.’ The importance of measuring the child’s engagement and enjoyment is acknowledged in the literature, with engagement in life situations a central concept in participation.³³⁻³⁵ In other studies, parents comment on their child’s enjoyment and ‘being engaged’ as two distinct descriptors,¹²⁷ whereas researchers suggest a child’s ‘self-engagement’ refers to enjoyment, self-determination and an understanding that comes from participating.² Although evaluating a combination of family and child participation is important to all children and families,² it is critical for younger children and those with significant impairments.³⁵ In keeping with a child and family-centred approach,²⁹ therapists can enhance individuals’ participation by understanding what is important both for the child and their family.¹³ Seeking the best ‘fit’ between the child’s and family’s desired activities, (power) mobility options, and the environments in which they are used²⁰ is critical both when recommending specific wheelchair features, and when facilitating discussions about mobility options for specific activities. PM not only impacts the child, but families too. This is a reciprocal relationship: child

and family participation influences types of PM features selected, and wheelchair features impact their participation. Evaluating the child-family dynamic as children grow is also important as their relationships and roles change over the lifespan,³⁵ influencing their interests and priorities. Finally, children's choice of wheeled mobility options can be strongly influenced by barriers and facilitators.^{20, 21, 158} Moreover, measuring participation with a 'barriers and supports approach' may be useful for policy purposes⁶⁶ as suitable interventions can be identified and plans implemented to support optimal participation for wheeled mobility users.^{20, 157}

3.4.2 Measurement Tools

As our findings demonstrate, several tools met the top-ranked elements, each having a somewhat different focus to measuring participation along with influencing personal and environmental factors.^{2, 3, 8, 19} The idea of creating a toolkit^{156, 232} of participation measurement tools is substantiated given that no single tool met all elements deemed important to measure by the panel. One may argue that developing a new tool that addresses all the important elements for our population might be a better option,¹⁵¹ however, this would take significant time, effort, and funding. Furthermore, the number of elements addressed in one tool would need to be balanced against the complexity of the tool, and amount of respondent and administrative burden. In a recent critical appraisal of outcome measures for adult seating and wheelchair provision, the authors suggested that no single outcome measure could collect all necessary information, and instead recommended that clinicians make informed choices about outcome measures most suited to their practice given adequate information about tools' strengths and limitations.²⁵³ Although they did not explicitly discuss need for a toolkit, one might surmise the idea of toolkit is indicated. Likewise, in a systematic review measuring activity and participation outcomes for

children and youth with brain injuries, Dunford and colleagues suggested that no single tool would be sufficient, rather a ‘basket’ of outcome measures may be more reasonable.¹⁵² Having tools categorized in a toolkit may help the decision-making process, and facilitate picking the right tool for the desired purpose.

Interestingly, only one tool -- the PEM-CY¹⁷⁸ -- achieved 80% consensus for inclusion in a toolkit. This recently developed tool addresses several elements deemed essential for children who use PM. The COPM,⁹⁶ the second choice for both age groups, elicits information about what is meaningful from parents’ and children’s perspectives. The importance of eliciting these subjective perspectives has been recognized in the literature^{13, 66, 80} and was confirmed by our expert panel, especially for school-age children.

Several reasons may explain why more tools did not achieve consensus. Many of the tools under consideration were not well known to participants. Although the COPM⁹⁶ was familiar to nearly half of the panelists, the others were not. This may also offer an explanation as to why participation tools have not been used more readily for paediatric PM interventions.¹⁰ Several tools did not fully address the selected age range for each developmental stage; this was most notable for the early childhood group where only one tool⁹⁶ addressed the entire age range while three tools^{1, 178, 245} were for 5 year olds only. Similarly for the older age group, two tools^{49, 180} were for 6 year olds only, and another¹⁷¹ did not address the entire age range. Perhaps because of a tool’s limited age range, panelists might have hesitated to agree with their suitability for toolkit inclusion across the full age categories. Another possible reason tools were not selected for the toolkit might have to do with their reported measurement properties. Evidence of

measurement rigour is extremely valuable when determining suitability of a specific tool for a specific population.^{12, 38, 121} Although some tools under consideration^{1, 96, 166, 245} have established evidence over the years, others have limited evidence. It is crucial that tools have sound measurement properties for their intended application so one has confidence in interpreting measurement findings.^{12, 112} We recommend further testing of selected participation tools with our population before adopting them for evaluation of PM efficacy and effectiveness.

3.4.3 Limitations

The success of a Delphi survey rests in the selection of an appropriate panel.^{236, 254} Different stakeholder perspectives are important,^{2, 237} and we intentionally sought a panel with diverse experiences and perspectives. We had uneven geographic representation, which may have biased the cultural contexts of participation considered. Despite our intent to recruit equivalent numbers, recruitment challenges resulted in uneven representation across stakeholder subgroups.

Achieving consensus across total group plus all subgroups minimized bias. We accepted all interested and eligible therapists, anticipating attrition and valuing knowledge exchange and collaboration. Given the relatively small and specialized community of paediatric PM practice, complete anonymity might not be possible. Recruitment of parents was much more challenging, despite significant efforts to recruit through multiple venues, and was heavily representative of western Canada. A systematic review of Delphi technique studies found few studies included families and children.²³⁷ We recognize that parents of children with complex conditions have significant demands on their time and energy, making it extremely difficult to engage in research. That 13/14 completed all rounds demonstrated exceptional commitment, and their input was invaluable. Although our initial thoughts included children on the panel in keeping with a

client-centred approach,²³⁷ feasibility issues were considerable, especially given the abstract and detailed nature of the material being covered. Interestingly, a systematic review of studies addressing the process of selecting outcomes to measure in paediatric clinical trials found no studies that included children in the process.²⁵⁴ Authors admitted that although inclusion of children is desirable, there was no evidence substantiating the benefits of including them in the process nor was there a framework to guide how best to involve them.²⁵⁴ We anticipate a future study confirming findings with children, as well as other stakeholders (e.g. teachers, funders, suppliers) to provide a more comprehensive overview. Another limitation of this study is that it did not specifically address considerations for children 13 to 18 years of age using PM. Our initial intent was to include this age group as a third group for participants to deliberate on, but we were very concerned that the additional time and effort would be detrimental to survey completion and participant retention over the course of the study.^{236, 243} We therefore made the decision to focus our efforts on the younger two age groups, as they are the ages when PM is more commonly introduced.^{14, 21} Recognizing that the literature suggests differences in participation are associated with age,^{40, 46, 55} we plan a future study explicitly examining elements of participation that are important to measure for children 13-18 years old using PM.

Our recruitment process yielded a panel with a diverse range of backgrounds, experiences, and perspectives. Participants' requirement to understand written English and have Internet access may have limited the sample and restricted the cultural context, reducing generalization of results. We acknowledge participants' different levels of understanding and experience with the construct of participation and how best to measure it, may have influenced results. We debated limiting Round Four to therapists and researchers only, given that parents may have a more

limited understanding of specific tool information and measurement concepts. However, we welcomed diversity,²³⁹ and saw it as an opportunity for knowledge mobilization, increasing awareness of therapy considerations to parents while examining measurement tools' relevance to a diverse group of stakeholders.²³⁷ We provided background information and definitions for a minimal standard of common understanding, expecting that some might have limited knowledge of theoretical rationale and measurement tools. We also provided summaries by total group and stakeholder groups, offering exposure to a broader set of ideas. Although background information was provided to assist decision-making, the amount of information might have been too dense or the presentation method overwhelming, influencing their capacity (e.g., level of understanding or time available) to evaluate the relevance of information. However, the response and completion rates across stakeholder groups demonstrated their strong commitment to the tasks at hand. Interestingly, some parents stated familiarity with a few participation tools.

It may be that we were too conservative in selecting 80% as our level of agreement as other studies have used a broader range of thresholds for Delphi consensus.^{128, 234} This may have bearing both on the number elements and suitable tools identified. Additionally, not all relevant elements of participation might have been brought forward for consideration, therefore we cannot assume that these are the only elements worthy of discussion. Some tools may have been missed in the literature review due to the search strategy or inclusion criteria (e.g. restrictions of English language, peer-reviewed publications with evidence supporting use with children). The limited number of participation tools for the younger age group is acknowledged, but this is an area of recent and continuing development.^{36, 66, 162} Other tools included in Chapter 2 were not published at the time of the Delphi survey, and might be worthy of future consideration.

Debate about the tools not selected for consideration by the panel may result, depending on how one defines participation and classifies test items.^{33-35, 122} To mitigate this, we shared excluded tools with panelists so these could be considered alongside nominated tools. Finally, we excluded adult participation tools designed for individuals with mobility limitations^{123, 157, 233, 255} because they lacked evidence of measurement properties with children. However, the way these tools handle the interaction between the individual, the mobility device, and environmental demands may be relevant. Future investigations to determine their concordance with important elements of participation in children who use PM may be worthwhile. Those deemed suitable might then be adapted for and tested with a paediatric population. We elected not to include these adult tools in our current study to make the identification and selection of candidate measures more manageable. Despite these limitations, this study lays the foundation for dialogue and future investigation about how children use PM to participate in everyday life. It also establishes groundwork for evaluating effectiveness of PM interventions.

3.5 Conclusion

Our research established consensus on elements of participation important to measure for children using PM and identified potential measurement tools addressing these elements. These findings further our understanding of measurement requirements for these children. Nonetheless, before selecting a tool, the desired purpose and context for participation measurement must be taken into consideration. Robust participation tools validated with this population are needed to support stronger quality of research evidence demonstrating the value of PM as a therapeutic intervention. Development of a toolkit offering a choice of tools might prove useful depending

on the intended purpose, and the characteristics of the child and their environment(s). Other options to consider include adapting tools developed specifically for adults who use wheeled mobility,^{123, 157} or creating new tools that better meet the needs of this population. In any case, it is vital to evaluate these tools specifically with children having PM needs to improve validity, reduce measurement error and provide greater confidence interpreting findings.^{112, 123} These findings informed the next phase of our research, which was to investigate the feasibility of conducting research with children needing PM, including establishing measurement properties of participation tools for our population.

Figure 3.1 Four Round Modified Delphi Survey Process

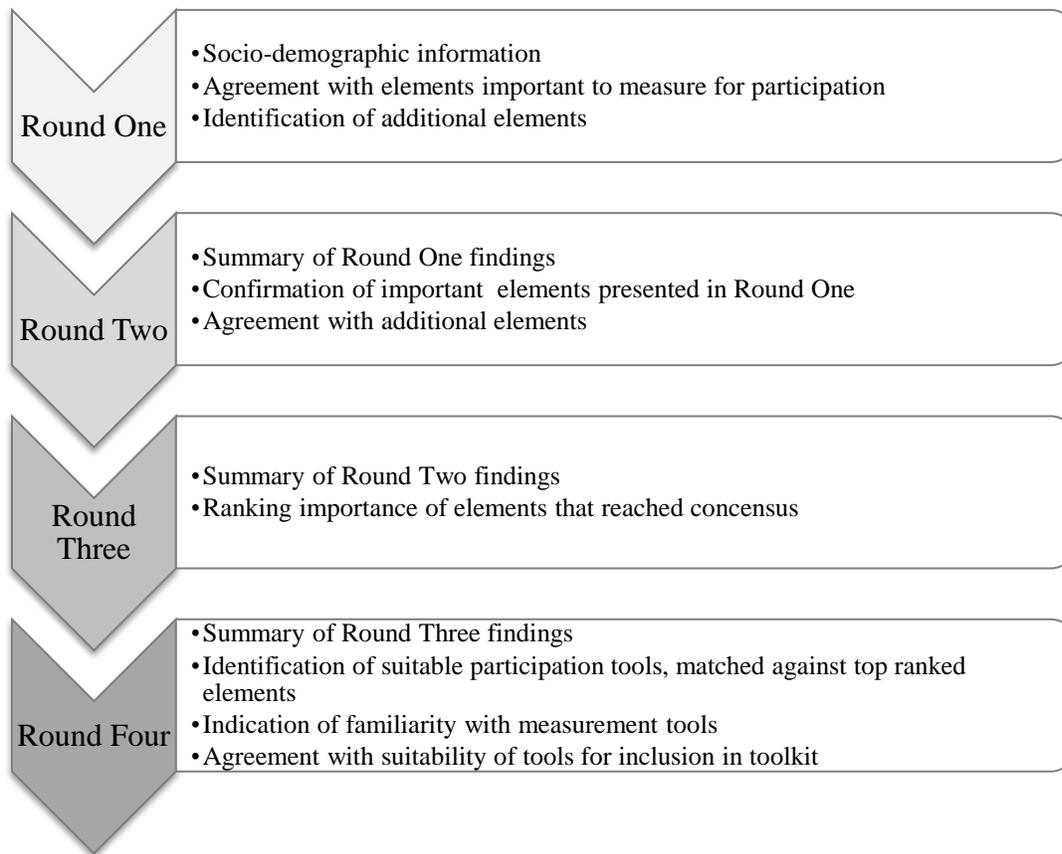


Figure 3.2 Inclusion and Exclusion Criteria

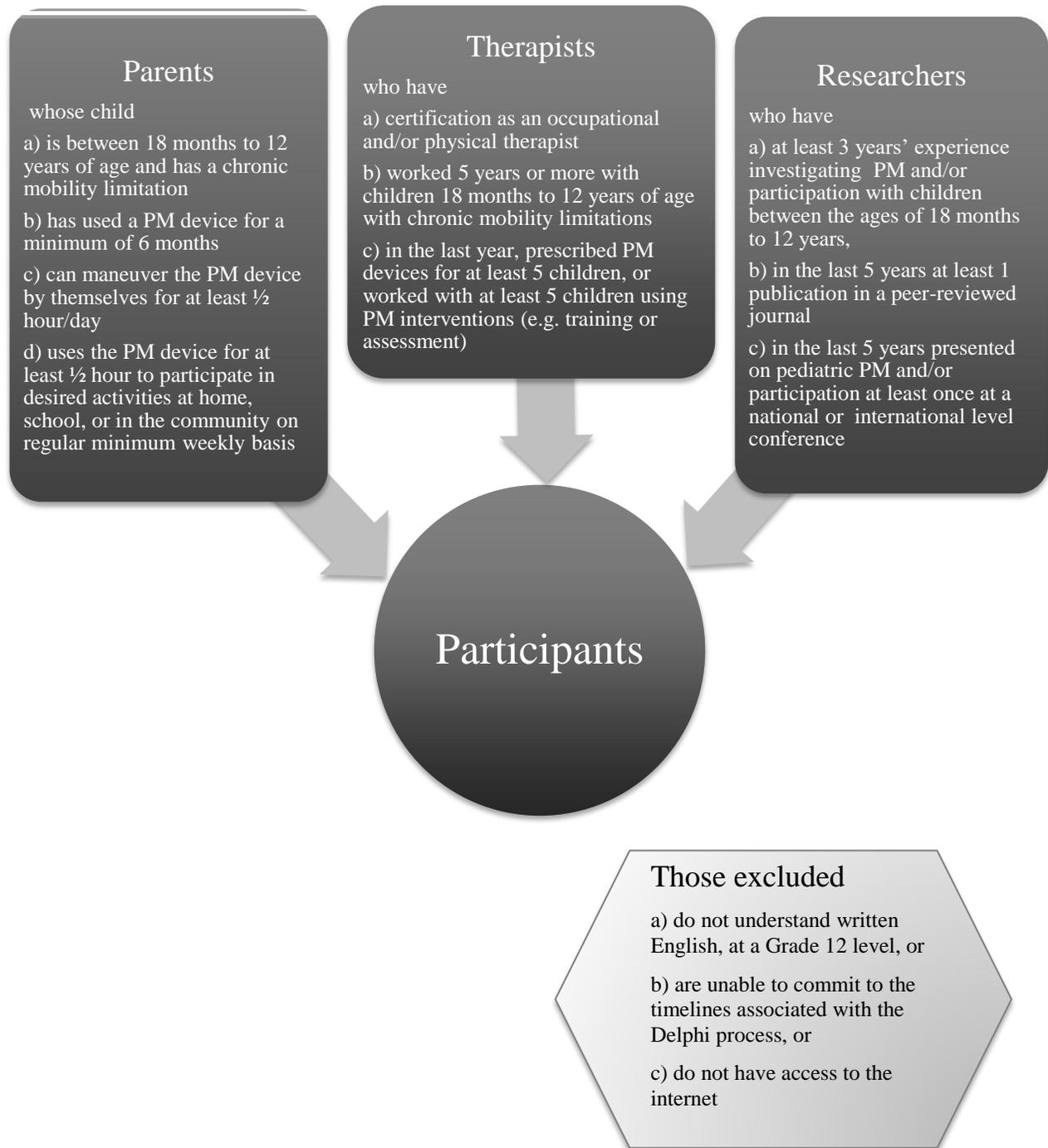


Table 3.1 Socio-Demographic Characteristics of Round One Participants Who Responded

		Parents n=14	Therapists n=40	Researchers n=20	Total n=74
Sex	male	3	2	1	6
	female	11	38	19	68
Age (in years)	20-29	0	2	0	2
	30-39	3	9	2	14
	40-49	11	18	12	41
	50-59	0	7	2	9
	60-65	0	4	4	8
Country of Residence	North America	14	26	9	49
	South America		1	0	1
	Australasia		2	4	6
	Asia		0	1	1
	Middle East		3	0	3
	Europe		8	6	14
<i>For Therapists and Researchers</i>					
Occupational Therapist			26	12	38
Physical Therapist			14	8	22
Years Paediatric Clinical Experience					
0-5			5	2	7
6-10			4	4	8
11-15			7	4	11
16-20			6	4	10
21-25			5	4	9
26-30			3	1	4
30+			7	1	8
not answered			3	0	3
Years Research Experience					
0-5			16	2	18
6-10			5	5	10
11-15			5	9	14
16-20			1	3	4
21-25			1	1	2
not applicable			10	0	10
not answered			2	0	2
<i>For Parents</i>					
Age of Children	mean	8yrs10mos			
	range	3 - 11yrs			
Sex of Children	male	12			
	female	3			
Years of PM use	mean	4yrs 6mos			
	range	1 - 9yrs			

Legend: n=sample size; yrs=years; mos=months

Figure 3.3 Summary of Recruitment Process

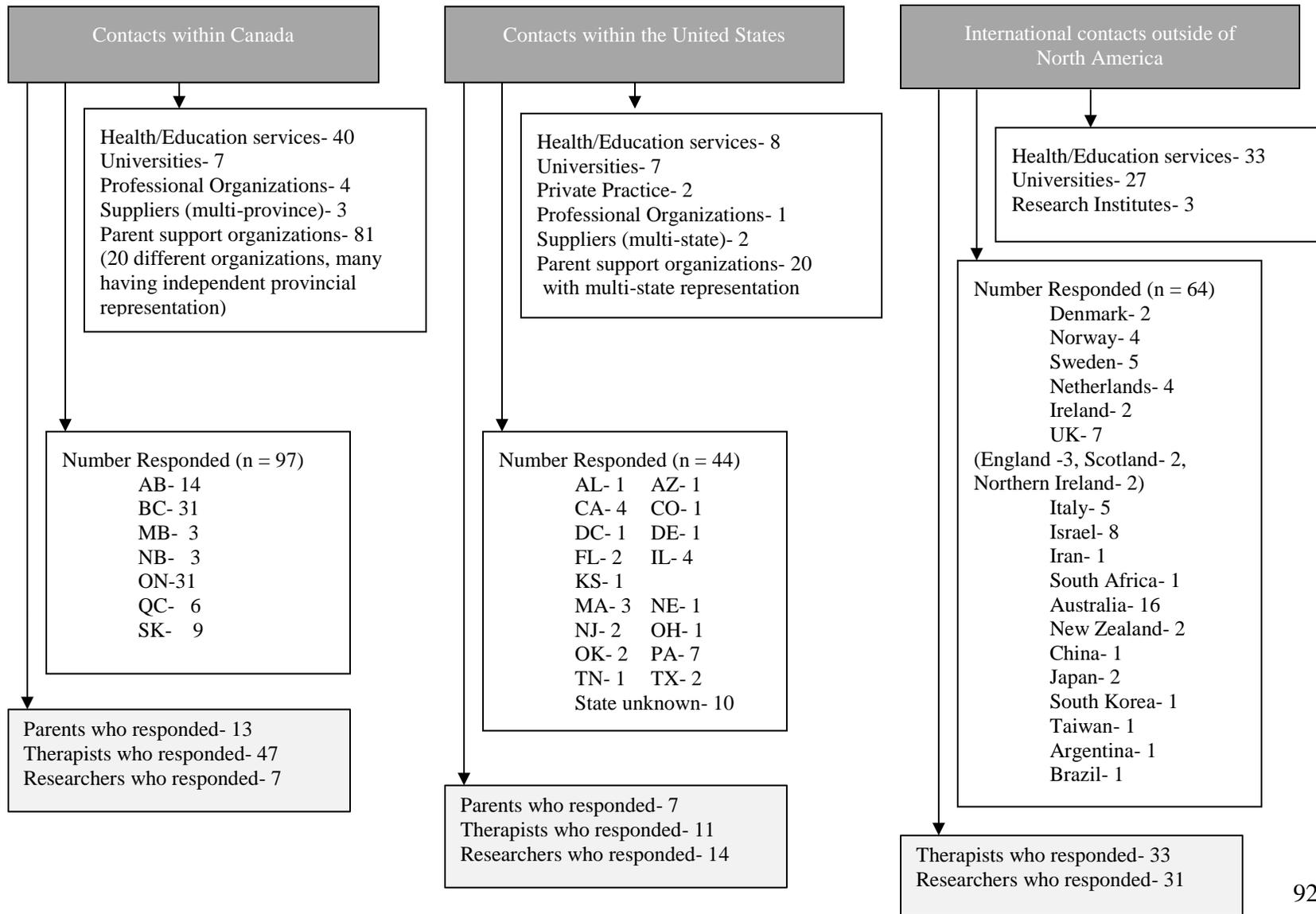


Table 3.2 Summary of Participants Invited versus Responded for Each Round

	Round One	Round Two	Round Three	Round Four
Parents	n=14	n=14 (100%)	n=13 (93%)	n=13 (93%)
Therapists	n=40	n=39 (98%)	n=37 (93%)	n=39 (98%)
Researchers	n=20	n=17 (85%)	n=17 (85%)	n=18 (90%)
Total	n=74	n=70 (95%)	n=67 (91%)	n=70 (95%)

Table 3.3 Elements Reaching Consensus in Rounds One and Two

Round One Elements Reaching Consensus ^{+,*,^}		Round Two Elements Reaching Consensus ^{+,^}	
18 Months to 5 Years Age Group	6 to 12 Years Age Group	18 Months to 5 Years Age Group	6 to 12 Years Age Group
WHO			
*A parent's report of their child's participation is most essential	+The child's self report of participation is most essential	+A parent's report of their child's participation is most essential	+The child's self report of participation is most essential
*A combination of a parent's report of the child's participation and the child's self report of participation is most essential	+A combination of a parent's report of the child's participation and the child's self report of participation is most essential		+A combination of a parent's report of the child's participation and the child's self report of participation is most essential
*A combination of family participation & child participation is most critical	+A combination of family participation & child participation is most critical	+A combination of family participation & child participation is most critical	+A combination of family participation & child participation is most critical
WHAT			
*A combination of a standard list of scenarios along with user defined scenarios is most valuable	+A combination of a standard list of scenarios along with user defined scenarios is most valuable		+A combination of a standard list of scenarios along with user defined scenarios is most valuable
*A combination of objective and subjective information is most critical	+A combination of objective and subjective information is most critical		+A combination of objective and subjective information is most critical
	+Specifying the location where participating is most essential		+Specifying the location where participating is most essential
	*Documenting the frequency of participation is most essential	+The child's engagement in participation is critical	+The child's engagement in participation is critical
*The child's enjoyment of participation is most essential	+The child's enjoyment of participation is most essential	+The child's enjoyment of participation is most essential	+The child's enjoyment of participation is most essential
	+The child's importance of his/her participation is most essential		+The child's importance of his/her participation is most essential
	+The child's preference of participation is most essential		+The child's preference of participation is most essential

Round One Elements Reaching Consensus ^{+,*,^}		Round Two Elements Reaching Consensus ^{+,^}	
18 Months to 5 Years Age Group	6 to 12 Years Age Group	18 Months to 5 Years Age Group	6 to 12 Years Age Group
*The child's satisfaction with his/her participation is most essential	+The child's satisfaction with his/her participation is most essential	+The parent's satisfaction with the child's participation is most essential	+The child's satisfaction with his/her participation is most essential
	*Measuring performance is most essential (i.e. what the child actually does in everyday life)		+Measuring performance is most essential (i.e. what the child actually does in everyday life)
*Measuring a combination of capacity, capability & performance is most essential	*Measuring a combination of capacity, capability & performance is most essential		
	+Participation should include activities that are done alone		+Participation should include activities that are done alone
WHERE			
*Participation in a combination of settings (e.g. home, school & community) is most critical	+Participation in a combination of settings (e.g. home, school & community) is most critical	+Participation in a combination of settings (e.g. home, school & community) is most critical	+Participation in a combination of settings (e.g. home, school & community) is most critical
	*Participation in school life is most critical	+Participation in home life is most critical	+Participation in school life is most critical
			+Participation in community life is most critical
HOW			
*Barriers and facilitators of participation should be included in an assessment of participation	+Barriers and facilitators of participation should be included in an assessment of participation	+Barriers and facilitators of participation should be included in an assessment of participation	+Barriers and facilitators of participation should be included in an assessment of participation
*Comparison with self over time is critical	+Comparison with self over time is critical		+Comparison with self over time is critical
*Documenting the strategy needed to participate is critical	*Documenting the strategy needed to participate is critical		
*Documenting the amount of assistance needed is critical	*Documenting the amount of assistance needed is critical		
Total number of elements where consensus was reached^{+,*,^}		Total number of elements where consensus was reached^{+,^}	
0 ⁺	14 ⁺	8 ⁺	18 ⁺
13 [*]	6 [*]		

Legend: ^ Consensus was set *a priori* as $\geq 80\%$ agreement.

+ = Consensus reached for total group plus each of the 3 stakeholder subgroups (implemented to remove bias of uneven subgroups)

Round One: total participants (n = 74), parents (n = 14), therapists (n = 40), researchers (n = 20)

Round Two: total participants (n = 70), parents (n = 14), therapists (n = 37), researchers (n = 19)

* = $>80\%$ reached for total group only [Round One: n = 74] (elements did not achieve consensus across all three stakeholder subgroups)

Table 3.4 Elements Not Achieving Consensus in Round Two

Round Two Elements That Did Not Reach Consensus (^)	
18 Months to 5 Years Age Group	6 to 12 Years Age Group
WHO	
The child's self report of participation is most essential	A parent's report of their child's participation is most essential
A therapist's report of participation is most essential	A therapist's report of participation is most essential
A combination of a parent's report of the child's participation and the child's self report of participation is most essential	
Child-only participation is most critical	Child-only participation is most critical
Family participation is most critical	Family participation is most critical
WHAT	
A combination of a standard list of scenarios along with user defined scenarios is most valuable	
A standard list of scenarios is most valuable	A standard list of scenarios is most valuable
A set of user defined scenarios is most valuable	A set of user defined scenarios is most valuable
A combination of objective and subjective information is most critical	
Objective information that documents observed behavior is most critical	Objective information that documents observed behavior is most critical
Subjective information that reflects the individual's personal view is most critical	Subjective information that reflects the individual's personal view is most critical
Documenting the number of situations the child is involved in is most essential	Documenting the number of situations the child is involved in is most essential
Documenting the frequency of participation is most essential	Documenting the frequency of participation is most essential
Specifying who the child is participating with is most essential	Specifying who the child is participating with is most essential
Specifying the location where participating is most essential	
The child's preference of participation is most essential	
The child's importance of his/her participation is most essential	
The child's satisfaction with his/her participation is most essential	The parent's satisfaction with the child's participation is most essential
The parent's importance of the child's participation is most essential	The parent's importance of the child's participation is most essential
The child's autonomy of participation is most essential	The child's autonomy of participation is most essential

Round Two Elements That Did Not Reach Consensus (^)	
18 Months to 5 Years Age Group	6 to 12 Years Age Group
WHAT	
Measuring performance is most essential (i.e. what the child actually does in everyday life)	
Measuring capacity is most essential (what child is able to do given their best effort & set-up)	Measuring capacity is most essential (what child is able to do given their best effort & set-up)
Measuring capability is most essential (what child could do in everyday life, if he/she desires)	Measuring capability is most essential (what child could do in everyday life, if he/she desires)
Measuring a combination of capacity, capability & performance is most essential	Measuring a combination of capacity, capability & performance is most essential
Participation should only involve activities where there are interactions with others	Participation should only involve activities where there are interactions with others
Participation should include activities that are done alone	
Personal care activities should be considered as participation	Personal care activities should be considered as participation
WHERE	
	Participation in home life is most critical
Participation in school life is most critical	
Participation in community life is most critical	
HOW	
Barriers and facilitators of participation should not be evaluated when assessing participation	Barriers and facilitators of participation should not be evaluated when assessing participation
Barriers and facilitators of participation should be evaluated, but done as a separate assessment from participation	Barriers and facilitators of participation should be evaluated, but done as a separate assessment from participation
Comparison with self over time is critical	
Comparison with peers is critical information	Comparison with peers is critical information
Evaluations with peers and with self are equally important	Evaluations with peers and with self are equally important
Documenting the strategy needed to participate is critical	Documenting the strategy needed to participate is critical
Documenting the amount of assistance needed is critical	Documenting the amount of assistance needed is critical
Select the number of minutes acceptable for administering a therapist report: i) Less than 15 minutes is acceptable ii) 15-30 minutes is acceptable iii) More than 30 minutes is acceptable	Select the number of minutes acceptable for administering a therapist report: i) Less than 15 minutes is acceptable ii) 15-30 minutes is acceptable iii) More than 30 minutes is acceptable

Round Two Elements That Did Not Reach Consensus (^)	
18 Months to 5 Years Age Group	6 to 12 Years Age Group
HOW	
Select the number of minutes acceptable for administering a parent report: i) Less than 15 minutes is acceptable ii) 15-30 minutes is acceptable iii) More than 30 minutes is acceptable	Select the number of minutes acceptable for administering a parent report: i) Less than 15 minutes is acceptable ii) 15-30 minutes is acceptable iii) More than 30 minutes is acceptable
Select the number of minutes acceptable for administering a child report: i) Less than 15 minutes is acceptable ii) 15-30 minutes is acceptable iii) More than 30 minutes is acceptable	Select the number of minutes acceptable for administering a child report: i) Less than 15 minutes is acceptable ii) 15-30 minutes is acceptable iii) More than 30 minutes is acceptable
Select the maximum number of minutes acceptable for scoring an assessment: i) Less than 15 minutes to score the assessment is acceptable ii) 15-30 minutes to score the assessment is acceptable iii) More than 30 minutes to score the assessment is acceptable	Select the maximum number of minutes acceptable for scoring an assessment: i) Less than 15 minutes to score the assessment is acceptable ii) 15-30 minutes to score the assessment is acceptable iii) More than 30 minutes to score the assessment is acceptable
Total number of elements where consensus not reached 40	Total number of elements where consensus not reached 30

Legend: ^ Consensus was set *a priori* as $\geq 80\%$ agreement.

Table 3.5 Round Three Top Ranking Elements That Reached Consensus

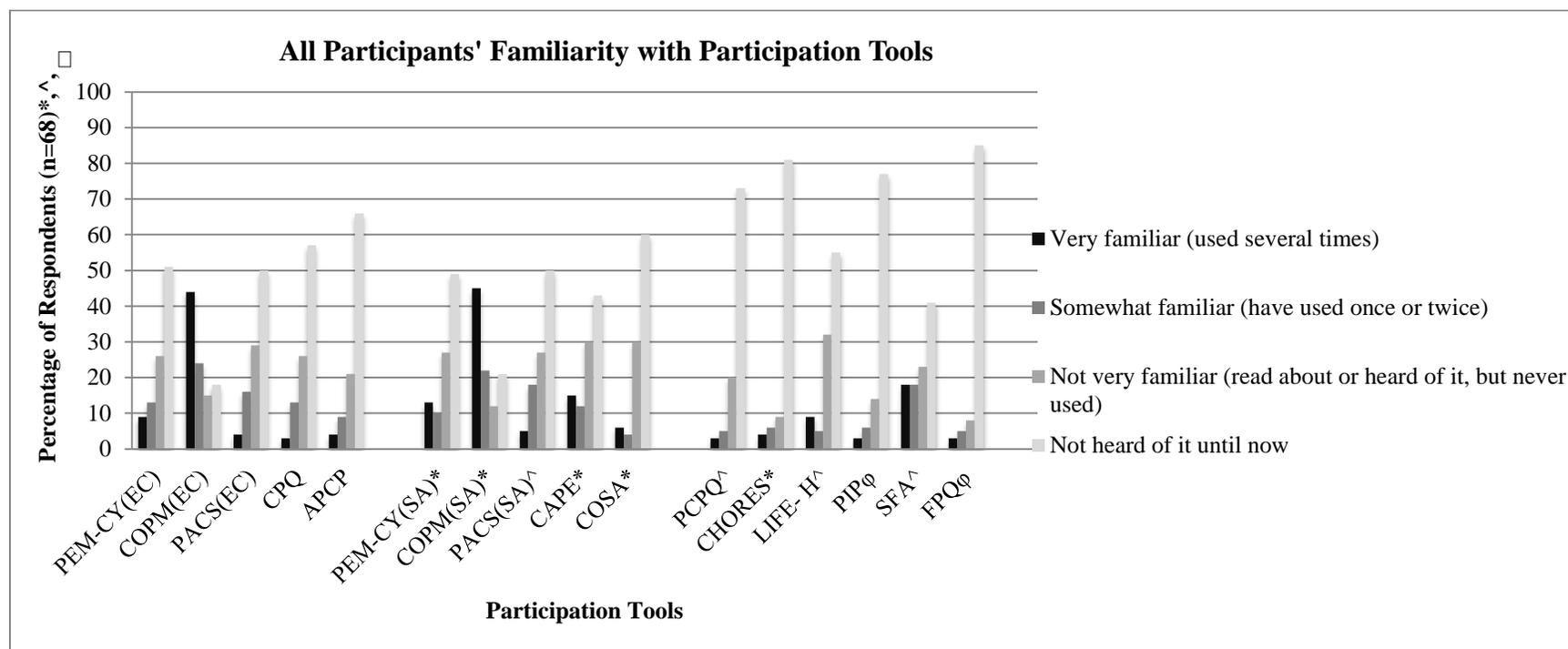
(In Descending Order)

Priority	18 Months to 5 Years	6 to 12 Years
1	Participation in a combination of settings (e.g. home, school & community)	Participation in a combination of settings (e.g. home, school & community)
2	Combination of family participation & child participation	Combination of parent's report of child's participation and child's self report of participation
3	Child's engagement in participation	Child's engagement in participation
4	Barriers and facilitators of participation	Barriers and facilitators of participation
5	Child's enjoyment of participation	Combination of family participation & child participation

Legend:

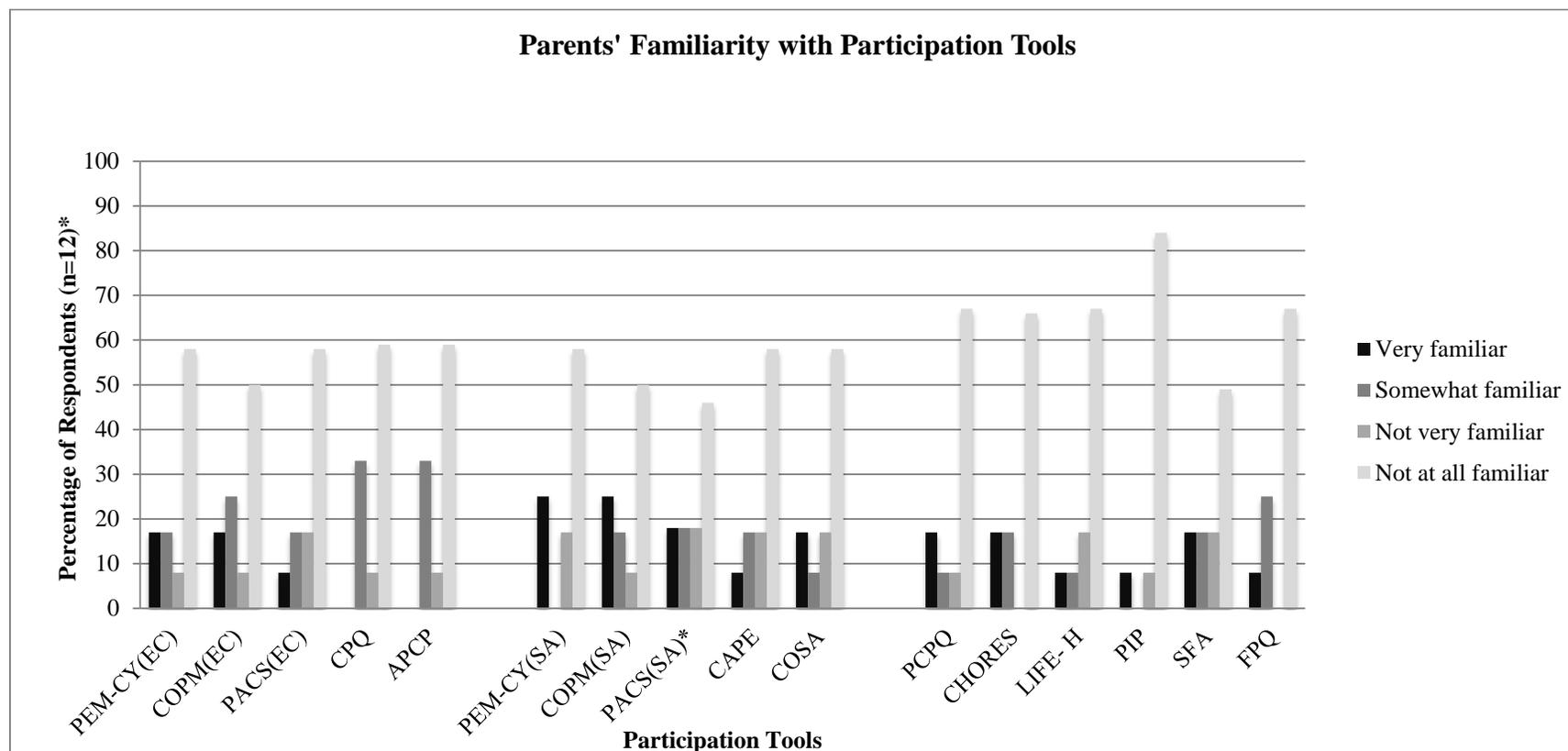
Elements that reached consensus in both age groups and matched in exact priority
Elements that reached consensus in both age groups but were of different priorities
Elements that reached consensus in one age group only

Figure 3.4 Participants' Familiarity with Participation Tools under Consideration



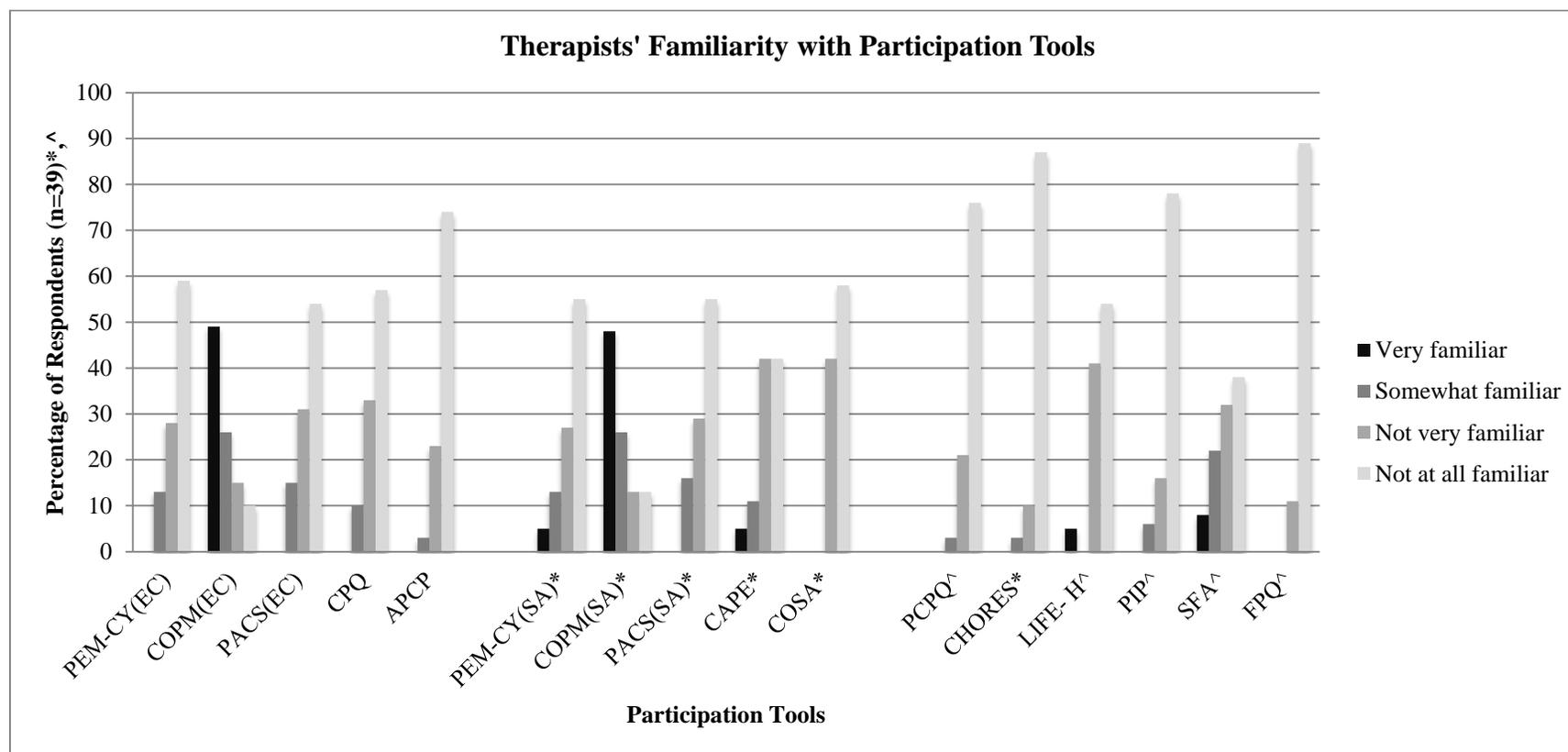
Legend: PEM-CY = Participation and Environment Measure for Children and Youth;¹⁷⁸ (EC) = Early Childhood; (SA) = School Age; COPM = Canadian Occupational Performance Measure;⁹⁶ PACS = Preschool Activity Card Sort;¹⁸⁰ CAPE = Children's Assessment of Participation and Enjoyment;¹⁶⁶ CPQ = Children Participation Questionnaire;⁴⁹ LIFE-H = Assessment of Life Habits;⁹³ SFA = School Function Assessment;²⁴⁵ PIP = Pediatric Interest Profiles;¹⁷⁹ COSA = Child Occupational Self Assessment;¹⁹⁷ APCP = Assessment of Preschool Children's Participation;¹⁶² CHORES = Children Helping Out: Responsibilities Expectations and Supports;¹⁷¹ PCPQ = Pediatric Community Participation Questionnaire;¹⁷⁷ FPQ = Frequency of Participation Questionnaire.¹⁷⁴
 * For tools PEM-CY¹⁷⁸(SA), COPM⁹⁶(SA), CAPE,¹⁶⁶ COSA,¹⁹⁷ CHORES¹⁷¹ (n = 67); ^ PACS¹⁸⁰(SA), PCPQ,¹⁷⁷ LIFE-H,⁹³ SFA,²⁴⁵ (n=66); φ PIP,¹⁷⁹ FPQ¹⁷⁴ (n=65).

Figure 3.5 Parents' Familiarity with Participation Tools under Consideration



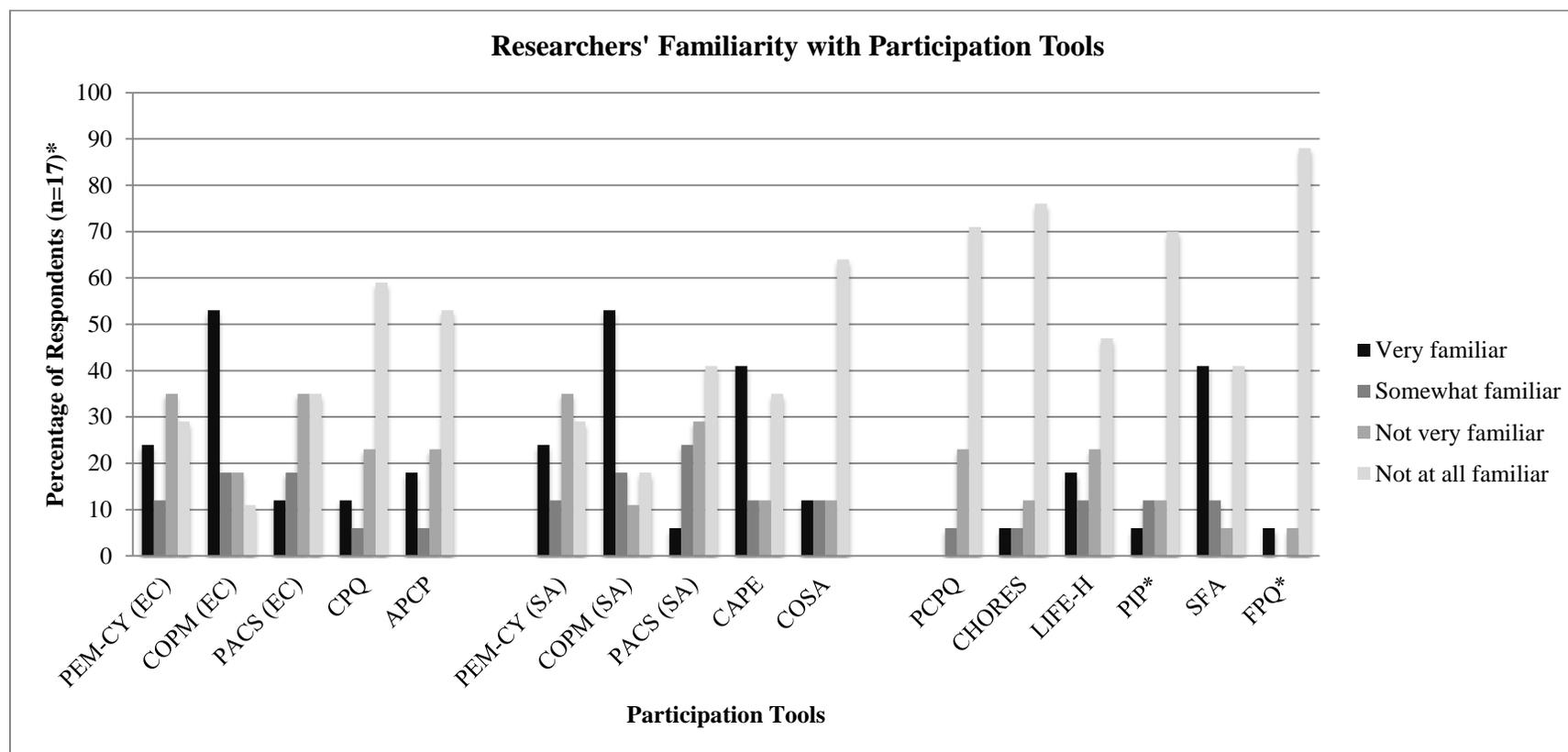
Legend: PEM-CY = Participation and Environment Measure for Children and Youth; ¹⁷⁸ (EC) = Early Childhood; (SA) = School Age; COPM = Canadian Occupational Performance Measure; ⁹⁶ PACS = Preschool Activity Card Sort; ¹⁸⁰ CAPE = Children's Assessment of Participation and Enjoyment; ¹⁶⁶ CPQ = Children Participation Questionnaire; ⁴⁹ LIFE- H = Assessment of Life Habits; ⁹³ SFA = School Function Assessment; ²⁴⁵ PIP = Pediatric Interest Profiles; ¹⁷⁹ COSA = Child Occupational Self Assessment; ¹⁹⁷ APCP = Assessment of Preschool Children's Participation; ¹⁶² CHORES = Children Helping Out: Responsibilities Expectations and Supports; ¹⁷¹ PCPQ = Pediatric Community Participation Questionnaire; ¹⁷⁷ FPQ = Frequency of Participation Questionnaire. ¹⁷⁴
 * For tool PACS ¹⁸⁰ (SA) (n = 11).

Figure 3.6 Therapists' Familiarity with Participation Tools under Consideration



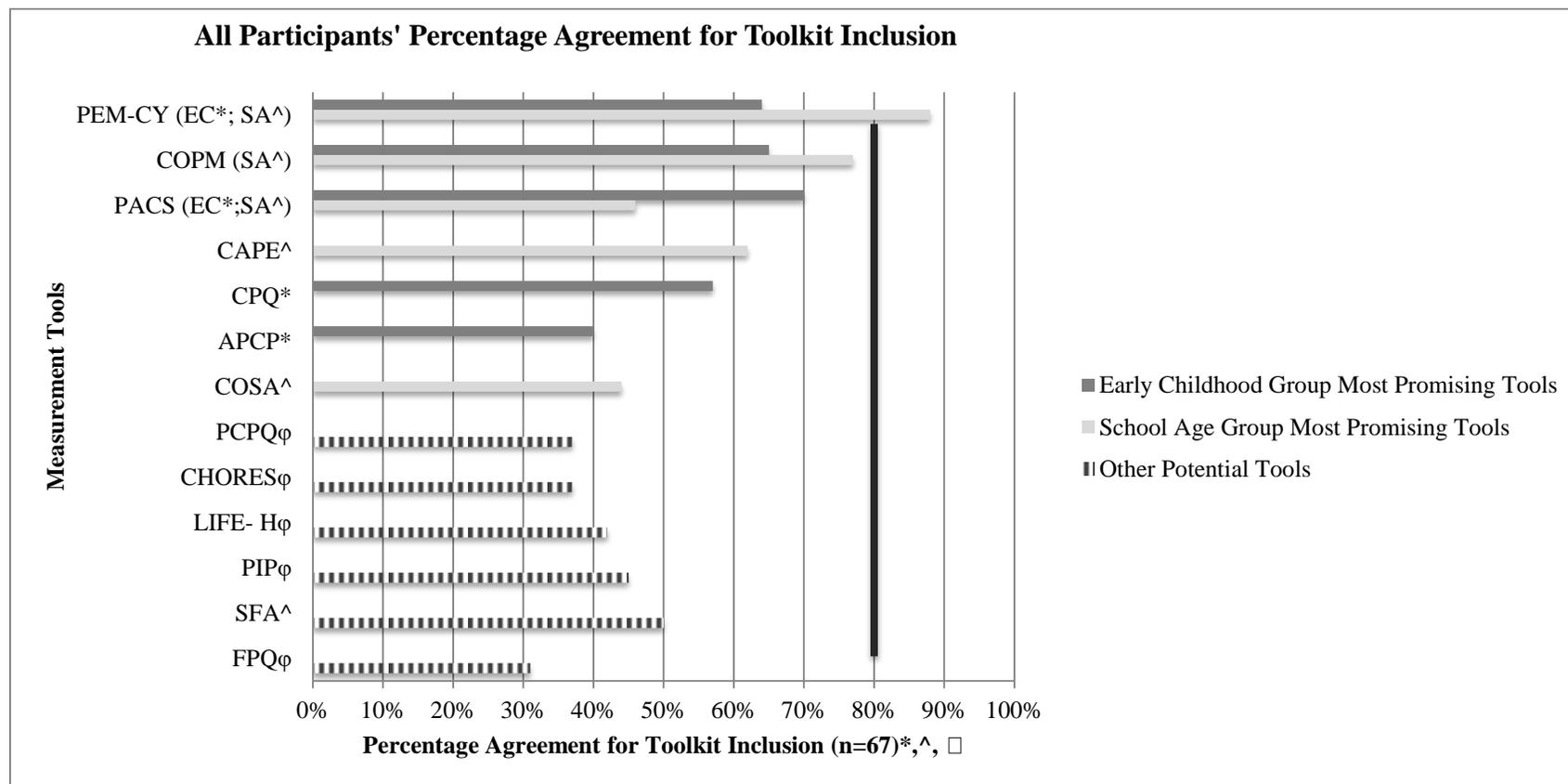
Legend: PEM-CY = Participation and Environment Measure for Children and Youth; ¹⁷⁸ (EC) = Early Childhood; (SA) = School Age; COPM = Canadian Occupational Performance Measure; ⁹⁶ PACS = Preschool Activity Card Sort; ¹⁸⁰ CAPE = Children's Assessment of Participation and Enjoyment; ¹⁶⁶ CPQ = Children Participation Questionnaire; ⁴⁹ LIFE- H = Assessment of Life Habits; ⁹³ SFA = School Function Assessment; ²⁴⁵ PIP = Pediatric Interest Profiles; ¹⁷⁹ COSA = Child Occupational Self Assessment; ¹⁹⁷ APCP = Assessment of Preschool Children's Participation; ¹⁶² CHORES = Children Helping Out: Responsibilities Expectations and Supports; ¹⁷¹ PCPQ = Pediatric Community Participation Questionnaire; ¹⁷⁷ FPQ = Frequency of Participation Questionnaire. ¹⁷⁴ * For tools PEM-CY ¹⁷⁸ (SA), COPM ⁹⁶ (SA), PACS ⁴⁰ (SA), CAPE, ¹⁶⁶ COSA, ¹⁹⁷ CHORES ¹⁷¹ (n = 38); ^ For tools PCPQ, ¹⁷⁷ LIFE- H, ⁹³ PIP, ¹⁷⁹ SFA, ²⁴⁵ FPQ ¹⁷⁴ (n = 37).

Figure 3.7 Researchers' Familiarity with Participation Tools under Consideration



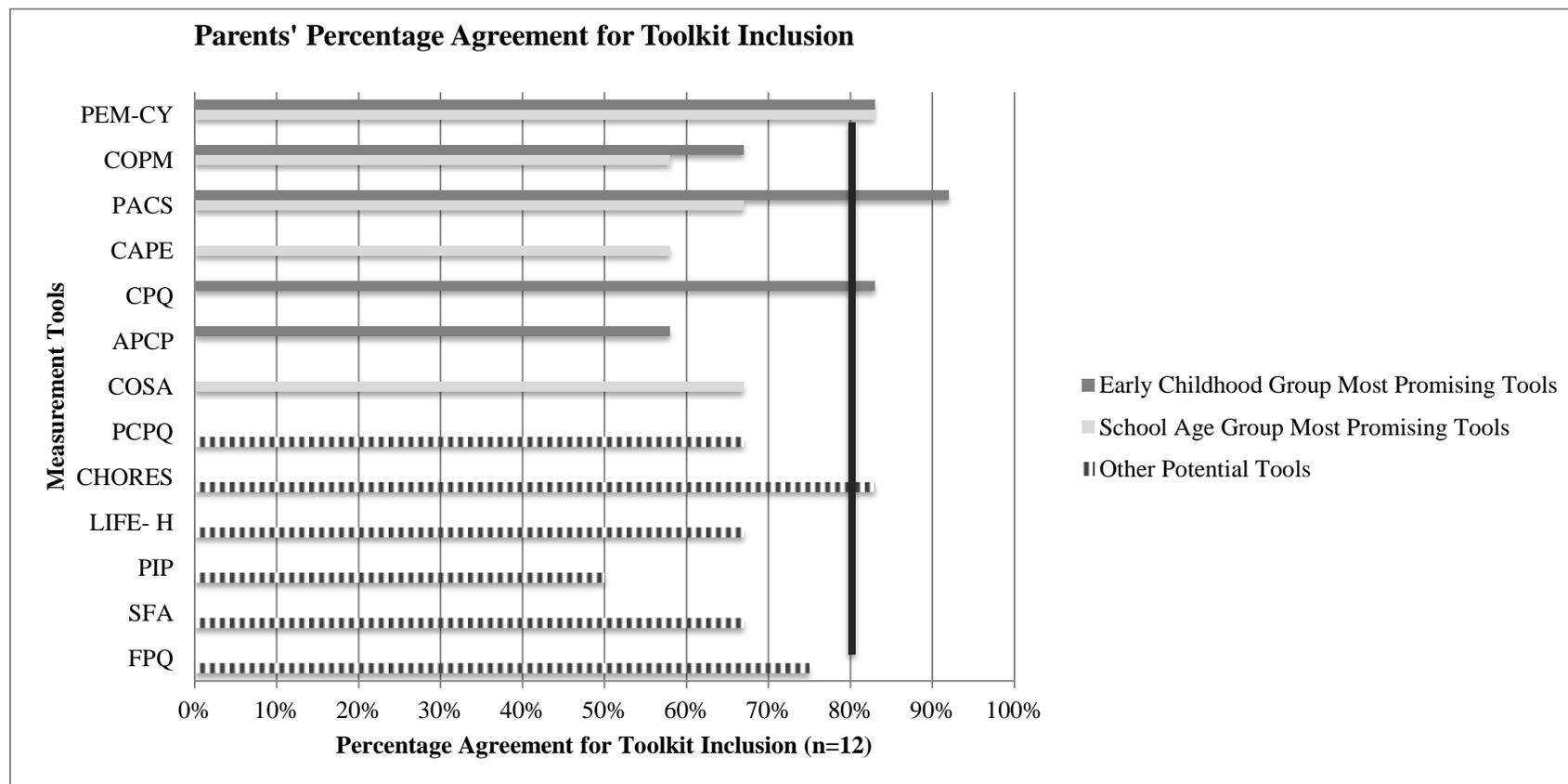
Legend: PEM-CY = Participation and Environment Measure for Children and Youth; ¹⁷⁸ (EC) = Early Childhood; (SA) = School Age; COPM = Canadian Occupational Performance Measure; ⁹⁶ PACS = Preschool Activity Card Sort; ¹⁸⁰ CAPE = Children's Assessment of Participation and Enjoyment; ¹⁶⁶ CPQ = Children Participation Questionnaire; ⁴⁹ LIFE- H = Assessment of Life Habits; ⁹³ SFA = School Function Assessment; ²⁴⁵ PIP = Pediatric Interest Profiles; ¹⁷⁹ COSA = Child Occupational Self Assessment; ¹⁹⁷ APCP = Assessment of Preschool Children's Participation; ¹⁶² CHORES = Children Helping Out: Responsibilities Expectations and Supports; ¹⁷¹ PCPQ = Pediatric Community Participation Questionnaire; ¹⁷⁷ FPQ = Frequency of Participation Questionnaire. ¹⁷⁴ *For tools PIP¹⁷⁹ and FPQ¹⁷⁴ (n = 16).

Figure 3.8 All Participants' Percentage Agreement of Participation Tools Considered for Inclusion in a Measurement Toolkit§



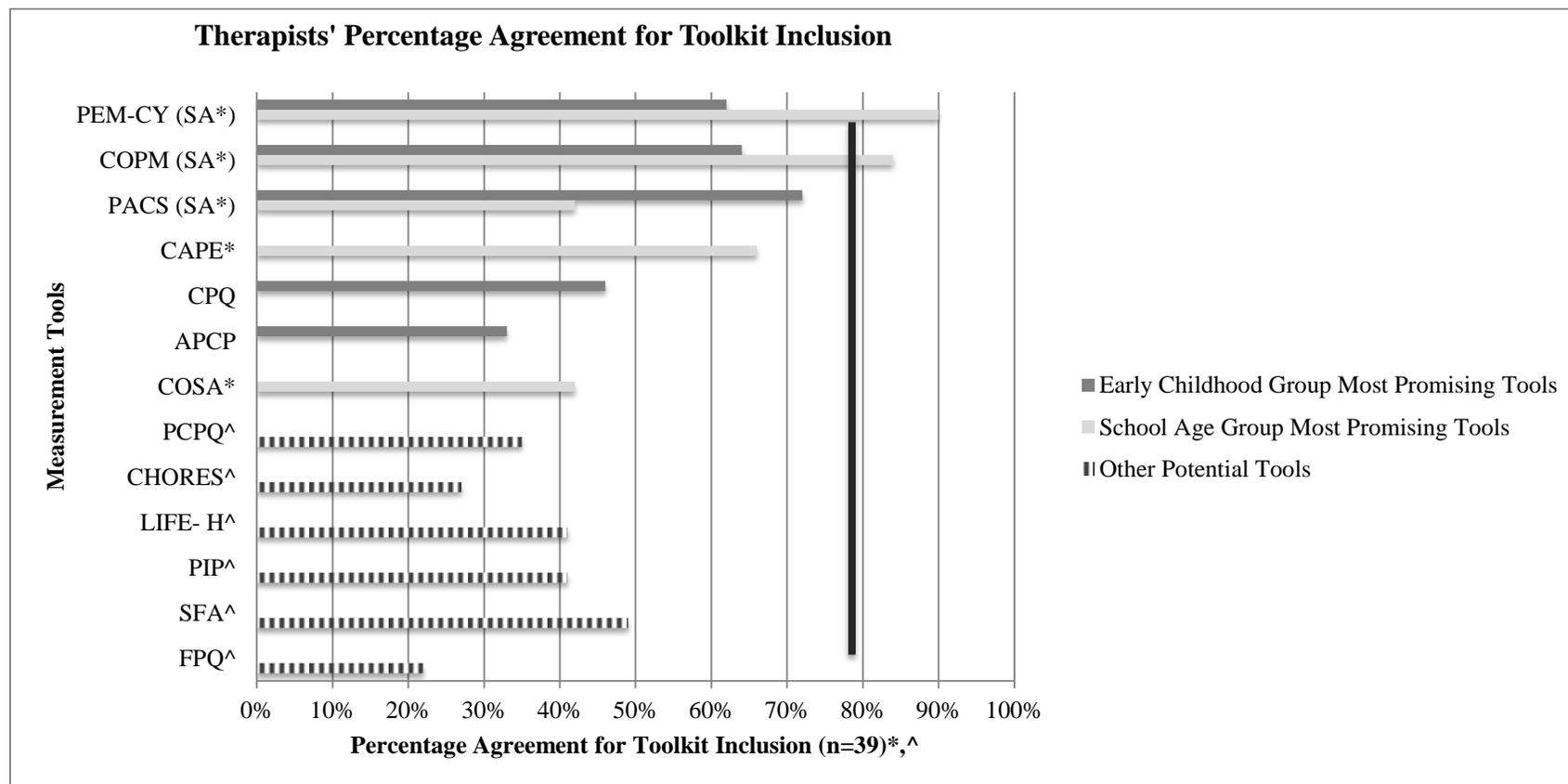
§Consensus set at $\geq 80\%$ agreement. Legend: PEM-CY = Participation and Environment Measure for Children and Youth;¹⁷⁸ COPM = Canadian Occupational Performance Measure;⁹⁶ PACS = Preschool Activity Card Sort;¹⁸⁰ CAPE = Children's Assessment of Participation and Enjoyment;¹⁶⁶ CPQ = Children Participation Questionnaire;⁴⁹ LIFE- H = Assessment of Life Habits;⁹³ SFA = School Function Assessment;²⁴⁵ PIP = Pediatric Interest Profiles;¹⁷⁹ COSA = Child Occupational Self Assessment;¹⁹⁷ APCP = Assessment of Preschool Children's Participation;¹⁶² CHORES = Children Helping Out: Responsibilities Expectations and Supports;¹⁷¹ PCPQ = Pediatric Community Participation Questionnaire;¹⁷⁷ FPQ = Frequency of Participation Questionnaire;¹⁷⁴ % = percentage; \geq = greater than or equal to. * For tools PEM-CY¹⁷⁸(EC), PACS¹⁸⁰(EC), CPQ,³⁹ APCP,¹⁶² (n = 67); ^ PEM-CY¹⁷⁸(SA), COPM⁹⁶ (SA), PACS¹⁸⁰(SA), CAPE,¹⁶⁶ COSA,¹⁹⁷ SFA,²⁴⁵ (n=66); φ PCPQ,¹⁷⁷ CHORES,¹⁷¹ LIFE-H,⁹³ PIP,¹⁷⁹ FPQ¹⁷⁴ (n=65).

Figure 3.9 Parents' Percentage Agreement of Participation Tools Considered for Inclusion in a Measurement Toolkit§



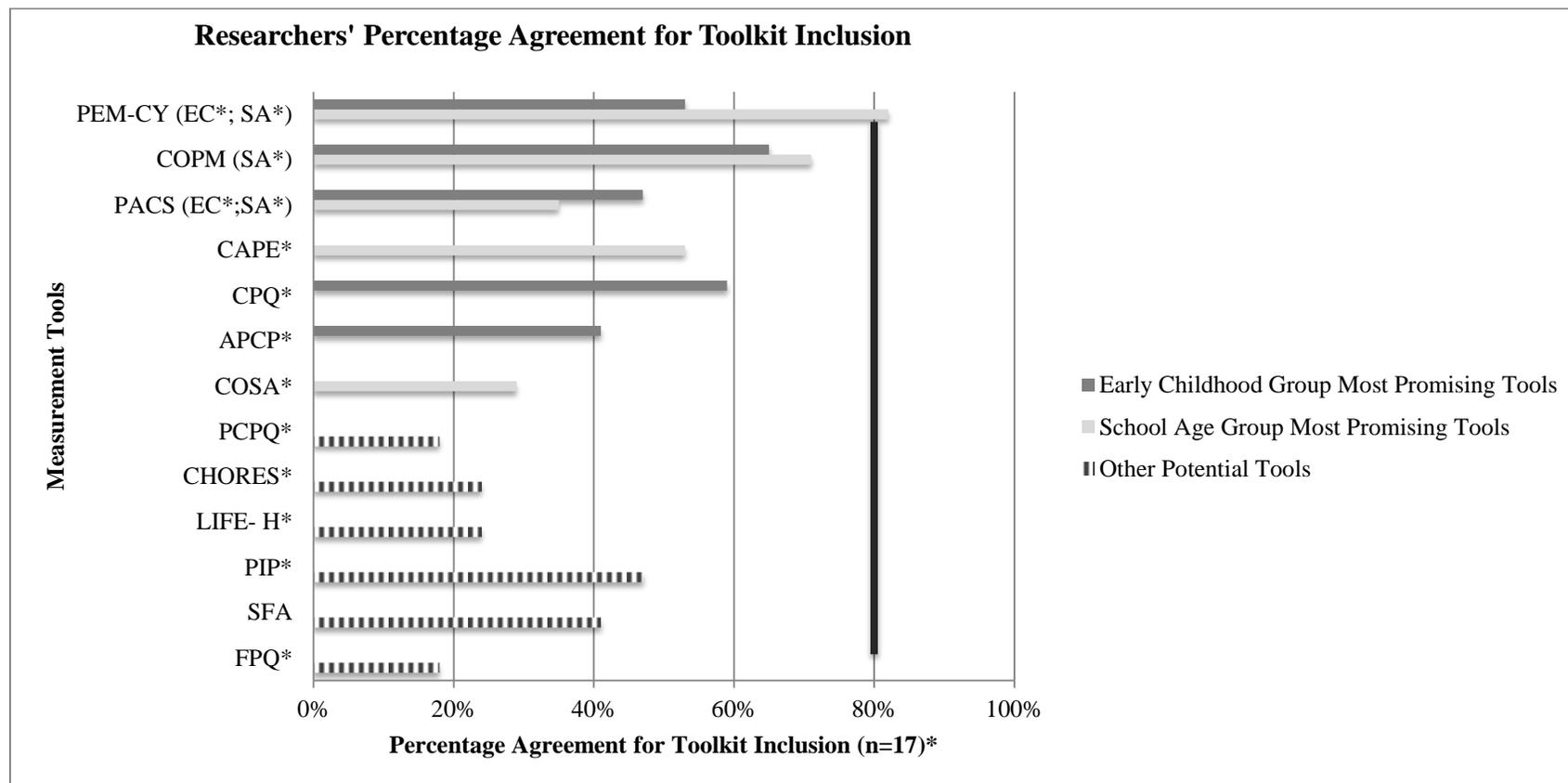
§Consensus set at $\geq 80\%$ agreement. Legend: PEM-CY = Participation and Environment Measure for Children and Youth;¹⁷⁸ COPM = Canadian Occupational Performance Measure;⁹⁶ PACS = Preschool Activity Card Sort;¹⁸⁰ CAPE = Children's Assessment of Participation and Enjoyment;¹⁶⁶ CPQ = Children Participation Questionnaire;⁴⁹ LIFE- H = Assessment of Life Habits;⁹³ SFA = School Function Assessment;²⁴⁵ PIP = Pediatric Interest Profiles;¹⁷⁹ COSA = Child Occupational Self Assessment;¹⁹⁷ APCP = Assessment of Preschool Children's Participation;¹⁶² CHORES = Children Helping Out: Responsibilities Expectations and Supports;¹⁷¹ PCPQ = Pediatric Community Participation Questionnaire;¹⁷⁷ FPQ = Frequency of Participation Questionnaire;¹⁷⁴ % = percentage; \geq = greater than or equal to.

Figure 3.10 Therapists' Percentage Agreement of Participation Tools Considered for Inclusion in a Measurement Toolkit§



§Consensus set at $\geq 80\%$ agreement. Legend: PEM-CY = Participation and Environment Measure for Children and Youth;¹⁷⁸ COPM = Canadian Occupational Performance Measure;⁹⁶ PACS = Preschool Activity Card Sort;¹⁸⁰ CAPE = Children's Assessment of Participation and Enjoyment;¹⁶⁶ CPQ = Children Participation Questionnaire;⁴⁹ LIFE- H = Assessment of Life Habits;⁹³ SFA = School Function Assessment;²⁴⁵ PIP = Pediatric Interest Profiles;¹⁷⁹ COSA = Child Occupational Self Assessment;¹⁹⁷ APCP = Assessment of Preschool Children's Participation;¹⁶² CHORES = Children Helping Out: Responsibilities Expectations and Supports;¹⁷¹ PCPQ = Pediatric Community Participation Questionnaire;¹⁷⁷ FPQ = Frequency of Participation Questionnaire;¹⁷⁴ % = percentage; \geq = greater than or equal to. * For tools PEM-CY¹⁷⁸(SA), COPM⁹⁶(SA), PACS¹⁸⁰(SA), CAPE,¹⁶⁶ COSA,¹⁹⁷ (n = 38); ^ PCPQ,¹⁷⁷ CHORES,¹⁷¹ LIFE-H,⁹³ PIP,¹⁷⁹ FPQ,¹⁷⁴ SFA,²⁴⁵ (n=37).

Figure 3.11 Researchers' Percentage Agreement of Participation Tools Considered for Inclusion in a Measurement Toolkit§



§Consensus set at $\geq 80\%$ agreement. **Legend:** PEM-CY = Participation and Environment Measure for Children and Youth;¹⁷⁸ COPM = Canadian Occupational Performance Measure;⁹⁶ PACS = Preschool Activity Card Sort;¹⁸⁰ CAPE = Children's Assessment of Participation and Enjoyment;¹⁶⁶ CPQ = Children Participation Questionnaire;⁴⁹ LIFE- H = Assessment of Life Habits;⁹³ SFA = School Function Assessment;²⁴⁵ PIP = Pediatric Interest Profiles;¹⁷⁹ COSA = Child Occupational Self Assessment;¹⁹⁷ APCP = Assessment of Preschool Children's Participation;¹⁶² CHORES = Children Helping Out: Responsibilities Expectations and Supports;¹⁷¹ PCPQ = Pediatric Community Participation Questionnaire;¹⁷⁷ FPQ = Frequency of Participation Questionnaire;¹⁷⁴ % = percentage; \geq = greater than or equal to. * For tools PEM-CY,¹⁷⁸ COPM⁹⁶ (SA), PACS,¹⁸⁰ CPQ,³⁹ APCP,¹⁶² CAPE,¹⁶⁶ COSA,¹⁹⁷ PCPQ,¹⁷⁷ CHORES,¹⁷¹ LIFE-H,⁹³ PIP,¹⁷⁹ FPQ¹⁷⁴ (n=16).

Chapter 4: Establishing Measurement Properties of Participation Tools for Children Using Power Mobility

4.1 Introduction

In the previous chapter, we established participation-related elements that are important to measure for children using PM, and examined how current measurement tools addressed these elements. Our on-line Delphi survey documented and synthesized knowledge gained through panelists' experience, highlighting important considerations when measuring participation of children using PM. Thirteen participation tools^{45, 49, 93, 96, 162, 166, 171, 177-180, 184, 197} addressed some but not all of these elements within a single tool. One tool was endorsed for its suitability with children using PM, however as Chapter 2 suggests, little direct evidence supports the use of participation tools specifically with children using PM.^{11, 131} This leads us to question: What *are* the measurement properties of selected participation tools when used specifically with children benefiting from PM?

Establishing a tools' measurement properties for use with a specific population and context is critical for meaningful interpretation of measurement results and should be substantiated in terms of reliability and validity evidence.^{106, 112, 114} Recall in Chapter 1, we introduced common forms of reliability and validity evidence.^{108, 113} Frequently, reliability evidence for self-report measurement scales explores internal consistency and test-retest reliability,¹¹⁰ while validity evidence may be derived from numerous strategies investigating content, relationship with other variables, internal structure, response processes and consequences of tool use.^{107, 113, 114}

Recognizing that evidence supporting the routine use of select measurement tools for research and clinical practice accumulates over time, we decided that our initial evaluation of participation tools' measurement properties with those using PM should focus on tools identified as having potential for inclusion in a measurement toolkit by Delphi participants. Participants indicated that the PEM-CY¹⁷⁸ and Canadian Occupational Performance Measure (COPM)⁹⁶ had the highest levels of agreement for inclusion in a toolkit across early childhood and school age groups, along with the Children's Assessment of Participation and Enjoyment (CAPE)¹⁶⁶ for school-aged children, and the Preschool Activity Card Sort (Preschool ACS)¹⁸⁰ for those in early childhood.

Although initial studies evaluating the PEM-CY^{178, 201, 217, 218} CAPE^{39, 50, 52, 57, 166} or Preschool ACS^{180, 181, 221} included children with physical disabilities, details of wheelchair use were not reported, leaving us unsure of how to interpret their scores when implemented with those using PM. By comparison, the COPM⁹⁶ has been used in several studies with adults and children with mobility limitations.^{7, 67, 130, 256-263} However, previous research with individuals using wheeled mobility suggests that the COPM⁹⁶ may be too broad in its measurement of occupational performance goals when used with seating and mobility interventions.^{256, 258} In one study evaluating occupational performance challenges for adults receiving seating and mobility interventions, participants identified occupational performance goals using the COPM⁹⁶ with instructions modified to cue participants to think about how their seating and mobility equipment affected their occupational performance.²⁵⁶ Interestingly, after reviewing the COPM⁹⁶ occupational performance items reported by Barlow's participants,²⁵⁶ few items specifically addressed the ICF^{33, 34} component of 'participation,' (Chapters 6-9 by our definition) while most

items related to ‘activities’ such as transfers, sitting balance, reaching, or wheelchair skills. Her recommendations for seating and mobility intervention outcomes research were to (i) use tools that measure occupational performance with more focus on seating and mobility interventions, (ii) simplify the scoring, (iii) include a measure of pain or comfort, and (iv) for participants unable to complete the COPM,⁹⁶ obtain caregivers’ perceptions of wheelchair users’ occupational performance.²⁵⁶ In paediatric studies, where the COPM⁹⁶ was used with families and children with mobility limitations, identified outcomes were primarily self-care and ‘activities’ focused, not participation-related.^{130, 259-262} One exception was a study where adolescents who self-reported identified their most-common occupational performance challenges as participation-related, however parents of adolescents unable to self-report, focused on outcomes related to self-care and ‘activities.’²⁶³ Taken together, this information suggests using the COPM⁹⁶ with individuals with mobility limitations who require seating and mobility interventions may have its limitations and that participation tools developed specifically for this population might be more suitable.¹⁵⁷

Two measurement tools developed specifically for individuals using wheeled mobility employed the COPM⁹⁶ to inform their development.^{258, 264} Functioning Everyday with a Wheelchair (FEW)²⁶⁴ evaluated functional changes associated with seating and mobility interventions as perceived by the individual using, or transitioning to, a wheeled mobility device. Now known as the Functional Mobility Assessment (FMA),²⁶⁵ the tool uses a 7-point Likert scale to rate users’ agreement with 10 statements that address functional tasks.²⁶⁵ Notably, most functional tasks related to (our operationalized definition of) ICF ‘activities’ rather than ‘participation,’^{33, 34} and for that reason, it did not meet our purpose. The Wheelchair Outcome

Measure (WhOM),²⁵⁸ was also based on the COPM.⁹⁶ It examines the client's self-perceived importance and satisfaction with performance on client-identified participation outcomes influenced by seating and/or wheeled mobility use within home and community settings.²⁵⁸ Clinicians and researchers suggest the WhOM²⁵⁸ as an alternative to the COPM⁹⁶ when evaluating seating and mobility interventions because of its focus on outcomes impacted by seating and mobility interventions,^{257, 258} its simpler scoring system, and its' questions about comfort, sitting position and skin integrity.^{257, 258} In a recent critical appraisal of outcome measures for wheelchair and seating interventions, the WhOM²⁵⁸ was one of five tools selected from 20 tools identified, citing its' strengths of being client-centred, having strong measurement properties [for adults], and being focused on participation-related outcomes.²⁵³ Moreover, the COPM⁹⁶ was not among the 20 tools.²⁵³ Initial research evaluating the WhOM²⁵⁸ with a younger population²⁶⁶ has resulted in the development of the Wheelchair Outcome Measure for Young People (WhOM-YP).²⁶⁷ The WhOM-YP did not have any publications describing its measurement properties for children at the time of our systematic review and so was not included in our Delphi survey. However, given that the WhOM²⁵⁸ (and WhOM-YP) are very similar to the COPM⁹⁶ in design, we chose to evaluate the WhOM-YP's measurement properties (instead of the COPM⁹⁶) and determine if it might be a useful participation tool for our purpose.

If we are to advance research in paediatric PM, its' important that the measurement tools we must have evidence of reliability and validity with our population before we can be confident using them to describe the participation needs of children using PM.^{20, 130} Therefore, additional research is warranted to demonstrate the measurement properties of possible tools with children using PM.

4.1.1 Purpose

The purpose of this study was to estimate the reliability and validity for three participation tools with children using PM (as part of a larger feasibility study). Measurement properties explored in this study included internal consistency and test-retest reliability evidence, as well as validity evidence associated with content and relation to other variables of the PEM-CY¹⁷⁸ (a parent report and our primary measurement tool), the CAPE¹⁶⁶ (a child report) and the WhOM-YP (a client-specified individualized outcome measurement tool). See the data analyses section below for investigated hypotheses.

4.2 Method

4.2.1 Research Design

Data reported in this chapter are from an imbedded measurement study within a feasibility study that used a non-equivalent time series design.^{110, 268} Figure 4.1 presents a visual flow diagram outlining the study's design. As outlined in Chapter 1, this chapter reports on reliability and validity evidence collected at the first two evaluation time points (T1 and T2) and will describe study protocol, participation and descriptive tools used, along with T1 and T2 results. Chapter 5 describes other feasibility indicators, including process, resources, and management indicators with the entire sample as well as treatment-related indicators with a sub-sample that received a new PM device and included T3 to T5 results. Human ethics approval was obtained from ethic review boards associated with recruitment sites. School district approvals were sought if necessary, depending on policies of each school district.

4.2.2 Participants

A convenience sample of parent-child dyads consisted of two streams of participants. Children, aged 5 to 17 years, included (i) those who had a new PM device recommended by their therapist, (referred to as the ‘new PM’ group), and (ii) those who were current PM users not expecting a change in the PM device within the next year, (referred to as the ‘stable PM’ group). The ‘new PM’ group included children new to PM (who ambulated or used a manual mobility device) as well as those who were experienced PM users who needed a new PM device due to growth, change in medical condition or change in mobility requirements. A two-week test-retest period was selected because we did not expect change in children’s participation during that time while accommodating family scheduling and reducing influence of recall.¹¹⁰ Over the course of the two-week period, participants reportedly maintained their typical routines; those who were new to PM did not have access to PM devices, while those who were experienced drivers continued to use their current PM equipment.

4.2.2.1 Sampling Procedure

Children and their parents were recruited from four children’s health centres in British Columbia (BC) that address positioning and mobility as well as other child health and rehabilitation needs. Participating centres included Sunny Hill Health Centre for Children and BC Children’s Hospital in Vancouver (collectively sharing administrative functions, and also known as the Children’s and Women’s Health Centre of BC), the Centre for Child Development in Surrey, and Queen Alexandra Centre for Children’s Health in Victoria. Therapists in these facilities often consult closely with community-based therapists working in school districts or child development

centres around the province, and so community-based therapists formed part of the recruitment network to identify eligible participants.

Primary therapists for PM interventions most often introduced the study to children and parents/guardians, and provided an introductory letter with a study brochure. Parents were given the option to initiate contact with the coordinator directly if interested or have their therapist share their contact information (with their consent) with the study coordinator for follow up within the following week. Additionally posters were placed in locations visited by children and their families-including the four rehabilitation centres' waiting rooms, wheeled mobility vendor locations (with the agreement of the vendor), physical or electronic research bulletin boards or posted on the investigators' websites. To share information about the study with families of children in the 'stable PM' group, the study coordinator consulted with centre staff who reviewed client lists of the rehabilitation centres' seating/wheeled mobility services and coordinated mail-outs of an introductory letter and study brochure. The letter introduced the study and asked parents/guardians to contact the study coordinator directly if they were interested in learning more about the study. A reminder post-card was sent one month later to those that did not respond to the earlier mail-out.

The study coordinator served as primary research contact, introducing the study and maintaining regular contact with therapists and interested parents. The coordinator shared study details, discussed the elements of consent with families/guardians, answered questions, established eligibility and explored if they were willing to participate in the study. If interested, the coordinator then scheduled the first one or two appointments. Additionally, the coordinator

communicated with community-based therapists employed to work in the schools as many children used PM at school only. This often required additional communication and collaboration with school district staff, sharing study information and arranging appointments as necessary, which was usually facilitated by the children's community-based therapists.

4.2.2.2 Inclusion Criteria

Participating families resided in BC, with parents providing informed written consent and children 7 years of age and older providing assent to participate in the study. All children had a long-term physical disability that made walking challenging and were candidates for using PM as recommended by their therapists. They needed to be able to operate a PM device by themselves (with age-appropriate supervision) and have opportunities to use PM to participate in desired activities at home, at school, or in the community on a regular (minimum weekly) basis (after delivery of the PM device for the 'new PM' group). Primary caregivers other than parents (e.g., foster parents, grandparents, registered nurses) were included with written consent of the legal guardian. For ease of reading, 'parent' will be used throughout the remainder of this chapter to imply primary caregiver. Children 5 to 17 years old age were selected because: (i) provincial funding sources indicated this group received a high number of PM devices (Meaning S, Children and Youth with Special Needs Therapy Manager BC Ministry of Child and Family Development (MCFD), 2013, January 22, email communication) and (ii) the three participation tools under study were developed for children within this age range.

4.2.2.3 Exclusion Criteria

Parents and children in both groups were excluded if the parent or child did not understand English or they were unable to commit to the timeline for the assessment sessions. Additionally, those in the ‘new PM’ group, were excluded if the child had an illness, or surgery planned within three months after receiving the new PM device that affected their ability to use PM for greater than 3 weeks.

4.2.3 Study Protocol

4.2.3.1 Participation Measurement Tools

4.2.3.1.1 Participation and Environment Measure for Children and Youth¹⁷⁸

A recently developed parent-report, available by purchase for those aged 5 to 17 years, the Participation and Environment Measure for Children and Youth (PEM-CY)¹⁷⁸ assesses children’s participation in everyday life at home, school or out in the community. Although the PEM-CY¹⁷⁸ also evaluates environmental supports and barriers to children’s participation in the three settings, those results were not included in this dissertation. Items evaluated frequency of participation within the last four months, extent of involvement, and desire for change in participation at home (10 items), at school (5 items) and in the community (10 items).^{178, 200} Each of these dimensions were scored separately across each setting, providing nine summary scores. Frequency was scored using an 8-point ordinal scale ranging from 1 (daily) to 8 (never participating). Parents’ perception of their child’s involvement (indicating extent to which child was engaged in activities) was scored on a 5-point ordinal scale, ranging from 1 (minimally involved) to 5 (very involved). Parents’ degree of desired change (indirectly indicating parents’ satisfaction with child’s current participation) was scored on a nominal scale including 0 (no

change desired) and 1 (change desired). Five ‘yes’ options, not affecting the summary score, clarified type(s) of change desired (i.e., being more or less involved, doing the activity more or less often, or being involved in a broader variety of activities). Scores were reverse-coded for frequency as per instruction manual. When calculating summary scores, higher scores across settings indicated greater frequency and involvement while desired change was presented as a dichotomous variable (i.e., changed desired or not).¹⁷⁸ Greater frequency of participation or participation in more items were not indicative of ‘better’ participation, but rather were used for group comparison.²⁰⁰ Average frequency scores summed parents’ frequency responses within each setting divided by the number of items within each setting that the child engaged in, while frequency percent (%) possible scores were derived by counting the number of items within each setting that the parent responded that their child participated in divided by total number of items available in each setting. This score is of benefit when comparing scores where missing data might be related to not all items being applicable.²⁶⁹ The questionnaire reportedly takes 30 minutes to complete. Refer to Chapters 2 and 3 for reliability and validity evidence for children 5 to 17 years with and without disabilities.^{178, 200, 201, 217-219}

4.2.3.1.2 Children’s Assessment of Participation and Enjoyment¹⁶⁶

The Children’s Assessment of Participation and Enjoyment (CAPE)¹⁶⁶ is a 55-item child report that measures out-of-school participation across five dimensions, also available by purchase. For each item, the child rated diversity (i.e., did they engage in the activity or not within the last four months), intensity (i.e., how frequently they engaged in the activity within the last four months) enjoyment, with whom and where participation took place.¹⁶⁶ Reportedly taking 30 to 45 minutes to complete, it may be self-administered or completed in a semi-structured interview,

and parents may assist as needed.¹⁸⁹ All items were scored using ordinal scales, ranging from 0 to 7 (depending on dimension), except for the dichotomous diversity score. Summary scores for each of the five participation dimensions included total score (55 items); informal (40 items relating to non-structured leisure) or formal domains (15 items relating to structured lessons or group activities, often with an instructor or coach, or having rules or specific goals); or recreational (12 items), active-physical (13 items), social (10 items), skill-based (10 items), and self-improvement (10 items) types.¹⁶⁶ Diversity scores counted the number of items the child engaged in within that particular summary score category, intensity scores were summed and divided by the total number of items available in each category, while each of the other dimensions were summed and divided by the diversity score to obtain an average score within that summary score category. Higher scores indicated greater diversity, intensity, enjoyment, and engagement beyond the family and home environments, but similar to the PEM-CY,¹⁷⁸ greater frequency scores should not be interpreted as better participation.¹⁶⁶ Developers recommended intensity and diversity summary scores be used together as diversity summary scores indicate absolute number of items engaged in, while intensity summary scores provide a relative indicator of frequency based on total number possible.¹⁶⁶ Chapters 2 and 3 summarized evidence of the CAPE's¹⁶⁶ reliability and validity for those 6 to 21 years with and without disabilities.^{39, 50, 52, 57,}

166, 186

4.2.3.1.3 Wheelchair Outcome Measure for Young People

The Wheelchair Outcome Measure for Young People (WhOM-YP) evaluates importance and satisfaction with self-identified participation outcomes influenced by the child's seating and mobility interventions (Appendix L). The WhOM-YP, developed for use with those 18 years and

younger, was included as a potential hybrid of child and parent reports addressing self-selected meaningful participation outcomes. The WhOM-YP was completed by the child and/or parent, depending on the child's age and abilities; if the child was unable to independently express his/her views, both child and parent outcomes and ratings were solicited and recorded separately, along with the degree of parental input. The WhOM-YP, reportedly taking less than 30 minutes to administer using a semi-structured interview format, encompasses two parts.²⁵⁸ Part I is comprised of up to 5 self-identified participation outcomes desired for home (referred to as inside participation) and community settings (including school; referred to as outside participation). Individuals rated their perceived importance along with their satisfaction of the child's current performance when using wheeled mobility for each of their participation outcomes using an 11-point ordinal scale ranging from 0 (not important or not satisfied) to 10 (very important or very satisfied). Part II consists of three questions addressing sitting comfort, body posture and skin integrity, rated using the 11-point scale.²⁵⁸ WhOM-YP Part I summary scores provide several options: a total score (sum of identified items) or a mean score (sum of identified items divided by number identified), calculated for importance, satisfaction, or [importance×satisfaction].²⁵⁸ Higher WhOM-YP summary scores indicate greater importance and greater satisfaction. WhOM-YP Part II comfort, posture and skin integrity scores relate to ICF 'body structures and functions',^{33, 34} and therefore were not included in this dissertation. Although reliability and validity evidence supports the WhOM's use with adults,^{258, 270-273} this was the first study investigating the WhOM-YP's measurement properties with children.

4.2.3.2 Descriptive Participant Information

All descriptive data were gathered at the first session (T1). Selection of measurement tools were informed by literature review and conceptual models introduced in Chapter 1.^{2,3,8-11,13,19,80}

4.2.3.2.1 Demographic Profile of Participants

We used a parent-report form designed for the study to collect socio-demographic information (e.g., age, sex, diagnosis, school grade, and family descriptors, see Appendix M) and historical information related to PM device use (e.g., age of first PM device, how many PM devices used, and why equipment was changed, see Appendix N).

4.2.3.2.2 Gross Motor Functional Classification System (GMFCS)²²⁹

Reportedly taking only a few minutes to complete, this five-point ordinal scale described children's gross motor ability. Parents indicated which level was most like their child after reading a brief description, based on their child's age (4 to 6 years, 6 to 12 years, 12 to 18 years), of each of five levels (Level I indicated greater gross motor abilities than Level V). Reliability and validity evidence has been reported for children with CP^{229, 274-278} although the GMFCS²²⁹ has been used with children who have diagnoses other than CP.²⁷⁹⁻²⁸² The GMFCS²²⁹ is freely available at https://www.cpqcc.org/sites/default/files/documents/HRIF_QCI_Docs/GMFCS-ER.pdf.

4.2.3.2.3 Manual Ability Classification Scale (MACS)²⁸³

The MACS,²⁸³ a five-point ordinal scale, classified fine motor abilities of children. Developed for children aged 4 to 18 years where Level I indicated better fine motor abilities than Level V.

Reportedly taking only a few minutes to complete, parents indicated which level was most like their child, after reading descriptions of all five levels. Reliability and validity evidence for children with CP has been reported,²⁸³⁻²⁸⁵ although it has been used with children with diagnoses beyond CP.^{279, 280, 286, 287} The MACS is freely available at <http://www.macs.nu/download-content.php>.

4.2.3.2.4 Functional Mobility Scale (FMS)²⁸⁸

Parents indicated their child's functional mobility for distances of 5 metres (m), 50 m and 500 m using a six-point ordinal scale to describe mobility methods from 1 (using a wheelchair) to 6 (walking independently over all surfaces) (Appendix O). It requires less than 5 minutes to complete.^{289, 290} Reliability and validity evidence has been reported for children with CP.^{289, 290}

4.2.3.2.5 Level of Sitting Scale (LSS)²⁹¹

Sitting ability was evaluated to provide a more discriminative description of seated motor control (Appendix P), as it was anticipated that most children would be classified as GMFCS²²⁹ levels IV or V and have a FMS²⁸⁸ score of 1 (used a wheelchair). The eight-point ordinal scale ranged from 1 (individual unable to sit for 30 seconds supported by one adult) to 8 (individual able to move with control, in and out of their base of support while sitting on a flat bench with feet unsupported).²⁹¹ The LSS reportedly takes 5 minutes to complete and reliability and validity evidence for children and adults with physical disabilities has been reported.²⁹¹⁻²⁹⁴

4.2.3.2.6 Modified Mini-Mental Status Exam (MMSE)^{295, 296}

The MMSE^{295, 296} was used as a screening tool for children's cognition, and reportedly takes approximately 10 minutes to administer. Items examined orientation, registration, attention, calculation, recall and language (Appendix Q). A total score 2 standard deviations (SD) below the age mean for different age groups, out of a possible 37 points, reportedly indicates cognitive dysfunction.^{295, 296} Reliability and validity evidence have been reported for children as young as three years.²⁹⁵⁻²⁹⁸

4.2.3.2.7 Assessment of Learning Powered Mobility Use (ALP)⁷⁹

Driving ability was described using the ALP, an eight-point ordinal scale that ranged from Novice (level 1) to Expert (level 8) (Appendix R).⁷⁹ A score of zero was added to indicate those not yet using PM. Behavioral observations when driving were rated under subheadings of attention, activity and movement, understanding of tool use, expressions and emotions and interaction and communication. The level with the most positive occurring observations present identified driving level. The ALP⁷⁹ was a recently developed collaboration between two researchers who each developed a learning continuum for PM anchored in grounded theory research.⁷⁷⁻⁷⁹ Reliability and validity evidence have been published using earlier versions.⁷⁷⁻⁷⁹

4.2.4 Data Collection

The assessor, an occupational therapist with at least two years' experience working with children using PM, learned administration instructions and evaluation protocol for all measurement tools, and pilot tested them with 4 children before initiating data collection. The child's parent completed the parent-report measurement tools, while the assessor completed the WhOM-YP

and CAPE¹⁶⁶ with the child, accepting parental assistance as needed. The assessor also administered tools requiring observation of the child's behavior (LSS,²⁹¹ MMSE,^{295, 296} ALP⁷⁹). Each session was no longer than two hours, with breaks as needed. Multiple shorter sessions were offered if deemed necessary or preferred by participants (to address children's attention or fatigue, or family schedules). The first two sessions (T1 and T2) were scheduled on average 2 weeks apart, but not less than 1 week and no more than 4 weeks apart, to evaluate test-retest reliability.

All three participation tools were administered at Time 1 (T1), with the PEM-CY¹⁷⁸ and WhOM-YP administered again at Time 2 (T2). We would have liked to complete the CAPE¹⁶⁶ on both occasions (T1 and T2), however, given its length (55 items, each with 5 parts) and extended administration time, we decided response burden would be too great to re-administer this tool at T2. We did not want to jeopardize participant retention, especially for those receiving a new wheelchair as they had an additional three sessions post-wheelchair delivery (see Chapter 5 for details). Both T1 and T2 occurred before participants received their new PM devices (if deemed appropriate by their therapist).

Participants and their families chose the most convenient time and location for the sessions. Given that the two sessions (T1 and T2) were relatively close in occurrence, we expected rapport would develop quickly between the assessor and participants, facilitating adherence. However, to offset time and expenses, and to reduce dropouts, we offered an honorarium of \$20/session on completion.

4.2.5 Data Analyses

Raw data were entered into Excel²⁴⁴ spreadsheets, checked, transformed and imported to SPSS version 23²⁹⁹ for analyses. Descriptive statistics described the sample as well as distribution of each measurement tool's summary scores. Data type and distribution determined specific measures of central tendency and dispersion used (e.g. means or medians, standard deviations or inter-quartile range). Reliability estimates were sought for internal consistency (for PEM-CY¹⁷⁸ and CAPE¹⁶⁶), test-retest reliability and standard error of measurement (SEM) (for PEM-CY¹⁷⁸ and WhOM-YP) while evidence of validity was sought using four different strategies, referencing the validity framework suggested by the Standards for Educational and Psychological Testing.^{113, 300} Incomplete participation data were excluded from analyses using pairwise deletion, except for internal consistency analyses where listwise deletion was employed.

Internal consistency was examined using Cronbach's alpha for PEM-CY¹⁷⁸ and CAPE¹⁶⁶ summary scores. Examining internal consistency was not appropriate for the WhOM-YP as it relied on client-specified individualized items. We hypothesized that Cronbach's alpha coefficient for PEM-CY¹⁷⁸ average frequency, frequency % possible, average involvement, and % change desired scale scores for home, school and community settings and CAPE¹⁶⁶ overall intensity, diversity and enjoyment scores would achieve at least $\alpha > 0.60$, similar to previous studies reporting PEM-CY¹⁷⁸ and CAPE¹⁶⁶ reliability evidence with children having physical disabilities.^{166, 178, 186, 301}

For test-retest reliability, PEM-CY¹⁷⁸ and WhOM-YP summary scores were examined over a two-week period. Intraclass correlation coefficient estimates using a two-way random effects

model with absolute agreement (ICC_(2,1)) and 95% confidence intervals (CI₉₅) were chosen to provide support for the tools' consistency and agreement of scores over time with different subjects and different raters, in keeping with Generalizability theory.^{110, 112} We hypothesized that PEM-CY¹⁷⁸ (average frequency, percent possible frequency, average involvement, and percentage change desired) summary scores for home, school and community¹⁷⁸ along with WhOM-YP mean satisfaction and mean [importance x satisfaction] summary scores for inside home and outside home participation would demonstrate test-retest reliability over a two week period with an Intraclass correlation coefficient estimate (ICC_{2,1}) ≥ 0.70 . Similar to other measurement studies using these tools,^{178, 270, 272} our anticipated level of reliability is adequate for group-level research applications.^{112, 302}

We examined different sources of validity evidence to support the use of the three selected measurement tools with children benefiting from PM.^{112, 113} The first source explored appropriateness of the selected scales and test items for our population. Descriptive information about the three tools provided an initial indication of the tools' relevance and acceptability of content and structure to children and their parents. Individualized participation outcomes, identified using the WhOM-YP, were classified using the ICF^{33, 34} 'activities and participation' components according to the process outlined by Cieza et al.^{303, 304} Classification involved: (1) identification of ICF^{33, 34} participation outcomes from the WhOM-YP self-identified inside and outside participation outcomes; and (2) selection of ICF^{33, 34} domains and categories that best represented the participation outcomes. Frequency counts summarized the self-identified participation outcomes.

The second source of validity evidence explored relationships among the three participation tools' summary scores as evidence of their relationship with other variables.^{112, 113} Correlation coefficient values closer to 1 indicated stronger associations than values closer to 0, with positive numbers indicating a relationship between variables in the same direction, while negative numbers suggest an inverse relationship.¹¹⁰ The specific type of correlation coefficient (e.g., Pearson product-moment correlation coefficients (r) or Spearman's rank correlation coefficients (r_s)) depended on descriptive findings of summary scores and fit with parametric assumptions (i.e., continuous, normally distributed data from a randomly selected sample with no outliers).^{110, 112} Given the different focus of measurement and strategies employed by each of the three tools,^{13, 35} we hypothesized the following associations, based on theoretical models of children's participation:^{2, 3, 13}

- PEM-CY¹⁷⁸ home and community participation frequency percent possible summary scores and CAPE¹⁶⁶ overall intensity and diversity scores will be $0.3 \geq r \leq 0.8$,
- PEM-CY¹⁷⁸ home and community participation average involvement scores and CAPE¹⁶⁶ overall enjoyment score will be $0.0 \geq r \leq 0.4$,
- PEM-CY¹⁷⁸ home participation percent possible frequency summary score and WhOM-YP parent inside [mean importance x satisfaction] summary scores will be $0.0 \geq r \leq 0.4$,
- PEM-CY¹⁷⁸ school and community participation percent possible frequency summary scores and WhOM-YP parent outside mean [importance x satisfaction] summary scores will be $0.0 \geq r \leq 0.4$,
- CAPE¹⁶⁶ overall enjoyment score and each of WhOM-YP child mean inside and outside [importance x satisfaction] summary scores will be $0.0 \geq r \leq 0.5$.

While each of the measurement tools' selected summary scores measured children's

participation in everyday life, we expected most relationships between selected summary scores not to be very strong because they evaluate different aspects of participation, although we anticipated that frequency and diversity scores would be more closely aligned.^{2, 3, 13, 35, 66} In addition to correlations between the parent report PEM-CY¹⁷⁸ and child report CAPE¹⁶⁶ we also expected a relationship ($0.2 \geq r \leq 0.7$) between parent and child scores on the WhOM-YP mean [importance x satisfaction] summary scores in similar settings, indicating that the two perspectives are related but not identical.^{13, 35, 66}

The third source of validity evidence used the known-group method to explore predicted differences across summary scores for groups known to differ on specific variables of interest.^{112, 113} Based on prior research where age differences were noted for children's participation,^{42, 46, 50, 53, 61} we hypothesized that there would be statistically significant differences in mean scores ($p \leq 0.05$ significance level)(as demonstrated using either independent sample t-test for data fitting parametric assumptions or Mann Whitney U Test, the nonparametric alternative), for children 12 years and older compared to children under 12 years of age on PEM-CY¹⁷⁸ school frequency percent possible summary scores, and CAPE¹⁶⁶ overall intensity scores.

A further known-group analysis explored differences between children who were new to PM compared to those experienced with PM on the PEM-CY¹⁷⁸ community participation frequency percent possible summary scores as well as WhOM-YP outside home participation [importance x satisfaction] summary scores. Previous research exploring participation differences in children between those experienced with PM versus those who are not experienced with PM are limited as Chapter 1 outlined, although adult literature suggests there may be differences.^{147, 233, 305-308}

Therefore, to provide guidance on this set of analyses, we relied on clinical expertise,^{10, 21, 66, 80,}
²⁴⁰ and literature suggesting a difference in children's participation based on motor abilities.^{1, 63,}
^{65, 309, 310} For both comparisons a Bonferroni adjustment to protect against a Type I error was
calculated using a family-wise error rate of 0.05/4 planned comparisons, giving an adjusted alpha
= 0.0125.^{110, 112}

As a final source of validity evidence,^{115, 116} we determined the Minimal Detectable
Difference (MDD) for PEM-CY¹⁷⁸ and WhOM-YP summary scores, as one estimate of a
measurement tool's responsiveness, or ability to detect change.^{117, 118} MDD values for CAPE
summary scores were not determined because we did not re-administer the tool at T2. The
Minimal Detectable Difference, sometimes referred to as Minimal Detectable Change (MDC),
was defined as the smallest amount of change considered above the threshold of measurement
error in a group of individuals who were expected to be stable (on the variable under
investigation).^{110, 112, 117} We calculated MDDs using a 95% confidence interval (CI₉₅; $z = 1.96$)
with the formula $MDD_{95} = SEM \times \sqrt{2} \times z$.^{110, 112} A MDD₉₅ suggests that 95% of the time
individuals will demonstrate random variation less than the MDD₉₅ value when tested under
stable conditions on multiple occasions.^{110, 112} Higher MDD₉₅ values indicated that larger
changes in scores were necessary to reflect a true change beyond measurement error.^{110, 112} The
standard error of measurement (SEM) quantifies the scores' precision within the sample using
the reliability estimates, with higher SEM values indicating less precise measurements.^{110, 112} We
calculated SEM for each summary score using the formula $SEM = s \times \sqrt{1 - ICC_{(2,1)}}$, where s =
SD of the test at T1, and $ICC_{(2,1)}$ = test-retest reliability coefficient of the respective participation
summary scores.^{110, 112}

4.2.5.1 Sample Size Calculation

Thirty participants were selected to provide a large enough sample to assess feasibility criteria and address feasibility outcomes reported in Chapter 5,¹³³ as well as to investigate preliminary test-retest reliability estimates.³¹¹ Communication with the primary BC provincial funding agency for paediatric PM (MCFD) indicated that this target was reasonable based on annual power wheelchair provision rates (Meaning S, Children and Youth with Special Needs Therapy Manager BC MCFD, 2013, January 22, email communication).

4.3 Results

A total of 82 potential participants were identified by primary therapists. This total included 54 potential participants introduced to the study by their therapist (of which 41 connected with the study coordinator) and 32 who were mailed an introduction package (none responded). At the end of the study, we learned that four on the mail-out list were also contacted by their primary therapist (at a later date). Nine of the 41 parents declined to participate stating they were too busy, while one child had acute medical complications after initial contact. Additional information was shared by the primary therapist on 10 of the 13 potential participants who did not contact the study coordinator: two decided not to pursue funding for a power wheelchair, two children became too old for the study shortly after being introduced to the study by their therapist, two families had significant medically-related situations and four had yet to secure funding for a new power wheelchair prior to the end of study recruitment. Of the 32 children enrolled, one child passed away suddenly and unexpectedly after the first session (with a

diagnosis of Duchenne muscular dystrophy), two did not have sufficient time for the second session prior to receiving their new power wheelchair, and a third had too long a period between T1 and T2 (greater than 4 weeks). As a result, T2 data were collected on 28 participants.

Participant characteristics of the 32 children and parents that took part are described in Table 4.1. Parents were primarily mothers, with post secondary education, between the ages of 20 and 49 years. Fifty nine percent of children were male, with the full eligible age-span represented (mean age 11.4 years (standard deviation (SD) 4)). Children with cerebral palsy were most prevalent, followed by those with muscular diseases. As the GMFCS,²²⁹ MACS,²⁸³ FMS²⁸⁸ and LSS²⁹¹ scores illustrate, children had a range of motor abilities. Although all used wheeled mobility for some activities, 10 walked with walking aids for distances ranging from 5 to 500 meters and seven walked independently for at least 5 meters. Of those using wheeled mobility, 10 required upper body external postural support to maintain a sitting position. Ten were new to PM use, while the remainder were experienced drivers. All children had an acceptable MMSE score,^{295,296} indicating that they had the cognitive ability to answer questions asked of them, although they varied in their communication strategies (e.g., voice, sign language, gestures including finger or eyepointing and use of electronic speech generating devices).

4.3.1 Reliability

4.3.1.1 Internal Consistency

Table 4.2 lists the internal consistency coefficient estimates for select PEM-CY¹⁷⁸ and CAPE¹⁶⁶ summary scores. Cronbach's alpha coefficients for PEM-CY¹⁷⁸ frequency of participation across all environments ranged from 0.37 to 0.69, involvement from 0.52 to 0.79 and desired change

was highest from 0.86 to 0.91. Cronbach's alpha coefficient estimates for CAPE¹⁶⁶ overall diversity, intensity, whom, where and enjoyment summary scores ranged from 0.84 to 0.91.

4.3.1.2 Test Retest Reliability

The average time for retest was 16.75 days (SD 7.3) CI₉₅ [14.0,19.4], with a sample of 28 participants. Test-retest reliability ICC_(2,1) point estimates and 95% confidence intervals are summarized in Table 4.2 for select PEM-CY¹⁷⁸ and WhOM-YP summary scores. Of the PEM-CY¹⁷⁸ average frequency summary scores, only the community participation summary had a CI₉₅ that did not include ICC_(2,1)=0 (i.e., home and school participation scores were not reliable). PEM-CY¹⁷⁸ frequency % possible ICC_(2,1) point estimates ranged from 0.64 to 0.74, while average involvement summary scores were 0.47 for home and 0.59 for community participation (school participation had a CI₉₅ including ICC_(2,1)=0). ICC_(2,1) point estimates were highest for the percent desired change summary score with values ranging from 0.71 to 0.85.

WhOM-YP test-retest reliability ICC_(2,1) point estimates for parent ratings ranged from ICC_(2,1) 0.85 to 0.95, while the CI₉₅ included ICC_(2,1)=0 for inside participation mean importance. For children's (aged 5-17 years) mean satisfaction and mean [importance x satisfaction] summary scores ratings, ICC point estimates ranged from 0.57 to 0.63 for inside participation and 0.93 to 0.94 for outside participation, while mean importance scores were 0.33 for inside participation and 0.48 for outside participation. For a subsample of children 8 to 17 years of age, reliability of inside and outside participation mean summary scores increased to ICC_(2,1)≥0.80 for mean satisfaction and mean [importance x satisfaction] estimates, while mean importance estimates increased but remained ICC_(2,1)<0.62 for inside and outside participation.

4.3.2 Validity

4.3.2.1 Appropriateness of Tools for Children Benefiting from Power Mobility

Table 4.2 provides descriptive information including the three tools' select summary scores' mean, CI₉₅, SD, number of items associated with each summary score and number of respondents for both sessions. Appendices S and T present additional information describing PEM-CY¹⁷⁸ and CAPE¹⁶⁶ results respectively, providing further evidence of score distributions, items' inter-relatedness and subscale associations within each of the three participation tools.¹¹¹ Table 4.3 and Appendix U(i,ii) list the WhOM-YP inside and outside participation outcomes that children identified along with the associated ICF^{33,34} domains and categories. Participants identified 67 inside participation outcomes compared to 116 outside participation outcomes, covering ICF^{33,34} Chapters 6 through 9.

4.3.2.2 Degree of Association Among the Three Participation Tools

As evidence of the degree of association between two variables, Table 4.4 presents correlation coefficient estimates between select summary scores of the three tools. Spearman's rank correlation coefficients were used because data were primarily ordinal in nature, and not normally distributed.^{110,112} Statistically significant correlation coefficient estimates were as follows:

- PEM-CY¹⁷⁸ frequency percent possible community participation and CAPE¹⁶⁶ overall diversity scores: $r_s=0.55$ ($p<0.001$).
- PEM-CY¹⁷⁸ frequency percent possible community participation and CAPE¹⁶⁶ overall intensity scores: $r_s=0.61$ ($p<0.001$).

- CAPE¹⁶⁶ overall enjoyment and WhOM-YP child outside participation mean [importance x satisfaction] scores: $r_s=0.35$ ($p=0.05$)
- WhOM-YP child vs. parent mean [importance x satisfaction] summary scores: $r_s=0.75$ ($p=0.01$) for inside participation and $r_s=0.79$ ($p<0.001$) for outside participation.

Hypothesized associations that were not statistically significant included:

- PEM-CY¹⁷⁸ home participation frequency percent possible and CAPE¹⁶⁶ overall diversity and intensity scores.
- PEM-CY¹⁷⁸ home participation frequency percent possible and WhOM-YP parent mean inside participation [importance x satisfaction] scores.
- PEM-CY¹⁷⁸ school participation and community participation frequency percent possible and WhOM-YP parent mean outside participation [importance x satisfaction] scores.
- PEM-CY¹⁷⁸ average home and community participation involvement and CAPE¹⁶⁶ enjoyment scores.
- CAPE¹⁶⁶ overall enjoyment and WhOM-YP child inside participation mean [importance x satisfaction] scores.

4.3.2.3 Differences Between Groups on Selected Variables

Table 4.5 summarizes differences in distribution of summary scores for two different groups.

The first two analyses compared children 12 years and older to children under 12 years of age.

As hypothesized, a statistically significant difference between the two age groups on the

distribution of their CAPE¹⁶⁶ overall intensity scores but not on their PEM-CY¹⁷⁸ school

participation frequency percent possible summary scores was demonstrated. The final two

analyses compared children who were new to PM to those experienced with PM. No significant difference was observed between these two groups on the distribution of their PEM-CY¹⁷⁸ community participation frequency percent possible summary scores, however a statistically significant difference was noted on their WhOM-YP outside mean [importance x satisfaction] summary scores.

4.3.2.4 Preliminary Investigation into the Tools' Usefulness to Detect Change

Table 4.2 provides the standard error of measurement (SEM) and Minimal Detectable Difference (MDD₉₅) values for select PEM-CY¹⁷⁸ and WhOM-YP summary scores. PEM-CY¹⁷⁸ MDD₉₅ values for frequency % possible ranged from 22.5 to 30.4, and % change desired ranged from 35.1 to 59.2. Average frequency MDD₉₅ values were 1.4 for community participation but not statistically significant for the other two scores. Similarly, average involvement MDD₉₅ values were 1.0 for home, 1.3 for community and not statistically significant for school participation. As for the WhOM-YP, MDD₉₅ values for inside participation mean satisfaction ranged from 3.2 for parents to 4.8 for children, and outside participation mean satisfaction scores ranged from 1.8 for parents to 2.5 for children. WhOM-YP MDD₉₅ values for inside participation mean [importance x satisfaction] summary scores ranged from 26.6 for parents to 46.5 for children, while outside participation mean [importance x satisfaction] summary scores ranged from 17.2 for parents to 20.2 for children. These MDD₉₅ values reflect the estimated threshold of measurement error for each of the selected summary scores, in other words the minimum score required to indicate that a change has taken place (beyond random error, 95% of the time).^{110, 112}

4.4 Discussion

This study explored measurement properties of three selected participation tools with a sample of 32 children needing PM, ranging from 5 to 17 years of age, and their parents. Reliability and validity estimates were sought to evaluate measurement properties of the PEM-CY¹⁷⁸ (our primary measurement tool, a recently developed parent report endorsed by a panel of parents, therapists and researchers in Chapter 3) along with the CAPE¹⁶⁶ (an established child report of out-of-school leisure participation) and the WhOM-YP (an evaluation of individualized client-specified outcomes developed for those using wheeled mobility devices, recently adapted for a paediatric population). Our sample included children across the desired age range who demonstrated a variety of gross motor, fine motor, postural control, cognitive and wheelchair driving abilities, similar to other studies examining paediatric PM^{9-11, 80} and typical of clients seen in our clinical practice.

4.4.1 Reliability Evidence

4.4.1.1 Evidence of Internal Consistency

Six of the nine PEM-CY¹⁷⁸ summary scores' Cronbach's alpha coefficients supported our hypothesis of $\alpha > 0.60$, with two $0.70 \geq \alpha < 0.80$ and three $\alpha \geq 0.80$. As a guide to interpreting Cronbach's coefficient alpha, Nunnally and Bernstein^{112, 302} recommended Cronbach's alpha coefficients between 0.70 and 0.90, however caution has been suggested adhering strictly to this guideline.^{111, 312} Cronbach alpha's values higher than 0.90 have been suggested to indicate item redundancy and values lower than 0.70 have been suggested to indicate some items may be measuring different constructs.^{110, 112} However, other considerations must be taken into account

when thinking about what values are appropriate, including the number of items in each scale, the type of construct being evaluated, and the sample's characteristics.^{111, 312} Other measurement studies examining internal consistency using the PEM-CY¹⁷⁸ and CAPE¹⁶⁶ have reported Cronbach's alpha coefficients lower than 0.7.^{166, 178, 301} Our PEM-CY¹⁷⁸ internal consistency findings were similar to the developers' range of 0.59 to 0.83.¹⁷⁸ They too found school participation to have the lowest Cronbach's alpha values;¹⁷⁸ not unexpected, given only 5 school items compared to 10 items for the other two settings. As for the CAPE¹⁶⁶ results, all five overall summary scores' Cronbach's alpha coefficients supported our hypothesis of $\alpha > 0.6$, all with $\alpha \geq 0.80$.¹⁶⁶ Our results were in line with others' findings for internal consistency of the various CAPE¹⁶⁶ summary scores.^{166, 186, 301}

Some researchers have distinguished between development and composition of scales, which include correlated items measuring an underlying unidimensional construct, compared to indexes, which include unrelated items that together provide important information about a state of being (e.g. the Apgar scale for newborns).³¹³ Given the suggested multi-dimensional nature of participation in everyday life situations,^{2, 3, 13, 35} and that several researchers have acknowledged an intentional decision not to use these unidimensional analytical methods when developing their measurement tools,^{183, 200} perhaps the 'standard' of measuring the tool's internal consistency (Cronbach's alpha; based on the assumption that it measures an unidimensional latent trait)^{124,}¹²⁵ is not appropriate for measuring a construct such as participation in everyday life. This perspective is one discussed in the literature.^{128, 166, 200, 234}

4.4.1.2 Evidence of Test Retest Reliability

Evidence of test-retest reliability for the PEM-CY¹⁷⁸ was more variable with four of 12 PEM-CY¹⁷⁸ summary scores supporting our hypothesis that test-retest reliability coefficient estimates ($ICC_{2,1}) \geq 0.70$. Of note are the wide 95% confidence intervals for these point estimates, suggesting that caution is needed as the true value for the population may be lower. Four of six WhOM-YP test-retest reliability coefficient estimates across parent-rated mean summary scores and two for child-rated mean summary scores (aged 5 to 17 years) supported our hypothesis, while four were supported for a subgroup of those aged 8 to 17 years. Confidence intervals (CI_{95}) for outside participation were much smaller than for inside participation. Similar to interpretations of internal consistency values, differing views exist for test-retest reliability coefficients' score interpretations.^{110, 112} Some suggest ICCs in the range of 0.40 to 0.74 represent moderate to good reliability while those above 0.75 may be considered good to excellent.¹¹⁰ The McMaster Outcome Measures Rating Form (OMRF),¹²⁵ used in Chapter 2 to evaluate measurement properties of participation tools identified in our systematic review, classified reliability coefficients as excellent if greater than 0.80, adequate if 0.60 to 0.79, and poor if the coefficient was less than 0.60. Adopting OMRF¹²⁵ guidelines for our findings in this chapter, PEM-CY¹⁷⁸ frequency percent possible and percent desired change summary scores were adequate, while average frequency and involvement summary scores were poor. This was surprising given the relatively short time between sessions, however it may reflect the variability in daily life situations often reported by children and their families in our clinical practice. Our results were for the most part lower than the developers' findings,¹⁷⁸ and suggest that caution may be needed when parents rate children's frequency and involvement in participation. Test-retest reliability may be influenced by parents' time-sensitive opinions regarding their children's

participation.¹¹²

In contrast, our test-retest reliability results for WhOM-YP parent mean satisfaction and mean [importance-x-satisfaction] summary scores were in the excellent range, and were similar or higher than those reported in the adult literature.²⁷⁰⁻²⁷³ Of interest is the children's mean satisfaction and mean [importance-x-satisfaction] summary scores, which ranged from poor (for inside participation) to excellent (for outside participation) for children aged 5 to 17 years, but were excellent for both inside and outside participation mean satisfaction and mean [importance-x-satisfaction] summary scores for children 8 years of age and older. Our results are consistent with findings reported by other researchers who suggest children 8 years and older are more reliable responders.^{172, 231, 241} Children as young as 5 years may demonstrate consistency over time in their outside participation responses, but the same cannot be said about inside participation responses at this time (perhaps because some children did not have the opportunity to use PM inside their homes and some used PM only at school-discussed further in Chapter 5). Test-retest reliability point estimates of the WhOM-YP mean importance scores for both parents and children were poor and 50% included an $ICC_{(2,1)}=0$ in the CI_{95} (suggesting that the true reliability may be much lower). This finding supports the developers' recommendation to use satisfaction and/or weighted [importance-x-satisfaction] summary scores for comparisons.^{272, 273}

Considering our test-retest reliability estimates in relation to Nunnally and Berstein's³⁰² recommendation that tools should have a minimum reliability coefficient of 0.70 when used for research and be at least 0.90 when used with individuals in a clinical situation, none of the PEM-CY¹⁷⁸ summary scores met the higher recommendation. Recognizing that scores averaged across

a group of people have less chance of measurement error than with only one person,^{110, 112} our recommendation is that the PEM-CY¹⁷⁸ should be used for group evaluation only at this time. PEM-CY¹⁷⁸ frequency percent possible for home participation, and percent desired change for all three settings may be most appropriate based on our evidence but caution should be exercised if selecting other summary scores. As for the WhOM-YP, outside participation mean satisfaction and mean [importance-x-satisfaction] summary scores may be useful in individual clinical applications for children and parents, while inside participation mean satisfaction and mean [importance-x-satisfaction] summary scores may be used for group evaluation for adults and children 8 to 17 years of age. Mean importance scores for all ages and inside participation mean satisfaction plus mean [importance-x-satisfaction] for children 5 to 7 years of age should be used cautiously.

4.4.2 Validity Evidence

The process of examining validity evidence included four strategies aimed at evaluating the tools' content and internal structures, relationships to other variables, and abilities to detect change.

4.4.2.1 Appropriateness of the Tools for Children Using Power Mobility

As Table 4.2 illustrates, most summary scores did not follow a normal distribution. Considerable variation in PEM-CY¹⁷⁸ summary scores existed across dimensions (frequency, involvement and desire for change) and settings (home, school and community), as might be expected. The PEM-CY¹⁷⁸ developers accounted for the possibility of not all scores being appropriate for all parents in their recommendations for using frequency % possible and % desired change summary scores.

^{178, 200, 314} Interestingly, when summary score means were compared to those published previously by the developers for children with disabilities and children who are typically developing, ¹⁷⁸ average frequencies for those benefiting from PM were considerably lower; however, our sample's frequency percent possible, average involvement and percentage change desired were comparable to the other groups. This pattern was similar for the CAPE's ¹⁶⁶ mean diversity and intensity summary scores. ^{166, 188} Along with considering the results of appendices S and T, this may suggest that children needing PM participate in a range of life situations, but not to the same frequency and diversity as children who are typically developing. Examining the PEM-CY's ¹⁷⁸ and CAPE's ¹⁶⁶ subscales and individual items suggest that those needing PM engaged more readily in certain life situations, whereas other items may be less relevant. Of particular interest are the PEM-CY ¹⁷⁸ items where more than 50% of parents desired change. The CAPE's ¹⁶⁶ 'with whom' and 'where' summary scores suggest children's participation for the most part, in our study, occurred more with family, and took place closer to home, although enjoyment was spread more evenly across CAPE subscales. The WhOM-YP participation outcomes listed in Table 4.3 and Appendix U represented life situations important to our participants. That the ICF ^{33, 34} domains and categories covered chapters associated with 'participation' (as defined by this dissertation) suggests that children using PM participate in a variety of life situations. Many, but not all outcomes, reflected the value placed on participating with family, friends or others, and lends support to the notion that social participation is one important aspect of participation in everyday life for children needing PM. ³¹⁵ Commonality of our participants' WhOM-YP participation outcomes was found. Despite some of these outcomes being similar to items on the PEM-CY ¹⁷⁸ and CAPE, ¹⁶⁶ the WhOM-YP quantified the importance and satisfaction children and parents placed on participating in those life situations.

Additionally, children identified unique outcomes not included in the PEM-CY¹⁷⁸ and CAPE,¹⁶⁶ for example joining a school remote control club and operating a remote controlled vehicle. Our results provide an initial snapshot of what participation in everyday life looks like for children using PM.

4.4.2.2 Degree of Association Among the Three Participation Tools

Correlation coefficients presented in Table 4.4 illustrate the degree of association among the three tools' select summary scores. One guide for interpreting correlations suggests 0 to 0.25 as a poor relationship, 0.25 to 0.50 a fair relationship, 0.5 to 0.75 a moderate to good relationship and above 0.75 as a good to excellent relationship (although authors emphasized interpretation needs to carefully consider data context).¹¹⁰ The following hypothesized associations were confirmed:

- PEM-CY¹⁷⁸ community participation frequency percent possible and CAPE¹⁶⁶ overall intensity and diversity scores were $0.3 \geq r \leq 0.8$.
- CAPE¹⁶⁶ overall enjoyment score and WhOM-YP child outside mean [importance x satisfaction] summary scores were $0.0 \geq r \leq 0.4$

Other hypothesized associations were not statistically significant (we did not expect these correlations to be very strong, if they were present). This correlational evidence supports the multi-dimensional nature of participation, with different summary scores measuring different elements of participation.^{2, 3, 13, 35, 66} Of particular interest were the different perspectives on children's participation that the different tools elicited depending on summary score selected.

Our findings support the idea that children and parents have differing, but related perspectives of children's participation in everyday life situations.^{35, 169, 241} This was evident in

the correlations between the PEM-CY¹⁷⁸ parent report and CAPE¹⁶⁶ child report summary scores, as well as the WhOM-YP's child and parent mean [importance x satisfaction] summary scores (for those children who had both child and parent scores collected on the WhOM-YP). Given the importance of child and family-centred approaches,^{13, 29} tools that seek out children's and parents' views of children's participation are valuable additions to therapists' measurement toolboxes.^{12, 232} Although best for children to provide their own perspective^{35, 121, 231} regarding their participation, our findings suggest that parents may act as proxies for younger children or for those who are unable to self-report because of communication, cognitive, sensory or motor challenges.^{65, 172, 262} Of interest, all of the children in our study were able to identify and rate participation outcomes despite their challenges.

Although one may have expected higher correlations between certain summary scores (especially between PEM-CY¹⁷⁸ and CAPE¹⁶⁶ since they both asked about children's participation over the last four months), the resulting lower correlations between summary scores may be explained by how each of the tools framed children's participation in everyday life. PEM-CY¹⁷⁸ items included groups of related life situations in which children may engage across home, school and community settings,¹⁷⁸ whereas CAPE¹⁶⁶ items asked about discrete activities limited to out-of-school leisure pursuits.¹⁶⁶ The WhOM-YP, on the other hand, was open-ended and identified participation outcomes of importance to participants.

4.4.2.3 Differences Between Groups on Selected Variables

Validity evidence based on relations to other variables under investigation was mixed with two of our four hypotheses supported, suggesting preliminary validity evidence for use of the CAPE

¹⁶⁶ and WhOM-YP with children using PM. Our findings supported hypothesized differences based on participants' age for the CAPE ¹⁶⁶ overall intensity summary scores, but not PEM-CY¹⁷⁸ frequency % possible for school participation. Children younger than 12 years of age participated more frequently than those 12 years and older, a pattern found in other studies. ^{42, 50, 52, 53, 61} Our hypothesized difference between PEM-CY¹⁷⁸ community participation frequency percent possible summary scores based on PM experience was not supported. We limited our comparison to community participation, thinking that the community setting would be most restrictive for those with mobility limitations. ^{9-11, 80} Environmental factors such as seasonality and weather as well as access to wheelchair accessible transportation may have influenced our findings. ^{316, 317} Given our results, the impact of environmental factors and the discriminative potential of the PEM-CY ¹⁷⁸ with our population require further examination (with larger samples to answer this more definitively).

Our hypothesis was supported for the WhOM-YP's outside mean [importance x satisfaction] summary scores being distinct for two levels of PM experience. These findings are among the first to demonstrate participation differences based on power wheelchair experience in a paediatric sample. To the best of our knowledge, only one other paediatric study explored participation differences based on wheelchair use, and that was between manual and power wheelchair users, ¹ not between power wheelchair users with different levels of driving experience. This suggests the WhOM-YP may have potential to be a discriminative tool for those needing PM, although this again would need to be further investigated with larger samples.

4.4.2.4 Preliminary Investigation into the Tools' Usefulness to Detect Change

This study provided an initial examination of the tools' responsiveness using a distribution-based approach to evaluate change in participation for children needing PM.^{110, 112, 117, 118} MDD₉₅ values are dependent on the measurement scale used in each summary score, and signal the minimum value required beyond random measurement error, if one were to use the selected summary score to measure change over time.^{117, 118} Considerable variation existed in the range of MDD₉₅ values for PEM-CY¹⁷⁸ and WhOM-YP summary scores, indicating that in some cases quite large values would be necessary before one could be confident that change was occurring beyond measurement error. This evidence, although useful, is not unexpected because of our relatively small sample size and varied sample characteristics and may be an underestimate of the true measurement error.^{110, 112, 124} To our knowledge, this is the first study to provide SEM and MDD values for the PEM-CY¹⁷⁸ and the WhOM-YP.

Calculating the MDD₉₅ in a group of individuals expected to be stable in the characteristic being examined is only one approach to examining a measurement tool's ability to detect change.^{117, 118} Other researchers have chosen more discriminative definitions of responsiveness, extending the definition to detecting *important* changes (some refer to this as the minimal clinically important difference), where importance is defined and determined by a variety of methods.^{115, 117, 118, 318} These approaches may include longitudinal intervention study designs, designs that incorporate two or more groups, or studies that use an external criterion as an indicator of meaningful change (often referred to as anchor-based approaches).^{115, 117, 118, 318} Further research is needed to provide responsiveness evidence supporting these participation tools' use when investigating participation changes with provision of PM interventions.^{110, 112, 117}

4.4.3 Limitations

Participants were sampled by convenience and may not be representative of the overall population, limiting generalizability of our findings. Our results should be viewed cautiously because (i) sample size was relatively small in comparison to other studies investigating measurement properties, (ii) measurement error due to variability within participants was a consideration, (iii) numerous summary scores existed for each participation tool and (iv) multiple analyses were conducted. Although some summary score precision estimates were adequate, some 95% confidence intervals were quite large, again suggesting careful consideration when interpreting scores. Other factors not accounted for in the analyses may have biased the results. Engaging in research sessions within the desired two-week timeframe was a consideration for many families as they had significant demands placed on their time, dealing with their children's needs along with other family commitments. Flexibility when scheduling appointments at times and locations of families' convenience helped address this issue, but demands might have influenced participants' ability to respond completely to all posed questions. We assumed that participation in children's everyday life would be stable over the two-week test-retest period, similar to other studies examining test-retest reliability of other paediatric participation tools;^{93, 171, 178, 183} however, given contextual factors which may have affected participants' degree of cooperation, fatigue, and distraction, this timeframe may not have been ideal. Given our small sample size, we were limited in our ability to conduct more in-depth analyses between subgroups of participants. Other relationships between collected variables may be addressed in future by having a larger sample.

4.5 Conclusion

This chapter provided preliminary investigations into the measurement properties of three paediatric participation tools (PEM-CY,¹⁷⁸ CAPE¹⁶⁶ and WhOM-YP) when used with children needing PM. Although some findings supported our hypotheses, other summary scores did not demonstrate adequate measurement properties in our study, possibly influenced by our small, yet diverse sample. Therefore, future studies with larger samples are recommended to confirm our findings.

When selecting a measurement tool, the desired purpose and context for participation measurement must be taken into consideration, along with the reliability and validity evidence surrounding specific summary scores. Our findings suggest that the PEM-CY¹⁷⁸ should be used to evaluate groups of children for research purposes at this time, although the WhOM-YP may be useful in clinical situations when completed by parents. Children as young as 5 years of age may provide reliable information on the WhOM-YP outside participation mean satisfaction and mean [importance x satisfaction] summary scores but similar ratings for inside participation outcomes would be more consistent with children 8 years and older. Finally, CAPE¹⁶⁶ reliability and validity evidence is promising, but would be enhanced with future examination of test-retest reliability with children needing PM.

This is the first study to examine reliability and validity evidence in regards to using the PEM-CY,¹⁷⁸ CAPE¹⁶⁶ and WhOM-YP with children benefiting from PM. Our findings also describe the diverse life situations in which children using PM engage, covering a broad range of

participation outcomes and dimensions and highlighting the complex nature of measuring participation in everyday life, along with developmental differences. The next chapter examines the feasibility of conducting research with this population in more depth and further investigates responsiveness when evaluating change in participation after provision of a PM device.

Figure 4.1 Feasibility Study Design

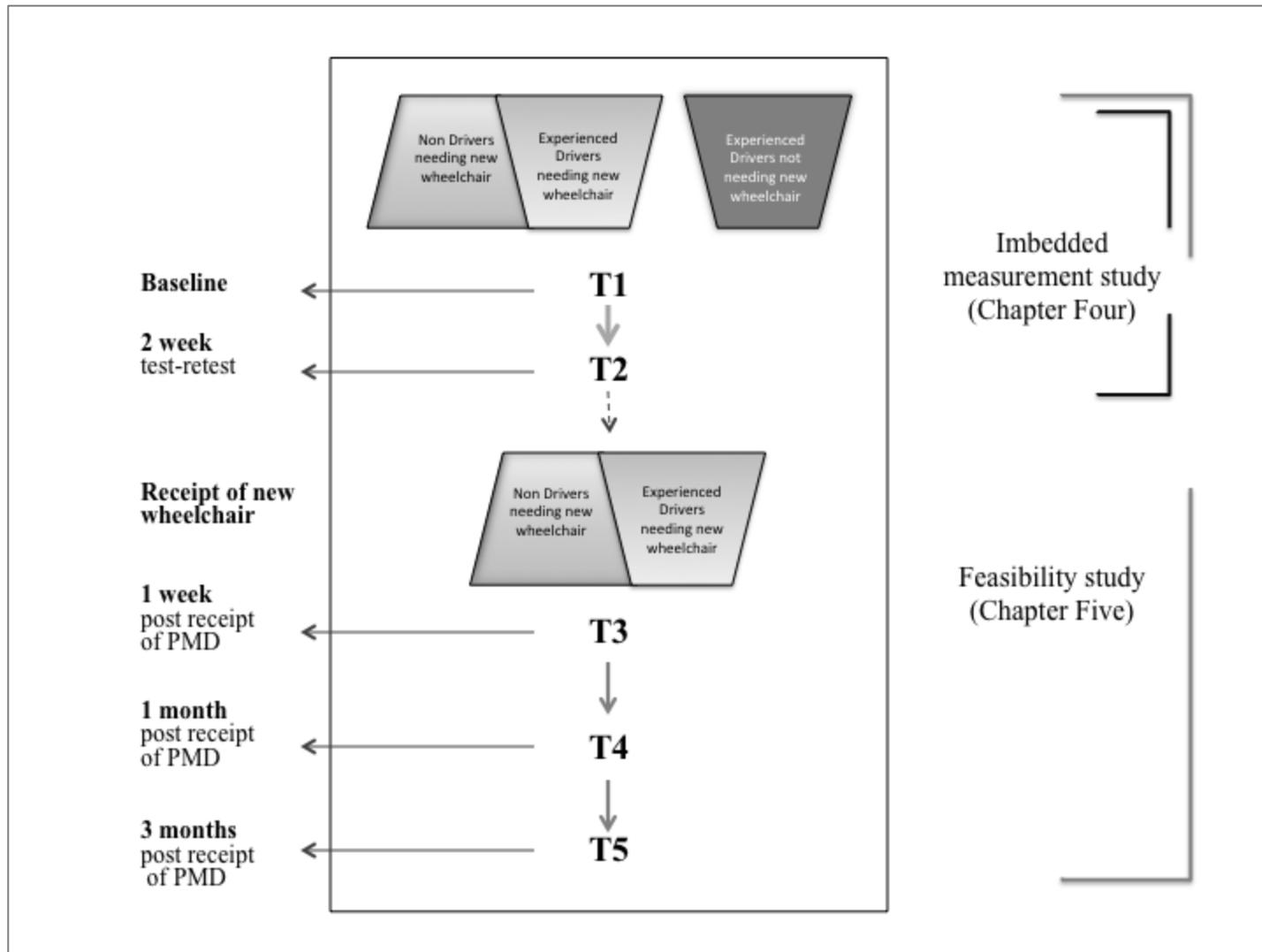


Table 4.1 Participant Characteristics

	Frequency Count n=32		Frequency Count n=32
Parent age		Child age	
19 to 29 years	2	5 to 11 years	15
30 to 39 years	10	12 to 17 years	17
40 to 49 years	15		
50 to 59 years	5	Child education	
Parent education		not yet in school	2
Attended secondary school	1	homeschooled (no grade)	1
Secondary school graduate	5	kindergarten to grade 3	9
College or Trades graduate	13	grade 4 to 7	7
University graduate	13	grade 9 to 12	13
Parent sex		Child sex	
female	25	female	13
male	7	male	19
Parent relationship		MMSE^{295, 296} total score	
mother	22	33 to 37	25
father	6	27 to 32	7
other (guardian, nurse, grandmother, foster parent)	4	<27	0
Child primary diagnosis (reported by parent)		Driving Status (indicated by ALP⁷⁹ score)	
cerebral palsy	15	No driving experience	10
Duchenne muscular dystrophy	7	Competent driver (score of 6)	6
other genetic syndromes	4	Proficient driver (score of 7)	7
spinal cord injury	2	Expert driver (score of 8)	9
other muscular dystrophies	2	Years of Driving Experience	
spinal muscular atrophy	1	No driving experience	10
acquired brain injury	1	1 to 5 years	14
Child GMFSC score		6 to 10 years	3
Level I	0	11 to 15 years	4
Level II	4	unknown	1
Level III	6	Child LSS score	
Level IV	11	Level 1 unsupported by 1	1
Level V	11	Level 2 support from head	2
Child MACS score		Level 3 support from trunk	7
Level I	5	Level 4 support from pelvis	4
Level II	8	Level 5 sits without moving	1
Level III	12	Level 6 leans forwards	7
Level IV	3	Level 7 leans sideways	3
Level V	4	Level 8- leans backwards	7

Legend: n = sample size; MMSE= Modified Mini Mental Status Exam;^{36, 37} ALP= Assessment of Learning Powered Mobility Use;⁷⁹ GMFSC = Gross Motor Classification System;^{276, 278} LSS = Level of Sitting Scale;²⁹¹ MACS = Manual Ability Classification Scale.²⁸³

Table 4.2 Summary of Measurement Properties for Three Participation Tools

Measurement Tool and Dimensions	Time 1 Sample Size (n) Mean (SD) [95% CI of Mean]	Time 2 Sample Size (n) Mean (SD) [95% CI of Mean]	Internal Consistency * Sample Size (n) Cronbach's alpha	Test Retest ** Reliability Sample Size (n) ICC _{2,1} [95% CI]	Standard Error of Measurement (SEM)	Minimal Detectable Difference (MDD₉₅)
Participation and Environment Measure for Children and Youth (PEM-CY)¹⁷⁸ (parent report)						
Home Participation (10 items)						
Average frequency	n=31 6.0 (0.7) [5.7, 6.2]	n=28 6.0 (0.5) [5.8, 6.1]	n=27 frequency 0.58	n=27 0.29 (NS) [-0.10, 0.60]	NS	NS
Frequency percent possible	n=31 83.2 (16.0) [77.4, 89.1]	n=28 87.5 (13.5) [82.3, 92.7]		n=27 0.74 [0.51, 0.87]	8.1	22.5
Average involvement	n=31 4.0 (0.5) [3.8, 4.2]	n=28 4.0 (0.6) [3.74, 4.22]	n=12 involvement 0.79	n=27 0.47 [0.11, 0.72]	0.4	1.0
Percent change desired	n=30 48.8 (28.4) [38.2, 59.4]	n=28 39.8 (31.4) [27.6, 60.0]	n=20 change desired 0.86	n=26 0.80 [0.59, 0.90]	12.7	35.1
School Participation (5 items)						
Average frequency	n=30 4.7 (1.2) [4.2, 5.2]	n=27 4.7 (1.1) [4.3, 5.2]	n=25 frequency 0.37	n=25 0.16 (NS) [-0.26, 0.53]	NS	NS
Frequency percent possible	n=30 64.7 (19.4) [57.4, 71.9]	n=27 65.2 (19.7) [57.4, 72.0]		n=25 0.68 (0.40 0.85)	11.0	30.4
Average involvement	n=30 3.9 (0.9) [3.6, 4.3]	n=27 3.8 (1.1) [3.4, 4.2]	n=5 involvement 0.79	n=25 0.34 (NS) [-0.04, 0.64]	NS	NS
Percent change desired	n=29 53.1 (39.8) [37.4, 68.8]	n=27 60.1 (41.3) [43.8, 76.5]	n=17 change desired 0.91	n=22 0.71 [0.43, 0.87]	21.4	59.2

Measurement Tool and Dimensions	Time 1 Sample Size (n) Mean (SD) [95% CI of Mean]	Time 2 Sample Size (n) Mean (SD) [95% CI of Mean]	Internal Consistency * Sample Size (n) Cronbach's alpha	Test Retest ** Reliability Sample Size (n) ICC _{2,1} [95% CI]	Standard Error of Measurement (SEM)	Minimal Detectable Difference (MDD₉₅)
Community Participation (10 items)						
Average frequency	n=31 3.8 (0.8) [3.5, 4.1]	n=28 3.7 (0.9) [3.3, 4.0]	n=27 frequency 0.69	n=27 0.60 [0.30, 0.80]	0.5	1.4
Frequency percent possible	n=31 58.7 (17.8) [52.2, 65.3]	n=28 63.9 (19.1) [56.5, 71.3]		n=27 0.64 [0.35, 0.82]	10.7	29.5
Average involvement	n=31 3.9 (0.7) [3.6, 4.2]	n=28 3.7 (0.9) [3.4, 4.0]	n=2 involvement 0.52	n=26 0.59 [0.28, 0.79]	0.5	1.3
Percent change desired	n=29 51.9 (33.8) [39.1, 64.8]	n=28 51.3 (38.0) [36.5, 66.0]	n=16 change desired 0.88	n=25 0.85 [0.69, 0.93]	13.1	36.1
Wheelchair Outcome Measure for Young People (WhOM-YP) (self-identified participation outcomes)						
Inside Participation						
Mean Importance	<i>5-17 yrs n=27</i> 8.6 (1.7) [7.9, 9.2] <i>8-17 yrs n=20</i> 8.4 (1.7) [7.6, 9.2] <i>Parents n=12</i> 8.7 (0.9) [8.1, 9.3]	<i>5-17 yrs n=24</i> 8.1 (1.9) [7.3, 8.9] <i>8-17 yrs n=18</i> 8.3 (1.7) [7.4, 9.1] <i>Parents n=10</i> 9.3 (1.4) [8.4, 10.3]	---	<i>5-17 yrs n=24</i> 0.33 [-0.07, 0.64] <i>8-17 yrs n=18</i> 0.61 [0.21, 0.84] <i>Parents n=10</i> 0.37 [-0.28, 0.79]	<i>5-17 yrs n=24</i> NS <i>8-17 yrs n=18</i> 1.0 <i>Parents n=10</i> NS	<i>5-17 yrs n=24</i> NS <i>8-17 yrs n=18</i> 2.9 <i>Parents n=10</i> NS
Mean Satisfaction	<i>5-17 yrs n=27</i> 7.3 (2.7) (6.2, 8.4) <i>8-17 yrs n=20</i> 6.9 (2.9) [5.4, 8.3]	<i>5-17 yrs n=24</i> 6.8 (3.2) [5.5, 8.2] <i>8-17 yrs n=18</i> 6.9 (2.9) [5.4, 8.3]	---	<i>5-17 yrs n=24</i> 0.57 [0.24, 0.79] <i>8-17 yrs n=18</i> 0.80 [0.55, 0.92] <i>Parents n=10</i> 0.85 [0.48, 0.96]	<i>5-17 yrs n=24</i> 1.8 <i>8-17 yrs n=18</i> 1.3 <i>Parents n=10</i> 1.2	<i>5-17 yrs n=24</i> 4.8 <i>8-17 yrs n=18</i> 3.5 <i>Parents n=10</i> 3.2

Measurement Tool and Dimensions	Time 1 Sample Size (n) Mean (SD) [95% CI of Mean]	Time 2 Sample Size (n) Mean (SD) [95% CI of Mean]	Internal Consistency * Sample Size (n) Cronbach's alpha	Test Retest ** Reliability Sample Size (n) ICC _{2,1} [95% CI]	Standard Error of Measurement (SEM)	Minimal Detectable Difference (MDD₉₅)
	<i>Parents n=12</i> 6.6 (3.0) [4.7, 8.5]	<i>Parents n=10</i> 7.5 (2.2) [5.9, 9.1]				
Mean Involvement x Satisfaction	<i>5-17 yrs n=27</i> 62.7 (27.7) [51.8, 73.7] <i>8-17 yrs n=20</i> 57.5 (29.2) [42.9, 72.0] <i>Parents n=12</i> 59.7 (29.0) [41.3, 78.1]	<i>5-17 yrs n=24</i> 57.8 (31.6) [44.4, 71.1] <i>8-17 yrs n=18</i> 57.5 (29.2) [42.9, 72.0] <i>Parents n=10</i> 67.5 (22.9) [51.1, 83.9]	---	<i>5-17 yrs n=24</i> 0.63 [0.33, 0.82] <i>8-17 yrs n=18</i> 0.85 [0.65, 0.94] <i>Parents n=10</i> 0.89 [0.61, 0.97]	<i>5-17 yrs n=24</i> 16.9 <i>8-17 yrs n=18</i> 10.3 <i>Parents n=10</i> 9.6	<i>5-17 yrs n=24</i> 46.5 <i>8-17 yrs n=18</i> 28.4 <i>Parents n=10</i> 26.6
Outside Participation						
Mean Importance	<i>5-17 yrs n=27</i> 8.7 (1.0) [8.3, 9.0] <i>8-17 yrs n=20</i> 8.5 (1.0) [8.1, 8.9] <i>Parents n=12</i> 9.5 (0.7) [9.1, 9.9]	<i>5-17 yrs n=24</i> 8.5 (1.6) [7.9, 9.1] <i>8-17 yrs n=18</i> 8.38 (1.6) [7.7, 9.1] <i>Parents n=10</i> 9.9 (0.2) [9.8, 10.0]	---	<i>5-17 yrs n=28</i> 0.48 [0.14, 0.72] <i>8-17 yrs n=22</i> 0.56 [0.19, 0.78] <i>Parents n=12</i> 0.12 [-0.28, 0.58]	<i>5-17 yrs n=24</i> 0.7 <i>8-17 yrs n=18</i> NS <i>Parents n=10</i> NS	<i>5-17 yrs n=24</i> 2.0 <i>8-17 yrs n=18</i> NS <i>Parents n=10</i> NS
Mean Satisfaction	<i>5-17 yrs n=32</i> 6.51 (3.16) [5.4, 7.7] <i>8-17 yrs n=25</i> 6.5 (3.0) [5.3, 7.7] <i>Parents n=14</i> 6.7 (2.9) [5.0, 8.3]	<i>5-17 yrs n=28</i> 6.4 (3.5) [5.1, 7.8] <i>8-17 yrs n=22</i> 6.3 (3.2) [4.9, 7.7] <i>Parents n=12</i> 7.1 (2.8) [5.3, 8.8]	---	<i>5-17 yrs n=28</i> 0.93 [0.85, 0.97] <i>8-17 yrs n=22</i> 0.91 [0.79, 0.96] <i>Parents n=12</i> 0.95 [0.84, 0.99]	<i>5-17 yrs n=28</i> 0.8 <i>8-17 yrs n=22</i> 0.9 <i>Parents n=12</i> 0.7	<i>5-17 yrs n=28</i> 2.3 <i>8-17 yrs n=22</i> 2.5 <i>Parents n=12</i> 1.8

Measurement Tool and Dimensions	Time 1 Sample Size (n) Mean (SD) [95% CI of Mean]	Time 2 Sample Size (n) Mean (SD) [95% CI of Mean]	Internal Consistency * Sample Size (n) Cronbach's alpha	Test Retest ** Reliability Sample Size (n) ICC _{2,1} [95% CI]	Standard Error of Measurement (SEM)	Minimal Detectable Difference (MDD ₉₅)
Mean Involvement x Satisfaction	<i>5-17 yrs n=32</i> 57.2 (29.8) [46.4, 67.9]	<i>5-17 yrs n=28</i> 57.6 (32.7) [45.0, 70.3]	---	<i>5-17 yrs n=28</i> 0.94 [0.88, 0.97]	<i>5-17 yrs n=28</i> 7.3	<i>5-17 yrs n=28</i> 20.2
	<i>8-17 yrs n=25</i> 55.6 (26.9) [44.5, 66.7]	<i>8-17 yrs n=22</i> 54.9 (28.6) [42.3, 67.6]		<i>8-17 yrs n=22</i> 0.92 [0.81, 0.97]	<i>8-17 yrs n=22</i> 6.4	<i>8-17 yrs n=22</i> 17.7
	<i>Parents n=14</i> 63.1 (27.8) [47.0, 79.1]	<i>Parents n=12</i> 67.2 (27.1) [50.0, 84.4]		<i>Parents n=12</i> 0.95 [0.85, 0.99]	<i>Parents n=12</i> 6.2	<i>Parents n=12</i> 17.2
Children's Assessment of Participation and Enjoyment (CAPE)¹⁶⁶ (child report)						
Overall Scores						
Diversity (55 items)	n=32 29.7 (9.8) [26.1, 33.2]	---	n=32 0.91 (54 items)	---	---	---
Intensity (55 items)	n=32 2.5 (1.0) [2.2, 2.9]	---	n=32 0.91	---	---	---
With Whom (55 items)	n=32 2.7 (0.4) [2.5, 2.8]	---	n=32 0.86	---	---	---
Where (55 items)	n=32 2.8 (0.51) [2.6, 3.0]	---	n=32 0.84	---	---	---
Enjoy (55 items)	n=32 4.0 (0.5) [3.8, 4.2]	---	n=32 0.92	---	---	---

Legend: CI = confidence interval; ICC = Intraclass correlation coefficient; SEM = standard error of measurement; MDD = minimal detectable difference; n = sample size; NA = not appropriate; NS = not statistically significant; yrs = years; # = number; * listwise deletion; ** pairwise deletion.

Table 4.3 Wheelchair Outcome Measure for Young People Participation Outcomes

Inside Participation Outcomes		Outside Participation Outcomes	
Domestic life	29	School education	46
Recreation and leisure	25	Community life	21
Interpersonal interactions and relationships	12	Recreation and leisure	18
School education	1	Interpersonal interactions and relationships	17
		Domestic life	13
		Religion and spirituality	1
Total	67	Total	116

Table 4.4 Correlations (Spearman’s Rho) Between Selected Participation Tool Summary Scores

Select Summary score	PEM-CY ¹⁷⁸ Home participation frequency % possible	PEM-CY ¹⁷⁸ School participation frequency% possible	PEM-CY ¹⁷⁸ Community participation frequency % possible	CAPE ¹⁶⁶ Overall Enjoyment	WhOM-YP Child Inside participation mean [import x sat]	WhOM-YP Child Outside participation mean [import x sat]
CAPE ¹⁶⁶ Overall Diversity	0.25 <i>p</i> =0.17 n=31		0.55*** <i>p</i> <0.001 n=31			
CAPE ¹⁶⁶ Overall Intensity	0.19 <i>p</i> =0.30 n=31		0.61*** <i>p</i> =0.001 n=31			
PEM-CY ¹⁷⁸ Home participation average involvement				-0.29 <i>p</i> =0.11 n=28		
PEM-CY ¹⁷⁸ Community participation average involvement				0.15 <i>p</i> =0.43 n=27		
WhOM-YP Child Inside participation mean [import x sat]				0.31 <i>p</i> =0.12 n=27		
WhOM-YP Child Outside participation mean [import x sat]				0.35* <i>p</i> =0.05 n=32		
WhOM-YP Parent Inside participation mean [import x sat]	0.34 <i>p</i> =0.30 n=11				0.75** <i>p</i> =0.01 n=12	
WhOM-YP Parent Outside participation mean [import x sat]		0.18 <i>p</i> =0.56 n=13	0.04 <i>p</i> =0.90 n=13			0.79*** <i>p</i> <0.001 n=14

Legend: PEM-CY = Participation and Environment Measure for Children and Youth;¹⁷⁸ CAPE = Children’s Assessment of Participation and Enjoyment;¹⁶⁶ [import x sat] = importance x satisfaction; n = sample size; WhOM-YP Wheelchair Outcome Measure for Young People; *p* = *p* value denoting statistical significance level; **p* ≤ 0.01; ***p* ≤ 0.05; ****p* ≤ 0.001.

Table 4.5 Comparisons Across Groups by Age Group and by Driving Experience

	T1 Mean (SD) [95% CI of mean]	T1 Median	Independent Samples Mann-Whitney U Test (difference in score distribution across groups using familywise error rate $\alpha=0.05$, & Bonferroni-adjusted $\alpha=0.0125$)
Comparison by Age Group			
Participation and Environment Measure for Children and Youth (PEM-CY) ¹⁷⁸ School Participation Frequency Percent Possible			
Children 11 years & under n=14	72.9 (16.8) [63.1, 82.6]	80.0	T1 $p=0.034$ (no difference across groups)
Children 12 years & older n=16	57.5 (19.2) [47.3, 67.7]	60.0	
Children's Assessment of Participation and Enjoyment (CAPE) ¹⁶⁶ Overall Intensity Score			
Children 11 years & under n=15	2.9 (0.7) [2.6, 3.3]	2.9	T1 $p=0.006$ (difference across groups)
Children 12 years & older n=17	2.2 (1.0) [1.7, 2.7]	1.8	
Comparison by Driving Experience			
Participation and Environment Measure for Children and Youth (PEM-CY) ¹⁷⁸ Community Participation Frequency Percent Possible			
Children new to PM n= 8	66.3 (14.1) [54.5, 78.0]	65.0	T1 $p=0.334$ (no difference across groups)
Children with PM experience n=19	57.9 (18.4) [49.0, 66.8]	60.0	
Wheelchair Outcome Measure for Young People (WhOM-YP) Outside Participation Mean Importance x Satisfaction			
Children new to PM n=10	31.4 (20.8) [16.5, 46.3]	32.9	T1 $p<0.001$ (difference across groups)
Children with PM experience n=22	68.9 (25.8) [57.5, 80.3]	74.2	

Legend: T1 = Time One; SD = standard deviation; CI = confidence interval; α = alpha level of statistical significance; n = sample size; $p = p$ value denoting statistical significance level; & = and; PM = power mobility.

Chapter 5: Determining Feasibility of Conducting Participation-Related Research with Children Using Power Mobility

5.1 Introduction

In Chapter 1, we reviewed studies that suggested PM interventions may improve children's participation in everyday life, but concluded little empirical information describing participation levels of those using PM, or demonstrating PM's impact on children's participation in meaningful life situations existed.^{9-11, 20, 80} There is a need to address this knowledge gap and investigate how children using PM participate in everyday life. Multi-site studies are often needed to obtain desired sample sizes to establish statistically and clinically meaningful results when investigating causal relationships in rehabilitation; however, these types of studies are often complex to develop and expensive to carry out.³¹⁹ Feasibility studies are often used to test the viability of the research design and process on a smaller but representative sample before going to the effort and expense of a larger, multi-site trial.^{132, 133} Although feasibility studies have a number of definitions and take several forms,^{132, 133} our feasibility study was guided by the definition 'a study designed to test the performance characteristics and capabilities of study designs, measures, procedures, recruitment criteria, and operational strategies under consideration for use in a subsequent, often larger, study.'¹³⁴ The previous chapter examined suitability of selected participation tools by estimating measurement properties when used with children needing PM.¹³² This chapter extends our evaluation to other feasibility concerns. As such, we followed the recommendation that feasibility studies have very clear objectives and measures in place to ensure examination of feasibility concerns such as recruitment, enrollment,

retention, resource and data management, measurement, and treatment effect.^{133, 134}

5.1.1 Purpose

This chapter's primary purpose was to examine feasibility related to process, resources, management and scientific indicators when conducting research with children using PM and their families.^{132, 133} Results of our feasibility study will inform planning of a larger, multi-site longitudinal study involving a team of researchers and knowledge users across Canada. Our secondary purposes were to describe changes in participation in everyday life situations for children using PM after provision of a new power wheelchair as a preliminary investigation of treatment effect, and to estimate responsiveness when using the three participation tools with this population. This preliminary investigation of responsiveness will guide selection of the three participation tools when measuring change in participation and may provide information for future sample size calculations.¹³⁴

5.2 Method

5.2.1 Research Design

This feasibility study involved an interrupted time series design^{110, 115} whereby the same quantitative measurement tools were administered 5 times over a 4-month period. This design (detailed in Figure 4.1 and Section 4.2) affords the opportunity to explore the most appropriate evaluation intervals when examining children's participation in everyday life post receipt of a new PM device and has the potential to evaluate change in participation scores over time.¹¹⁰ Such a design addresses practical and ethical challenges (such as blinding participants and

assessors to group assignment or withholding a therapeutic intervention) when random sampling is not viable.^{115, 268} End-of-study interviews during the final session with participants provided qualitative data using a phenomenological approach, contributing to the evaluation of study feasibility.

5.2.2 Participants

As described in Chapter 4 section 4.2.2, a convenience sample of parent-child dyads was recruited with children aged 5 to 17 years needing PM. To address issues related to treatment effect (evaluating change in participation with PM provision), analyses involved only participants in the ‘new PM’ group. You may recall those were children whose therapist recommended a new PM device, and included those who were new to PM along with experienced drivers. Sampling procedures, inclusion and exclusion criteria and sample size determination were detailed in Chapter 4 sections 4.2.2.

5.2.3 Study Protocol

For analyses related to change in participation with PM provision, the critical time points consisted of Time 1 (T1) through to T5 (see Figure 4.1). These time points enabled evaluation of change after participants received their new PM device (T3 -one week after; T4 -one month after; and T5 -three months after provision). T1 sessions were to occur within 4 to 6 weeks prior to receiving their new PM device (and no more than 8 weeks prior). As described earlier, those in the ‘stable PM’ group completed T1 and T2 to estimate test-retest reliability. Regular (at least monthly) communication between the study coordinator and principal investigator provided

project updates, problem-solved issues that arose, and maintained study quality. Regular contact by email or telephone was held as needed with other co-investigators.

5.2.3.1 Feasibility Indicators

To support our primary purpose, specific feasibility indicators,¹³³ described below, were identified, along with related questions we hoped to answer:

i. *Process indicators* of participant recruitment and consent

Are children who need PM and their families willing to engage in research requiring multiple sessions for data collection? and What recruitment strategies are successful?

ii. *Resource indicators* of recruitment effort, community access, burden on participants and assessors, retention, number and timing of measurement intervals

What is an appropriate number of evaluations and length of time in which to ask children and their families to engage?

iii. *Management indicators* of participant processing, protocol administration as well as equipment funding and performance

What considerations are needed when dealing with new PM devices?

iv. *Scientific indicators* of treatment effect and variance estimations, appropriateness of measurement intervals, suitability of measurement tools, treatment safety, data collection and analyses, and perceived benefit

Is there a difference in participation in everyday life between those new to PM versus those who have PM experience that necessitates considering them as separate groups?

And ‘What are the most appropriate evaluation intervals when examining participation outcomes after receiving a new power PM device?

Appendices V and W present documentation developed for this study used to record some of the feasibility data. Table 5.1 describes methods of evaluation for each feasibility indicator.¹³³

5.2.3.2 Clinical Outcomes

To support our secondary purposes, two of the three participation tools -- PEM-CY,¹⁷⁸ and WhOM-YP -- were administered at each session (T1 to T5), while the CAPE,¹⁶⁶ requiring a longer administration time, was administered only at T1 and T5. In addition, the Functional Mobility Scale (FMS),²⁸⁸ Level of Sitting Scale (LSS)²⁹¹ and Assessment of Learning Powered mobility use (ALP)⁷⁹ were administered at each session to document if change was occurring in walking ability, postural control or PM driving ability as possible explanatory factors. These measurement tools were described in Chapter 4 sections 4.2.3.

5.2.4 Data Analyses

Summary statistics (e.g., mean and 95% confidence intervals, standard deviation, median, minimum and maximum scores, skewness and kurtosis) described the sample, distribution of feasibility indicators and selected summary scores for each measurement tool. Data type and distribution determined specific measures of central tendency and dispersion as well as inferential statistics used for treatment-related considerations. Raw data were coded, entered into Excel²⁴⁴ spreadsheets, checked and imported to SPSS version 23²⁹⁹ for analyses. Pairwise deletion was used for missing data.

5.2.4.1 Feasibility Indicators

To address our primary purpose, specific analyses measured study process, resources, management, and scientific indicators detailed in Table 5.1 along with our *a priori* expectations for success for each indicator.¹³³ We hypothesized that the thresholds of acceptability set for each of these identified feasibility indicators would be sufficiently robust to support conducting a subsequent, larger multi-site prospective longitudinal study. The final recommendation was a dichotomous outcome based on how many indicators met *a priori* expectations. “Success” was indicated by the majority of expectations ($\geq 65\%$) being met and protocol sufficiently robust enough to move forward with a larger study with minimal adaptation, while “revise” indicated the majority of expectations were not met, and signaled a need for more substantive planning. The entire sample of 32 participants was used to analyze most feasibility indicators; however, a sub-sample of children receiving a new PM device was used for analyses of treatment indicators and outcomes related to participation change.

Some data related to process, resource and treatment indicators were collected during a semi-structured interview at study completion, using a semi-structured interview guide to direct questions (see Appendix X). Using a phenomenological approach, the interview explored participants’ experience with the new PM device as well as their experience participating in the study (child and/or parent depending on age and abilities of child). Use of qualitative methods in conjunction with clinical trial studies in rehabilitation has been recommended to support validity of quantitative outcome measures, identify contextual variables that mediate intervention outcomes, uncover unexpected findings and provide information regarding feasibility of conducting this type of research with children and their families.^{320, 321} Interviews were audio-

recorded and transcribed verbatim. Using Excel spreadsheets²⁴⁴ to document the process, we coded text in each interview that referred to power mobility use and its impact, as well as their experiences participating in this study. A directed content analysis approach was used where key concepts from existing evidence and study hypotheses informed development of the interview guide which formed the initial coding categories.³²² Individual first-order codes were combined into second-order themes common across participants and these were further analyzed using constant comparisons and combined to develop (third-order) overarching themes.

5.2.4.2 Clinical Outcomes

The PEM-CY¹⁷⁸ frequency percent (%) possible summary score was our primary clinical outcome of interest when estimating preliminary treatment effects of PM provision on participation in everyday life situations for children 5 to 17 years of age. Given this is a feasibility study, providing guidance when planning future studies, our main focus was not hypothesis testing,^{133, 134} but rather preliminary investigation of changes in home, school and community participation using PEM-CY¹⁷⁸ % frequency possible participation summary scores from T1 to T5 (i.e., measuring change over time from 1 month before to 3 months after receipt of their new PM device). We anticipated that change in community participation would be most prevalent as PM was reported anecdotally to have the greatest impact in this setting.^{9-11, 20, 80} We did not expect statistically significant differences in change scores between T1 and T2 (for stability of scores prior to PM intervention), nor between T1 and T3 evaluations (i.e., 1-week post wheelchair delivery would be too short a time to demonstrate change in participation), although we expected statistically significant change in participation might be seen between T1 and T4 (a two month period), and to a greater extent between T1 and T5 (a four month period).

We anticipated that change in participation would be greater for children new to PM compared to those with PM experience, but that all would experience positive change.

Treatment-related analyses included visual analysis of individuals' graphed summary scores and inferential statistics of group summary scores for participants receiving a new PM device. PEM-CY¹⁷⁸ frequency % possible summary scores, along with calculated change scores between time intervals, were compared across sessions. If parametric assumptions were met, a one-way repeated measures analysis of variance (ANOVA) was employed to determine if differences in participation occurred between sessions or, if not, the Friedman's test of repeated ANOVA using ranks was used, with *p*-level set at 0.05. Pairwise post-hoc analyses were carried out to identify where differences in central tendencies occurred, using Tukey pairwise comparison if parametric assumptions were met, or using Wilcoxon's related sample signed rank test if a non-parametric approach was taken. To address multiple computations for PEM-CY¹⁷⁸ home, school and community participation frequency % possible summary scores, a Bonferroni adjustment was calculated to protect against a Type I error (whereby a null hypothesis is rejected incorrectly, declaring an effect because of random error) using a family-wise error rate of 0.05/3 planned comparisons, giving a per comparison error rate of 0.017.^{110, 112} If sufficient sample distribution, post-treatment T5 PEM-CY¹⁷⁸ frequency % possible scores would be compared in two groups (those new to PM versus those experienced with PM) using analysis of covariance (ANCOVA) to control for T1 baseline scores as a covariate and to reduce error variance.^{110, 112}

Further exploratory investigations, to examine suitability of other participation tools' summary scores for future use in paediatric PM research, extended to (i) parent report of PEM-

CY¹⁷⁸ % change desired (of child's participation) in home, school and community summary scores; (ii) child self-report using the CAPE¹⁶⁶ overall diversity, intensity and enjoyment summary scores; and, (iii) WhOM-YP mean satisfaction summary scores for indoor and outdoor participation. Descriptive statistics were also explored for WhOM-YP mean [importance x satisfaction] scores, but we did not include these in this dissertation as they are closely aligned to mean satisfaction scores. Similar to the PEM-CY¹⁷⁸ frequency % possible summary scores, we expected support for positive effects of PM provision on these participation outcomes in everyday life for children.

We adopted the strategy of identifying a primary clinical outcome with secondary clinical outcomes viewed as exploratory investigations to diminish missing opportunities to contribute towards what measurement tools might be suitable for evaluating change.^{323, 324} This strategy addresses the situation whereby a potentially effective treatment might not be supported, because further adjustments to alpha (accommodating for multiple outcome measurements to minimize type I error) would increase chances of introducing type II error.^{323, 324}

Support for preliminary responsiveness^{117, 120} was sought by estimating the standardized response mean (SRM) using the formula $SRM = \text{mean}_{\text{post}} - \text{mean}_{\text{pre}} / SD_{\text{change}}$,^{110, 112, 117} referencing the validity framework suggested by the Standards for Educational and Psychological Testing.^{113, 116, 300} The SRM estimate employs a distribution-based approach to measure treatment effect of an intervention.^{110, 112, 117} We anticipated that our findings would support detection of $SRM \geq 0.2$ ^{112, 325} over a four-month period for each of the three participation tools' selected summary scores, thereby strengthening validity when using the tools

to evaluate change in participation with children needing PM.^{115-117, 119} This SRM = 0.2 value signals at least a small effect based on Cohen's conventional criteria whereby a SRM of 0.20 is considered a small effect, 0.50 a moderate effect and 0.80 a large effect.^{110, 119, 325}

5.3 Results

5.3.1 Participants

In Chapter 4 we described the entire sample of 32 participants who took part in our feasibility study, while Table 5.2 describes the subgroup of participants who received a new power wheelchair at their therapists' recommendation (n=14). The majority (n=10) had no previous experience with PM (except during PM assessment). The full 5-17 years age range was represented, with a mean age of 11.4 years (SD 4.2). Boys were slightly more prevalent than girls as were children with cerebral palsy compared to those with other diagnoses. As Table 5.2 illustrates, the children had a range of motor abilities as indicated by GMFCS,²²⁹ MACS²⁸³ and LSS²⁹¹ scores while all had MMSE scores reflective of adequate cognitive processing abilities.^{295, 296} All used wheeled mobility, although seven children could walk 5 meters and two could walk 500 meters. Five participants, across the age-span, had dysarthric or minimal speech, but used augmentative and alternate communication strategies (three used hand pointing while two used eye pointing and three also used a speech generating device). Most parents had post-secondary education, mothers being the majority, as were those between 30 and 49 years of age. As Chapter 4 described (and as part of the 14 in the 'new PM' group), one child passed away unexpectedly after the first session, and two did not complete T2 due to limited time prior to receiving their new wheelchair. Additionally, one did not complete T4 because of family issues,

and another did not complete T5 (in this last situation, there was no response to our communications to schedule a fifth appointment or to ascertain why they were unable to complete the study).

5.3.2 Feasibility Indicators

Table 5.1 summarizes results for each of our feasibility indicators and the following sections highlight findings further:

5.3.2.1 Process Indicators

Study recruitment was initiated in January 2014, with the first participant recruited in February 2014; sections 4.2 and 4.3 detailed recruitment and consent processes. Of the 41 potential participants who had communication with the study coordinator, 9 declined to participate after learning more about the study - a refusal rate of 22%. For 15 participants, even though a consulting therapist from one of the four sites had identified the child as a potential candidate, it was only after their community-based therapist became involved in the recruitment process that the family enrolled in the study. For one family, it was after a friend, who was also in the study, suggested they participate. Only one participant responded to a poster, while none of 32 potential candidates who were mailed an introduction package (without therapist introduction) responded, even after a reminder postcard was sent out. Four of the 32 enrolled were on the mail-out list, but they only took action after their therapist made direct contact. Online study information was a resource that many participants reportedly accessed once a personal connection was made. Recruitment finished in June 2015 with 32 participants enrolled, meeting our target. Process indicators met *a priori* expectations.

5.3.2.2 Resource Indicators

Recruitment of suitable participants required on-going effort, supporting therapists at the main sites, communicating with therapists in the community, and interacting directly with families and their school staff. Therapists at two of the sites became involved in recruitment immediately after initial ethics approval while those at a third site became active one month later. At the fourth site, facility and ethics approval took 1 1/2 years because of leadership changes, with only 5 months available for recruitment. Early on, it became obvious that recruitment efforts needed to extend to therapists working in child development centres and school districts around the province who had more frequent contact with potential participants and connections with school staff and administrators where many of the children used, or were planning to use, their power wheelchairs.

The study coordinator's communication frequency and methods in relation to recruitment (and scheduling of sessions) were influenced by differences in how receptive administrators, therapists, and supporting school personnel were to learning about the study, carrying out ethics approval processes within their institutions, identifying, sharing information packages and following up with potential candidates. In total, formal ethics reviews and approvals were obtained from the University of British Columbia (UBC), the four main sites (Sunny Hill Health Centre for Children (SHHC), British Columbia Children's Hospital (BCCH), Centre for Child Development (CCD) and Queen Alexandra Health Centre for Children's Health (QA)), one child development centre and two school districts. Other partners involved in recruitment were satisfied that ethics reviews had been conducted and approvals granted by the main sites. In total,

48 therapists across the province were contacted about the study (plus one nurse clinic coordinator), 42 responded and were involved in sharing information about the study with families, with 26 being from the four main sites. Four medical suppliers who serve children and families (at eight locations in BC including the Lower Mainland, Victoria, Nanaimo and Kelowna) were also involved in sharing information, either by posters or word of mouth, however none of the participants mentioned these as information sources.

The study coordinator met with therapists at each site to facilitate understanding of the study purpose and criteria for inclusion and exclusion. Presentations at staff meetings of three of four sites' were made to all occupational therapists (2 sites) and seating and mobility equipment team members (2 sites). Individual meetings were organized at a therapist's request to review study information, discuss generalities of who might be potential candidates, and work through issues related to school involvement. Meeting times (either in person or via telephone) ranged from approximately 10 minutes minimum for a one-time contact to a maximum time of 7.6 hours at one site, spread over 22 months. Email was preferred over telephone communication for all therapists and most families, although six families preferred smartphone texting. For therapists, the frequency of emails was dependent on the number of potential participants, the complexity of their situation, and how involved therapists were in the scheduling of sessions. Three potential participants had guardians that needed to be involved for consent and 14 of 32 needed sessions to take place at school as that was the primary location where power wheelchair driving took place or the family had no means of transporting the wheelchair home. One other participant did not have a vehicle for transporting the PM device in the community.

Recruitment processes varied with some therapists identifying potential participants then leaving it to the families and/or study coordinator to arrange further contacts, while other therapists were more involved. With most participants who had school-based sessions, community therapist involvement included communicating with necessary school personnel (i.e. principals and/or district administrators, resource teachers, educational assistants), and scheduling the first one or two appointments. However, one community therapist was involved in scheduling all five sessions, at the insistence of school personnel. When community-based therapists were more involved, it typically resulted in participant enrollment in the study. Sessions at school were either during the school day (n=9) or after school hours (n=14). Five participants had sessions both at school and at home, three required sessions at school to observe driving performance while their parents preferred to be interviewed at home, and two had sessions at home during summer months. Eleven families chose weekend sessions. Two families acknowledged timing and length of sessions were challenging after the school day, but stated it was better for them than doing sessions on the weekend. Most parents shared that flexibility in scheduling time and location for sessions were critical for their involvement. Although the study coordinator attempted to schedule sessions at similar times and locations to minimize measurement error, this was not always possible given families' and schools' availability.

Relating to community access and assessor burden, the mean travel time for the assessor to visit families (round-trip) for the 'new PM' group was 119.7 minutes/session (SD 57.5; CI₉₅ 105.2-134.2) with a mean distance of 85.7 kilometres/session (SD 56.5; CI₉₅ 71.4-99.9). The mean travel time (round-trip) for the 'stable PM' group was 120.7 minutes/session (SD 56.5; CI₉₅ 101.3-140.1) with a mean distance of 113.9 kilometres/session (SD 68.9; CI₉₅ 90.2-137.5).

Four trips were organized outside of the Lower Mainland to assess 'stable PM' group participants, with two involving a ferry trip to Vancouver Island and two involving a plane ride and car rental to the Okanagan region.

In regards to participant burden, most participants reported positive experiences related to study participation. Four teens and six parents verbalized they were glad to be "making a difference for others." Five others said they were happy to be helping with the coordinator's "school project". Most were pleased to receive an honorarium, with at least five stating the money was a motivator for study participation. At least three said having the time count for volunteer hours for school credit made it better (a certificate of participation was provided at the end of the study for each child, acknowledging total volunteered hours).

As for completion times, Appendix Y(i) documents session mean times for both groups. The average session was 81.3 minutes (SD 23.4; CI₉₅ 75.4-87.1) for the 'new PM' group and 85.6 minutes (SD 23.4; CI₉₅ 77.6-93.6) for the 'stable PM' group; typically the first and last sessions were a bit longer than the others. Sessions were completed in the expected time although two participants extended beyond 2 hours, each by 5 minutes for one session. These two sessions involved an extended break for personal care during each session. Our retention rate was 85% completing sessions to T5 for the new PM group and 94% completing T2 for the reliability sample. All *a priori* expectations for resource indicators were met.

5.3.2.3 Management Indicators

Table 5.1 summarizes the management indicators, while Appendix Y(ii,iii) details the participant processing intervals from initial contact to enrolment as well as between sessions. For one participant in the ‘new PM’ group, a significant delay between T2 and T3 was due to a mix up in funding and equipment processing (150 days compared to a mean of 31 days (SD 19.6 and range 8 to 60 days) for the others). As for deviations in protocol administration, one child (with an acquired brain injury) was unable to answer questions after the end of a full school day (because of fatigue) but was much more alert and engaged when the session was rescheduled to the weekend. On two occasions, the session was broken into two shorter times when weather limited driving observations. On four occasions (all occurring after the initial session), parents did not complete all questionnaires during the scheduled time due to family or school matters arising during the session. However, parents asked if they could take the questionnaire(s) and finish them later; all four were returned. Incomplete documentation without explanation was 8% overall.

In regards to equipment performance, one instance occurred where the electronics of the wheelchair tilting mechanism limited a participant’s ability to demonstrate driving during the session, but family reported it was fixed the next day by a wheelchair technician. All management indicator expectations were met. However, the majority of participants remarked on the need for seating and wheelchair modifications after initial PM delivery and the resulting impact on children’s participation in everyday life. Fifty-four percent required further changes to their seating system, 69% required electronic programming changes for safer and/or improved driving control and 23% required fine-tuning of joystick and/or switch positioning. Although on

the surface these problems appear peripheral to children's participation, participants commented on how disrupting these wheelchair performance issues were. As an example, one parent stated "we haven't really discussed seating but it is critical. Dealing with this pressure sore over the last week has really limited what he's doing, and has affected all of us we've had to change our routines." All but two participants had issues resolved by the final session (3 months after PM delivery).

5.3.2.4 Scientific Indicators

Treatment effect indicators are detailed in Section 5.3.3 Clinical Outcomes, below. Comments from participants were primarily positive regarding measurement intervals, however one family stated it was "one too many sessions" while another preferred more time between sessions.

As for acceptability of measurement tools, most comments were positive, although four parents commented that wording of PEM-CY¹⁷⁸ participation questions were fine, but the environment questions were not clearly worded or relevant, and were too repetitive across settings. Younger children and those with cognitive challenges were able to identify satisfaction ratings of their self-selected participation outcomes on the WhOM-YP prior to PM provision, but some found it challenging to rate satisfaction with an outcome they had not yet experienced once they had the new PM device. The CAPE¹⁶⁶ took about 30-45 minutes to complete all five subscales, as expected,¹⁸⁹ although those using augmentative communication strategies took longer, with several requiring two sessions for completion. Additionally, younger children and some with cognitive challenges needed parental assistance to answer intensity items. Several parents commented how informing it was to hear their child's perspective (when completing the CAPE¹⁶⁶ and the WhOM-YP).

As for safety, no adverse events occurred during data collection sessions, however on two occasions participants became somewhat anxious about their wheelchair's performance; one when the child drove over a deeper-than-expected muddy section of grass in the school playground (during a spring thaw) while the other drove up a hill with a hidden tree root at the top, causing an unexpected difference in traction between left and right wheels. In both cases, the assessor reassured the child and talked through the situation, facilitating a learning experience for the child and caregivers.

Perceived benefit was determined by directed content analyses of 13 semi-structured interviews conducted at the final session, as well as comments documented while completing the participation tools or in general conversation during the sessions. One theme was 'PM experience promotes growth, engagement, and quality of life'. One child stated "it's my gateway" then elaborated "without it I couldn't do anything." Another mother stated "she's getting to be more typical... and doing those sorts of things [that are] more age appropriate." Another theme was 'PM is good... but environmental challenges complicate daily life.' Environmental challenges included such things as the physical environment, transportation, equipment features, actions and attitudes of others, policies and procedures, and lack of suitable programs. One mother shared that the use of PM makes attending community events possible: "In the summer we headed to the PNE ...but crowds and those chairs can be a little nerve-racking... it's a big chair but people don't see it. The amount of people that almost bump into him amazes me ...so our awareness has to be extra high, which in a crowd is almost exhausting." Another mother stated: "Having more wheelchair friendly community programming. That's a

biggy!! There are no inclusive programs. Summer camps are a special challenge.” A final theme was ‘creative solutions can make a difference.’ Participants shared unique and creative solutions for improving their ability to participate while using PM such as adding cupholders so they can remain engaged in desired activities longer, using rear-view mirrors, and lights from the dollar store so they can extend their time out in the community while enhancing their comfort and safety, and making large, but light dice and replicating board games drawn in chalk on the driveway to promote play among family members.

5.3.3 Clinical Outcomes

5.3.3.1 Comparison of Individual Summary Scores

Figures 5.1(i-v) illustrate each child’s graphed summary scores. Of special note are the unique variations for each participant in all three participation tools’ score distributions across five sessions. For PEM-CY¹⁷⁸ frequency % possible scores, our primary clinical outcome, home participation remained constant for five participants, school participation remained constant for four, and community participation remained almost constant for two, with ceiling effects in home participation for five and school participation for one participant. CAPE¹⁶⁶ diversity scores changed more than 10 points from T1 to T5 for five participants (3 increasing and 2 decreasing) while the remaining six participants changed minimally. Intensity and enjoyment scores had considerably less magnitude of change, being scored out of 5 points. As for child-reported WhOM-YP scores, 9 participants increased inside participation mean satisfaction scores from T1 to T5, one participants decreased scores and two remained almost constant, while outside participation scores increased for 12 and remained almost constant for one. Seven parents reported WhOM-YP scores, because of an initial question about their child’s ability to complete

the WhOM-YP due to age or communication abilities. Five parents' inside participation mean satisfaction scores increased from T1 to T5 while five parents' outside participation scores increased and one decreased and one remained almost constant.

5.3.3.2 Comparison of Group Summary Scores

Table 5.3 summarizes descriptive statistics for the group across the participation tools' summary scores for each of the five sessions. First session results demonstrate little difference between summary scores including or excluding the child who passed away, for that reason remaining results will be presented as n=13. Additionally, PEM-CY¹⁷⁸ school participation scores had one less participant due to the parent stating questions were not relevant to their child's home-schooling. For PEM-CY¹⁷⁸ group mean frequency % possible scores, home participation was higher than school and community participation across all sessions. Interestingly, PEM-CY¹⁷⁸ school participation was higher than home and community participation for % change desired scores and CAPE¹⁶⁶ overall enjoyment scores were higher than overall intensity scores. As for WhOM-YP group mean satisfaction scores, both children and parent scores varied with inside participation scores being higher than outside participation scores for the first three sessions, then outside participation scores were higher than inside participation scores for the last two sessions.

Comparison of group mean summary scores over the five sessions are presented in Table 5.3. Our primary outcome, the PEM-CY¹⁷⁸ frequency % possible scores, did not demonstrate statistically significant differences over time. However, exploratory investigations found differences in other summary scores including PEM-CY¹⁷⁸ % change desired scores for home participation, child-rated WhOM-YP mean satisfaction scores for inside and outside participation

and parent-rated WhOM-YP mean satisfaction scores for outside participation. Although none of the CAPE¹⁶⁶ overall scores demonstrated differences over time, upon further exploration, the recreational activities subscale for intensity and enjoyment scores may have potential to demonstrate change for children using PM (however this needs to be further explored with a larger sample). To investigate changes across sessions further, Appendix Z summarizes descriptive statistics of group mean change scores along with comparison results. When comparing group mean change scores, only WhOM-YP child mean satisfaction scores for outside participation demonstrated a statistically significant difference over time.

5.3.3.3 Estimating Responsiveness

Table 5.3 presents SRM values, an estimate of change when change was occurring beyond measurement error.^{117, 119, 120} Results met our expected $SRM \geq 0.2$ for most PEM-CY,¹⁷⁸ CAPE¹⁶⁶ and WhOM-YP summary scores, with WhOM-YP SRM values being the highest. PEM-CY¹⁷⁸ community participation frequency % possible and school participation % change desired, as well as CAPE¹⁶⁶ overall diversity and intensity summary scores had $SRM < 0.2$.

5.4 Discussion

In Chapter 5 we sought to advance our understanding of how to measure participation in everyday life for children using PM. The findings of this feasibility study support our primary objective, which was to establish the feasibility of using an interrupted time series research design when investigating participation over time in children aged 5-17 who benefit from PM use. This was accomplished by examining process, resource, management and scientific

indicators defined *a priori* for two subgroups of participants. Most feasibility indicators referenced the total sample of 32 children, while the indicators relating to treatment effect included the 14 children who had a new PM device recommended by their therapist, along with their parents.

Our secondary objective examined the clinical outcome of participation change in everyday life over time after receipt of a PM device, by evaluating the ‘new PM’ group at one week, one month and three months after receipt of their PM device (for a total of five sessions). One participant passed away unexpectedly after the first session, leaving 13 children receiving new PM devices. Our findings suggest that select participation summary scores may demonstrate change over time after receiving a new PM device, as illustrated by visual analysis of individuals’ summary scores, differences between group mean summary scores over time and SRM values. Our findings also provide preliminary evidence of responsiveness when using select summary scores of the three participation tools to measure change in participation with our population, and may provide a foundation from which to calculate sample sizes for future studies. To help frame our discussion, we will address questions posed in the introduction worth exploring within the context of our feasibility study based on findings of our process, resources, management and scientific indicators.^{133, 134}

5.4.1 Process Indicators

Addressing issues of participant recruitment and consent, and answering our question ‘Are children who need PM and their families willing to engage in research requiring multiple sessions for data collection?’ our results suggest that engaging in multiple data gathering

sessions was acceptable to children aged 5 to 17 years and their families if effort was made to accommodate to their daily routines, availability and preferences for location of sessions. Our study measured participation across five time points over four months. Other studies involving multiple data collection sessions with children using PM have primarily been case reports collecting observational data related to PM device use,^{6, 71, 73-75, 89-91, 135} although some have used standardized developmental testing.^{70, 89-91} Previous group studies included two measurement sessions, (one pre and one post PM device delivery),^{7, 25} or three measurement sessions (either two pretest sessions and one post-test session,^{67, 86, 87} or one pretest session and two post-test sessions after receipt of a PM mobility device⁷⁰). Our study was the first study that we are aware of that employed more than three data collection sessions using standardized testing to explore change in participation outcomes after receipt of a PM device.

An interrupted time series research design, considered a quasi-experimental design because only one group is evaluated,^{110, 115} worked well for our purposes, given the relatively small number (in comparison to other paediatric populations) and the distinctness of children's abilities who use PM, as well as the cost and individualized nature of PM interventions addressing participants' needs.^{115, 268} In addition to helping account for variance in scores compared to a simple pretest-posttest design,^{110, 115} the interrupted time series design may alleviate challenges of finding a similarly-matched control group or the ethical dilemma imposed by withholding PM interventions when deemed therapeutically appropriate.^{255, 268} This ethical dilemma was acknowledged by Bottos and colleagues in their study of 25 children receiving a new PM device,⁶⁷ and was similarly dealt with in a randomized control trial (RCT) that explored impact of PM use on development and function.²⁵ In that study, matched controls were not found for 16

eligible children, leaving 34 to participate rather than 50.²⁵ Others researchers have promoted use of interrupted time series designs because their implementation aligns more closely with clinical practice and real-world conditions.^{110, 268}

More recently, a case example and small study (n=6) demonstrated feasibility of using an interrupted time series design when evaluating participation-related outcomes for youth with physical disabilities.^{268, 326} Although their multiple baseline design using three goals/participant and numerous data points collected twice weekly over 20 weeks strengthened their analysis and interpretation,^{110, 268, 326} the findings of our study suggest that implementing a more rigorous version of an interrupted time series design with more than five time points with children benefiting from PM might have its challenges (although it may be possible with a simple-to-use and quickly administered measurement tool).

To answer our question ‘What recruitment strategies are successful?’ findings suggest that multi-pronged recruitment strategies worked best.^{327, 328} Critically important was having study champion(s) within the organizations assisting with recruitment. Building on already-established personal relationships between our study team and therapists and administrators at recruitment sites, as well as among recruitment sites and therapists in various communities was also important for success. Connecting directly with community-based therapists who had regular contact (e.g. monthly as opposed to yearly) with children and their families facilitated recruitment and retention immensely. Additionally, if families indicated school as their preferred location to meet, their therapists’ knowledge of school personnel and practices (both at the district and individual school level) expedited permissions and organization of sessions. Families

often preferred to meet at school as PM training took advantage of school-day routines in an accessible environment especially when wheelchair accessible transportation was not readily available. Our study team did not anticipate the degree of involvement by some school-based therapists nor the amount of contact needed with school personnel. Although not expected, our study's success was in large part due to the willingness of therapists and school personnel to accommodate scheduling sessions during the school day if it was better for the student or family. For many children, school was where PM was of most benefit (as reflected in their WhOM-YP outside participation outcomes). Respect for school policies and schedules as well as flexibility when dealing with school personnel were extremely important.

Site visits along with regular communication helped ensure therapists kept study and eligibility criteria in mind; using only telephone or email was not as effective. This was reinforced by several therapists commenting that it was the study coordinator's physical presence that kept recruitment for the study in their consciousness. Also of value was adopting the process whereby therapists who had direct contact with participants asked parents if they were agreeable to sharing their contact information with the study coordinator for more detailed study information rather than leaving it to the families to initiate contact. Parents shared that this made it easier for them. Recruitment strategies that exclusively relied on posting study information in waiting areas on websites, e-newsletters, or conducting mail-outs of study information were not enough to entice people to contact the study coordinator on their own, although they served a purpose by increasing awareness of the study or provided a reference to information after initial therapist contact. Developing relationships and maintaining partnerships with therapists, families

and school personnel took time and effort but we believe this contributed significantly to our successful enrollment and retention.^{327, 328}

It is important to recognize that the population of children who benefit from PM may be considered a hard-to-reach population in comparison to other populations,^{35, 66, 328, 329} and this may be one reason explaining such limited research evidence. Making research accessible by offering sessions at times and locations of convenience for families was critical for their participation in the study.³²⁷⁻³²⁹ Also of importance was communicating an appreciation for their participation given that most had significantly-more-than-typical family demands on their time caring for their children and dealing with multiple service providers. Additionally, for many families, coping with their children's complex medical conditions, and/or other siblings in the family, required in-the-moment responses and unpredicted deviations from best-laid plans. Several families were single-parent families, which added another complexity to their situation. This necessitated considerable flexibility and sensitivity on the research team when communicating with families for recruitment, scheduling and carrying out sessions. Key elements of child and family-centred practices are also applicable when carrying out research with children using PM, and their families.²⁹

Several considerations are of particular importance when planning research with this population. The first consideration is the length of time experienced from initial PM assessment to equipment provision,^{11, 14, 330} impacting when to introduce the study to potential participants. A few potential participants expressed interest in the study when their therapist shared study information at time of equipment recommendation, however months later when the funding was

obtained they either were unable to be contacted, no longer interested or unavailable. In two other cases, families expressed an interest in the study but were still waiting (over 1 year later) for funding when study recruitment concluded. Our recommendation is to build relationships and initiate frequent communication with therapists and families to ensure timely introduction of recruitment information approximately one to two months prior to PM provision. The second consideration is that children using PM are a relatively small population with many health-related (and other life) needs, and as such several families were targeted by more than one study during our time with them, and it was a reason at least one family declined to enroll in our study. To be informed of potential (competing) research studies and collaborating with colleagues to develop recruitment plans that minimized demands on children and families is one recommendation arising from our experiences. A final recruitment recommendation is to recognize the value of, and devote time to, developing relationships especially with this population and the people who support them.³²⁷⁻³²⁹ Connecting with family-focused community groups, service providers and administrators, medical suppliers and manufacturers, funders and policy-makers even before a particular research idea becomes developed will promote an integrated knowledge exchange that better meets children's, families,' professionals' (and researchers') priorities (and facilitate recruitment).³³¹⁻³³³

5.4.2 Resource Indicators

Resource indicators of recruitment effort, community access were discussed in the previous section. As for indicators relating to participant burden, our findings although within acceptable limits, may be enhanced by further streamlining questions and format and by offering multiple ways of collecting data (particularly after the initial session). Options like using computer or

mobile phone-based communications and/or electronic formats rather than face-to-face sessions may be preferred, although not suggested by our families. Having the flexibility of sending questionnaires ahead of time, permitting completion of questionnaires outside of scheduled sessions, and providing postage-paid return-addressed envelopes for hard-copy returns, may extend families' willingness to participate in research while working around multiple demands on their time.³³⁴⁻³³⁶ Given the diversity of abilities within our sample, it was valuable having an assessor familiar and confident with using augmentative and alternative communication strategies, PM alternate access methods, and who was familiar with PM learning strategies. This clinical experience might have contributed to obtaining positive comments from participants about their participation in the study.^{337, 338} Consideration for future planning should include seeking out assessors with such experience.^{338, 339}

In answering our question 'What is an appropriate number of evaluations and length of time to ask children and their families to engage in research?' five data points over the study period were acceptable for most families. However, given the drop-out of one participant and the comment by another that it was 'one too many sessions,' four time points might be an option to consider for future studies. Based on our experience, 1-1½ hours was a reasonable length of time for one session, although flexibility for time and protocol administration is important when dealing with the needs and availabilities of children, families and school staff. A 2-hour maximum/session permits rest breaks and time to attend to other demands (e.g. toileting or feeding needs, accommodating other siblings or students) as needed.³³⁴⁻³³⁶

5.4.3 Management Indicators

Issues of participant processing, protocol administration as well as equipment funding and performance are tied intimately to our question ‘What considerations are needed when dealing with new PM devices?’ Several observations raise important issues to consider when involving children using PM in research. The complex issue of funding was discussed earlier in regards to recruitment and timing of study introductions. However its’ importance needs to be reiterated here related to scheduling of sessions. Government funding was sought and provided for many of the children who received a new PM device, however these programs usually offered support for medically essential equipment only, leaving families and therapists to search for other funding sources to cover the costs of features that made the device functional for the child’s and family’s circumstances. Staying in contact with the primary therapist regarding when the PM device was funded and to be delivered was critical for timing the first two sessions (needless-to-say, it was important to have parents’ consent before making this connection). Most families were agreeable to this arrangement, making the burden less on them to relay information about the new PM device to schedule the research sessions appropriately.

Additionally, most PM devices did not get funded or delivered as first planned, therefore expecting that, accommodating to changes, and staying connected with families and therapists is crucial for success. This is tricky though as situations change quickly, as we experienced with three of our participants. In two instances the PM device was delivered sooner than expected, making scheduling of sessions challenging in a different way (two did not have enough time prior to PM provision for T2). In the other instance, the participant experienced considerable delays between T2 and T3 (initially they were told the delay would take a few weeks but it was

in fact four months). Although in this case it would have been more rigorous to re-administer T2 questionnaires prior to receipt of the new PM device after such a delay, we did not because of the additional burden that would have been placed on the family, given that it was at the start of a new school year.

Fine-tuning seating and PM equipment challenges,^{141, 340} learning how to use the PM device^{77, 79} and then having opportunity to use PM in different settings,^{17, 28, 139, 141, 145} along with having wheelchair accessible transportation available^{17, 28, 92, 139} may have limited use of the new PM device and therefore children's participation in desired life situations. Although investigating the impact of these influences more systematically bears merit, it may also provide a rationale for altering the number of research sessions or extending the time intervals between sessions to measure PM's impact on participation in everyday life more comprehensively.

5.4.4 Scientific Indicators

Indicators related to treatment effect and variance estimations, appropriateness of measurement intervals, suitability of measurement tools, treatment safety, data collection and analyses, and perceived benefit will be discussed in order.

Our findings provide emerging evidence of change in participation in everyday life with provision of a PM device on select summary scores, as well as preliminary support for responsiveness when using select summary scores of the three tools to measure change in participation of children receiving a new PM device (for those summary scores that had a SRM over >0.2). We recognize however, that being a feasibility study with a small sample and

undertaking several different analyses, our results may have occurred by chance, and need to be confirmed with a larger sample.

In our exploratory investigations, findings suggest that participation differences across time using the WhOM-YP's child- and parent-reported mean satisfaction rating of the child's participation on self-selected, meaningful participation-related outcomes as well as the PEM-CY¹⁷⁸ home participation % change desired summary score may support PM use. Preliminary evidence supporting the three tools' responsiveness included the WhOM-YP mean outside participation satisfaction scores with our highest SRM values (1.54 for child-reported scores and 0.91 for parent-reported scores both considered a large effect (SRM ≥ 0.8) using Cohen's criteria).³²⁵ The PEM-CY¹⁷⁸ home participation frequency % possible and % change desired scores along with the PEM-CY¹⁷⁸ community participation % change desired scores were in the moderate effect range ($0.5 \geq \text{SRM} < 0.8$).³²⁵ Negative PEM-CY¹⁷⁸ % change desired SRM values reflected a decrease in desire for change, which we interpreted as a positive result. SRM values ($0.2 \geq \text{SRM} < 0.5$)³²⁵ signaling a small effect, were estimated for PEM-CY¹⁷⁸ school participation frequency % possible summary scores, CAPE¹⁶⁶ overall enjoyment scores, and WhOM-YP inside participation mean satisfaction summary scores for both child and parent report. This preliminary evidence contributes to building validity evidence supporting the use of select summary scores of these measurement tools with our population.^{106, 115, 117} Although we reported SRM values for select summary scores for all three participation tools in this dissertation, as some have recommended over other estimates of change for our study design,^{112, 115, 117, 119} we also calculated an effect size index^{110, 112, 325} from our results that can be used in future sample size calculations.^{110, 112}

Also related to treatment effect and variance is our question ‘Is there a difference in participation in everyday life between those new to PM versus those who have PM experience that necessitates considering them as separate groups?’ Unfortunately, given the small sample size and the unequal representation of those who were new to PM (10 children) versus those who had previous experience (3 children) we were unable to carry out appropriate analyses.

As for our question ‘What are the most appropriate evaluation intervals when examining participation outcomes after receiving a new power PM device?’ our findings suggest that although five times over a 4-month period was acceptable for most participants, longer measurement intervals post-PM delivery might be more manageable for families and allow for detection of a greater degree of change. We anticipated that changes in participation in everyday life would be discernable after three months of PM provision, a relatively short period of time of PM use, although our findings demonstrated mixed results. Issues related to fine-tuning PM equipment and learning to operate the PM device, along with seasonal conditions (e.g. colder temperatures, rain or snow)^{141, 317} and changes in daily routines related to the school calendar may have also influenced PM use and participation in daily life situations. With this in mind having evaluation sessions at 4 months, 8 months and/or 1 year after PM delivery might be considered, extending the research timeline to have more similar environmental contexts for comparison between sessions may also be valuable. We recognize that adopting a longer timeline might introduce other contextual factors influencing change in participation that would need to be accounted for in the design, methods and analyses. However, longer intervals may also support documentation of change more readily when using the PEM-CY¹⁷⁸ and CAPE¹⁶⁶ as

respondents are asked to consider activities over the last four months, while having a longer time between sessions may promote more opportunity to experience self-selected participation outcomes when using the WhOM-YP.

We had several observations related to suitability of measurement tools. Some accommodations were needed to complete questionnaires because of participants' abilities, but those were manageable within the confines of the measurement tool instructions and study protocol. Some children, especially those with dysarthric speech, restricted hand movement or who used augmentative communication strategies needed longer time to answer questions, using hand or eye pointing, their speech generating devices, or partner-assisted scanning strategies, whereby the assessor stepped through each choice one at a time, pausing between each choice to wait for a yes/no response.^{337, 338} Parents assisted with clarifying instructions or child's responses for six children in the 'new PM' group and four children in the 'stable PM' group during the first session. However, this was reduced to two parents in the 'new PM' group and one parent in the 'stable PM' group assisting on subsequent sessions.

Younger children and those challenged by mental and/or physical fatigue needed simplified instructions or more rest breaks to complete required tasks.³³⁷⁻³³⁹ The format and response scales for the WhOM-YP and CAPE¹⁶⁶ were conducive for these individuals because images as well as text and numbers helped children with emerging reading and numeracy literacy skills answer appropriately. Additionally having the option of a WhOM-YP parent-report to augment or provide a proxy measure increased its usefulness in rating individualized participation outcomes of importance with a more diverse population (age-wise and ability-wise). Further revision of the

WhOM-YP including larger images for examples, a more child-friendly presentation, and changes to improve ease of use with multiple responders (e.g. child and parent) and when using it over multiple sessions may further enhance its use.

Given that this was the first study to use the WhOM-YP, one feasibility question arose as to what ages the WhOM-YP is appropriate for. This study demonstrated that the WhOM-YP could be used with children as young as 5 years of age, although results had more variability in some (but not all) of the youngest participants' scores, suggesting caution is needed. For the two children that had decreased inside participation scores, both did not have opportunity to use the new PM device indoors as they had first anticipated. Similarly for one child whose outside participation score decreased, winter weather limited their outdoor play. Several other children shared that their satisfaction ratings were influenced by feelings of frustration because learning to maneuver the new PM device was harder than expected-- even for experienced drivers.

Although the CAPE¹⁶⁶ is a widely used tool in paediatric rehabilitation literature for ages 6 to 21 years, information supporting its responsiveness is limited (see Chapter 2 for details). Two papers investigating predictors of change in out-of-school leisure participation over time, found disability, gender and age differences on some physical and recreational activity subscales, using the earlier 49-item version.^{52, 58} We and other researchers found little change in CAPE¹⁶⁶ scores pre-post intervention, and items that were not relevant.³²⁶ Despite the CAPE's¹⁶⁶ value as a comprehensive measure for out-of-school participation,^{35, 189} its length may add unnecessary participant burden for most PM applications.

In regards to the parent-reported PEM-CY¹⁷⁸ school participation scores, several parents commented on their challenge answering those questions since they did not have first-hand knowledge of their children's participation in school routines. This along with the less-than-adequate values for measurement properties of school participation summary scores might suggest the PEM-CY¹⁷⁸ school participation section be used with caution.

Our study is, to the best of our knowledge, the first to investigate participation change over time using the PEM-CY.^{178, 201, 217-219} This is also the first study to investigate the WhOM-YP's measurement properties with children, adding to evidence supporting its use with adults.^{258, 270-272} Overall, each of the three participation tools evaluated participation in everyday life from a different perspective, giving valuable and often complementary rather than duplicating information.^{35, 66} That each tool measures participation differently lends support for their inclusion in a POWER Mobility toolkit whereby one can select from a range of measurement tools depending on the desired measurement purpose, age range and participation dimensions, as well as responder's perspective desired, an idea discussed earlier in Chapters 2 and 3, and supported in the literature.^{156, 232}

As for treatment safety, we were encouraged that no adverse events occurred, given the potential risk when introducing such technology.²⁸ Of note, we were not manipulating the intervention so much as observing the effects of PM interventions on participation, and as a result treatment safety may have a different connotation than in other more controlled studies. Having said that, what was valuable was connecting with children within the first week after PM provision. In many clinical situations, after initial PM provision, therapists leave it to the families

to initiate follow up with problems and concerns. We were surprised to learn that our participants receiving new PM devices had wheelchair operation and performance issues arise affecting their participation in daily life (even those with previous PM experience) that would potentially be left unaddressed until such time that it caused more serious problems. This was confirmed somewhat with decreased individual summary scores at T3 for some participants. The assessor's experience with PM facilitated discussion and encouragement for the family to contact their therapist for follow up when the child and family were experiencing PM-related challenges. A recommendation from this experience is for clinicians, equipment suppliers and funders to monitor PM provision more actively within the first few weeks, even with those who they might otherwise think would have little trouble adapting to a new PM device. Another recommendation is to provide PM training under different and varied conditions beyond clinical settings. This training should aim to equip children and their families with the knowledge and skill to cope successfully with everyday life situations.

In regards to data collection and analyses, and perceived benefit, most participants were supportive of the research strategies used and spoke positively about how use of PM impacted their (child's) participation in everyday life. However, as our findings comparing individuals' and group scores over time illustrate, the impact was not easily translated into quantifiable results because of significant variability among individuals as well as a multitude of contextual factors. Considerations for future study include using methods that take this variability into account such as growth curve analyses and other more sophisticated multivariate methods.^{112, 342} These methods typically require much larger samples, and future studies will likely benefit from collaborations across multiple sites and regions to obtain needed sample sizes. Stratifying the

sample to include individuals with specific characteristics and/or adjusting for covariates in the analysis might reduce measurement error within a larger sample. Characteristics that may be worthy of additional attention in future designs are children's developmental level, chronological age, gender, PM experience (i.e. new versus experienced drivers), PM access methods (e.g., proportional versus digital controls, or head control versus joystick), seating functions (tilt/recline/elevation or standing wheelchairs versus standard seat configurations), and/or access to wheelchair-accessible-transportation, and other environmental factors such as weather, setting and accessibility.^{17, 28} In addition to recruiting a larger sample, finding measurement tools that assess these environmental parameters more systematically and more discriminately for wheeled mobility users and using analyses that quantify their impact would be valuable.

5.4.5 Limitations

Given this was a feasibility study,^{132, 133} and participants were a small, convenience sample, results may not be representative of the population of children aged 5 to 17 years benefiting from PM, limiting generalization. Additionally, the study took place under one provincial health region, within a well-developed network of services supporting children who need PM and their families. Differences in equipment and service delivery programs as well as funding mechanisms, community supports and relationships between organizations may make our findings not as relevant across other regions. Biases such as recall and response shift,^{110, 112} might have influenced participants' responses, and interviewer bias^{110, 112} might have influenced how the data were recorded or interpreted (although we had only one assessor). Finally, a selection bias^{110, 112} whereby families who volunteered for the study may be different from families who did not enroll may exist. Our findings related to change in participation over time

for children receiving a new PM device demonstrated considerable variability within and across different activity settings, quite possibly reflecting the uniqueness of each individual's abilities and life situation. Measuring participation in daily life is complex,^{35, 268} and along with the added complexities of individuals with mobility limitations who use PM^{157, 308} we did not have the power to carry out more rigorous statistical analyses that might illuminate more information about contributing factors for the variability exhibited. With repeated measurement, on multiple measurement tools, our findings may be due to chance rather than because of true change. However, we mitigated this by adjusting for alpha to account for multiple testing of our primary outcome. Additionally other factors not accounted for may have influenced the results. Having said that, hypothesis testing was not the main purpose of this study, and our sample size was consistent with recommendations for feasibility studies.¹³²⁻¹³⁴

5.5 Conclusion

Understanding the impact of PM on participation in daily life is important for children who rely on PM, their families and those who support them, including health and education service providers, funders and suppliers of PM equipment, and public programming and policy decision-makers. This study was an important first step in learning how children who need PM participate in daily life, and pragmatically how we might go about measuring change in participation over time in future studies.

This is the first study to explore feasibility indicators when working with children who need PM, their families, and service providers, and was the first to investigate change over more than

three sessions using tools developed to evaluate children's participation in everyday life. Our results demonstrated that it was feasible to engage children as young as 5 years and as old as 17 years, with a diverse range of abilities who need PM, as well as their parents. Considerations when working with this population were put forward that might influence their receptiveness to participating in research and ultimately impact the success of future research endeavours. This study lays the groundwork for larger scale research involving multiple sites across Canada with repeated measurements using an interrupted time series design over an extended time. Such research with larger samples may facilitate more precise estimates of change in participation after introduction of a new PM device, provide additional evidence of reliability and validity when using select summary scores with our population, and help us make conclusions and recommendations more confidently when discussing how PM impacts participation in daily life for children who need this therapeutic intervention.

Table 5.1 Feasibility Indicators, Measurement Parameters and Results

Feasibility Indicator	Method of Evaluation	Parameter for Success	Result
<i>Process Indicators</i>			
Recruitment rate	# participants recruited	SHHC & BCCH - 25 participants CCD - 3 participants QA - 2 participants 30 participants total	Expectation met SHHC & BCCH – 27 participants CCD - 5 participants QA - 0 participants 32 participants consented coordinator had contact with 41 54 participants contacted by therapists; 32 had info mailed out 82 potential candidates identified
Consent rate	% consenting participants	< 25% participant refusal	Expectation met 9 of 41 in contact with study coordinator declined after study details provided 22% participant refusal
<i>Resource Indicators</i>			
Recruitment effort	Time spent preparing for and in communication with sites	< 6 hours spent/month/site	Expectation met Maximum meeting time was 7.6 hours spread over 22 months at one site
Community access	Time spent organizing school and community access	< 2 hours spent / participant	Expectation met Mean time spent organizing school and community access was 18.15 (SD 11.33) minutes per participant in the new PM group and 21.73 (SD 11.90) minutes per participant in the stable PM group

Feasibility Indicator	Method of Evaluation	Parameter for Success	Result
Participant burden	Data T1 collection Data T2- T5 collection Interviews at study completion with qualitative analysis to inform clinical significance	> 75% of participants complete in \leq 2.0 hours/session > 85% of participants complete in \leq 2.0 hours/session 80% of responses will report positive experiences	Expectation met 96.88% of participants completed in \leq 2.0 hours 96.88% of participants completed in \leq 2.0 hours 85% of participants described positive experiences related to study participation
Assessor burden	Time spent preparing for session Time spent after session	Mean time spent preparing & summarizing per participant is < 2 hours	Expectation met Mean time preparing for sessions was 17.26 (SD 7.23) minutes per participant in the new PM group and 15.56 (SD 1.61) minutes per participant in the stable PM group Mean time spent summarizing sessions was 26.89 (SD 7.99) minutes per participant in the new PM group and 26.98 (SD 3.02) minutes per participant in the stable PM group
Completion time	Time taken to complete	> 85% of sessions completed measure(s) in expected time	Expectation met 92.78% < 2 hours 5.16% sessions = 2 hours; 2.06% > 2 hours
Completion rate	% of measures completed/session	> 85% completion of measures/session	96% measures completed/session
Retention rate	% participants with T5 data for new PM group % participants with T2 data for stable PM group	> 75% of participants retained	Expectation met 12 of 14 completed T5 data 85% new PM group retained 17 of 18 completed T2 data 94% stable PM group retained

Feasibility Indicator	Method of Evaluation	Parameter for Success	Result
Management Indicators			
Participant processing	Time from initial contact to enrolment	Mean time per participant < 25 days	Expectation met 23.86 days (SD 18.09) mean time processing new PM group 19 days (SD 14.60) mean time processing stable PM group
Protocol administration	Issues documented on context form Completion of all documents	Any issues identified can be modified without substantial changes to the protocol < 20% incomplete documentation without explanation	Expectation met Issues identified were modified without substantial protocol changes 8% incomplete documentation without explanation overall; 11% in new PM group; 3% in stable PM group
Equipment performance	PMD breakdown during sessions and over course of study documented on context form	< 2 PMDs unable to complete one session < 2 PMDs dropped over study duration	Expectation met 1 PMD unable to complete one session (tilt in space mechanism locked out driving) 0 PMDs dropped over study
Scientific Indicators			
Treatment effect	ANOVA or ANCOVA comparison between groups Estimate of effect size and variance for future sample size/power calculations	A significant difference identified between time intervals for intervention group Estimation of effect size will enable sample size calculations for subsequent study	Expectation partially met See Section 5.3.2. for details See Section 5.3.2. for details
Measurement intervals	Comparison of change scores over different time intervals Interviews at study completion	Able to identify intervals for subsequent study 80% of responses will be favourable	Expectation met Current number and frequency of intervals manageable (reported by 94% of stable PM)

Feasibility Indicator	Method of Evaluation	Parameter for Success	Result
	with qualitative analysis to inform clinical significance		group and 77% of new PM group-85% overall)
Suitability of measurement tools	Reliability and validity evidence supports use	Internal consistency > 0.6 Cronbach alpha and Test-retest > 0.7 ICCs values Correlations & SRM as specified and MDD calculated 80% of participants will have positive comments related to participation tools	Expectation partially met See Section 4.3 and Section 5.3.2. for details
Treatment Safety	Adverse events during sessions Adverse events reported during study duration	No major injuries or adverse events reported No major injuries or adverse events reported	Expectation met No major injuries or adverse events were experienced during data collection sessions Three families reported child injuries that happened accidentally however they were not directly related to PM use over study period
Perceived benefit	Wheelchair use in last week questionnaire; Contextual observation form Interviews at study completion with qualitative analysis to inform clinical significance	80% of participants will describe positive experiences	Expectation met 100% of participants described positive participation experiences as a result of PM use

Legend: ANOVA = Analysis of Variance; ANCOVA = Analysis of Co-Variance; BCCH = British Columbia Children’s Hospital; CCD = Centre for Child Development; ICC = Intraclass correlation coefficient; MDC = Minimal Detectable Change; MID = Minimally Important Difference; PM = power mobility; PMD = power mobility device; QA = Queen Alexandra Centre for Children’s Health; SHHC = Sunny Hill Health Centre for Children; # = number; % = percentage; T(1-5) = Assessment Time (1-5); ‘=’ = equals to; ‘<’ = less than; ‘>’ = more than.

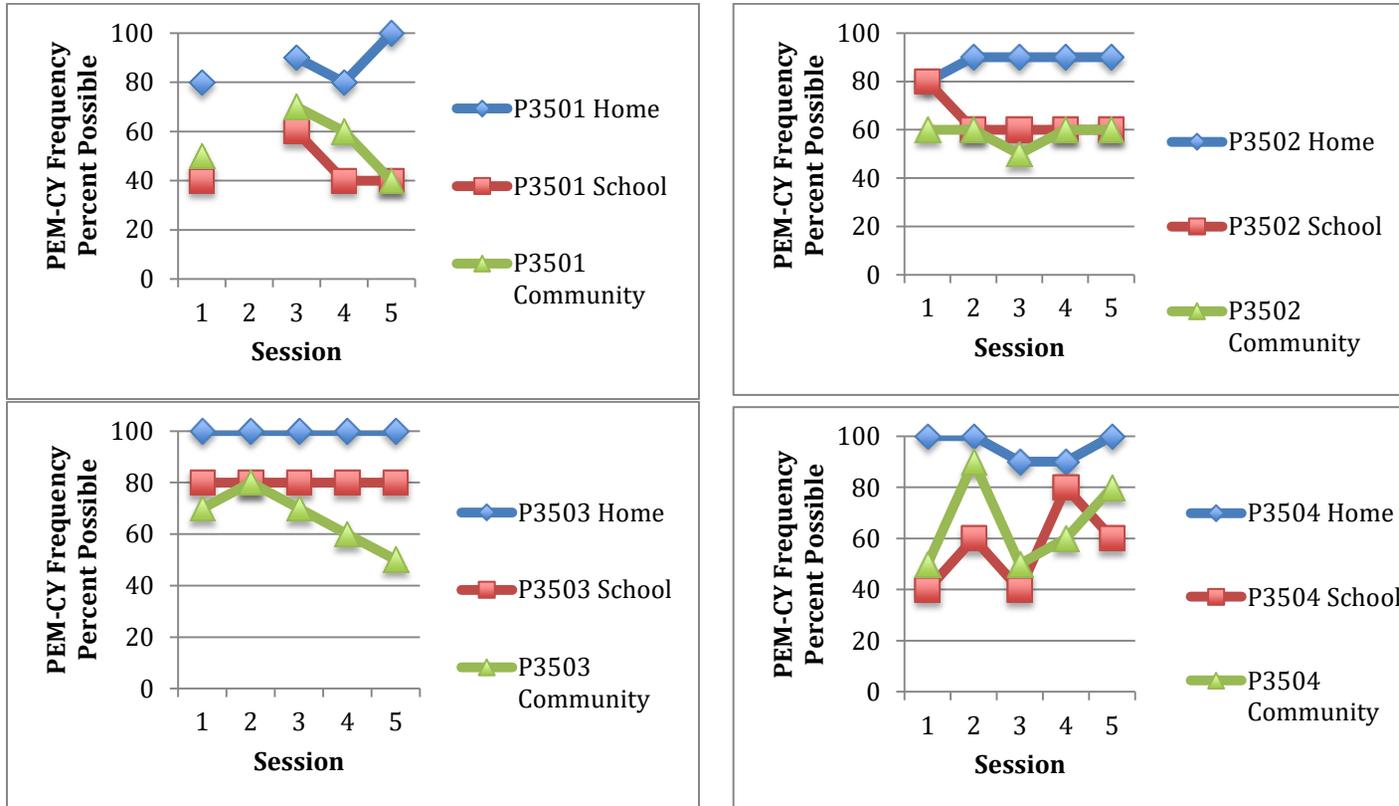
Table 5.2 Participant Characteristics of Those Receiving a New PM Device

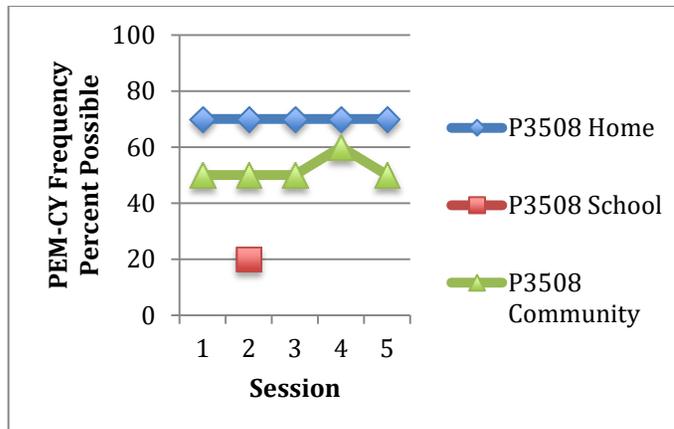
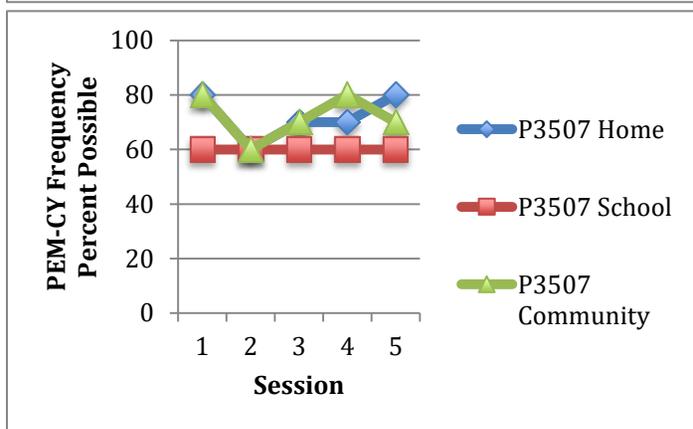
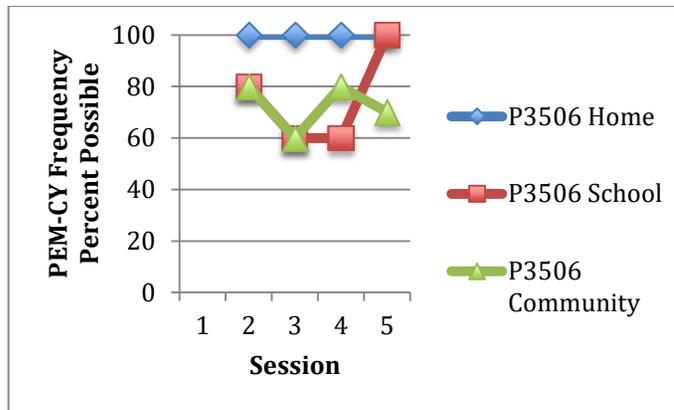
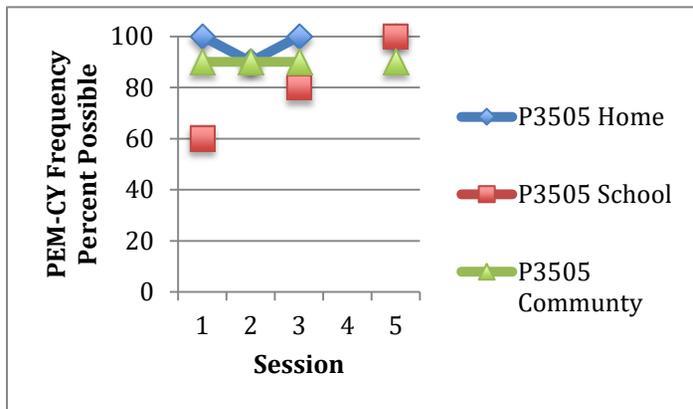
	Frequency Count n=14		Frequency Count n=14
Parent age		Child age	
19 to 29 years	1	5 to 7 years	3
30 to 39 years	4	8 to 10 years	3
40 to 49 years	9	11 to 13 years	2
50 to 59 years	0	14 to 17 years	6
Parent education		Child education	
attended secondary school	1	not yet in school	0
secondary school graduate	1	homeschooled (no grade)	1
college or Trades graduate	6	kindergarten to grade 3	5
		grade 4 to 7	2
university graduate	6	grade 9 to 12	6
Parent sex		Child sex	
female	9	female	6
male	5	male	8
Relationship to child		Child MMSE total score	
mother	7	<27	0
father	4	27 to 32	3
other (guardian, nurse, grandmother, foster parent)	3	33 to 37	11
		Child driving status (as indicated by ALP score)	
		No driving experience	10
Child primary diagnosis (reported by caregiver)		Competent driver (score of 6)	0
cerebral palsy	6	Proficient driver (score of 7)	2
Duchenne muscular dystrophy	4	Expert driver (score of 8)	2
other genetic syndromes	2	Child years of driving experience	
spinal cord injury	1	No driving experience	10
other muscular dystrophies	0	1 to 5 years	1
spinal muscular atrophy	0	6 to 10 years	1
acquired brain injury	1	11 to 15 years	2
		unknown	0
Child GMFSC score		Child LSS score	
Level I	0	Level 1 unsupported by 1	0
Level II	2	Level 2 support from head	1
Level III	3	Level 3 support from trunk	3
Level IV	4	Level 4 support from pelvis	1
Level V	5	Level 5 sits without moving	0
Child MACS score		Level 6 leans forwards	3
Level I	3	Level 7 leans sideways	3
Level II	2	Level 8- leans backwards	3
Level III	6		
Level IV	1		
Level V	2		

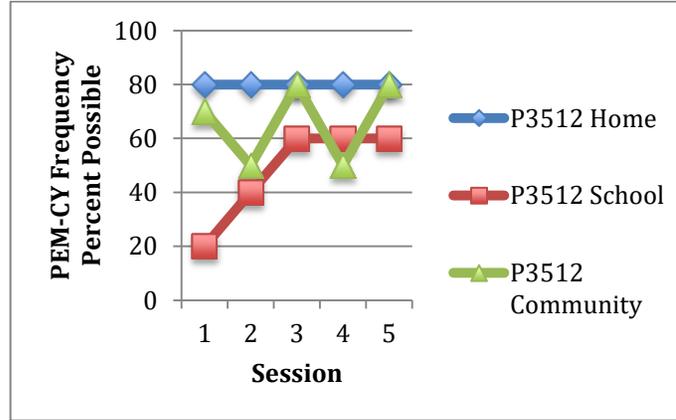
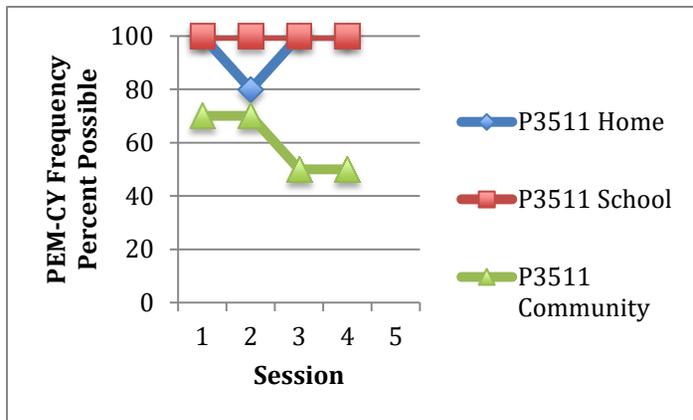
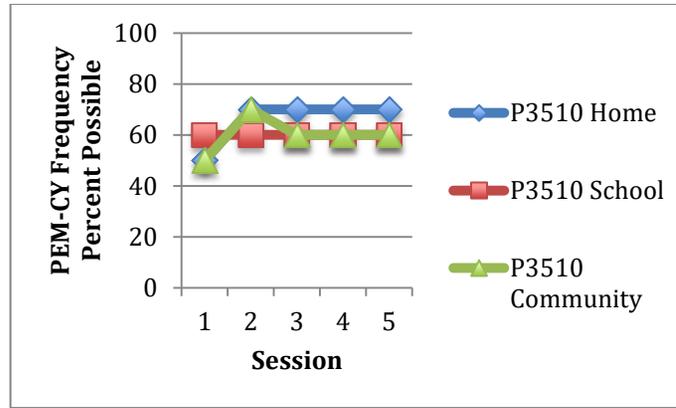
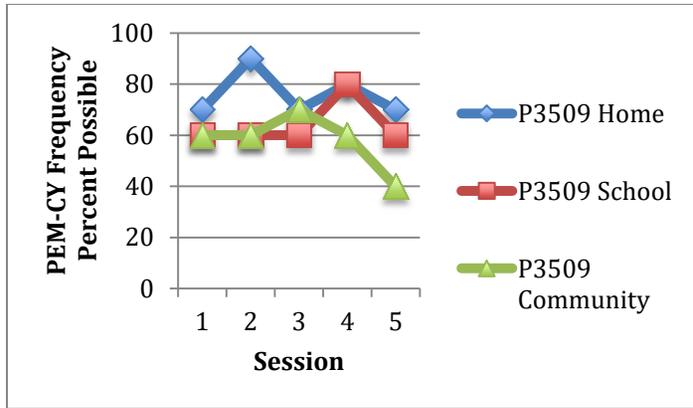
Legend: n = sample size; MMSE = Modified Mini Mental Status Exam;^{36, 37} ALP = Assessment of Learning Powered Mobility Use;⁷⁹ GMFSC = Gross Motor Classification System;^{276, 278} LSS = Level of Sitting Scale;²⁹¹ MACS = Manual Ability Classification Scale.²⁸³

Figure 5.1 Comparison of Individual Participants' Summary Scores

Figure 5.1(i) Comparison of Individual Participants' PEM-CY¹⁷⁸ Frequency % Possible Summary Scores







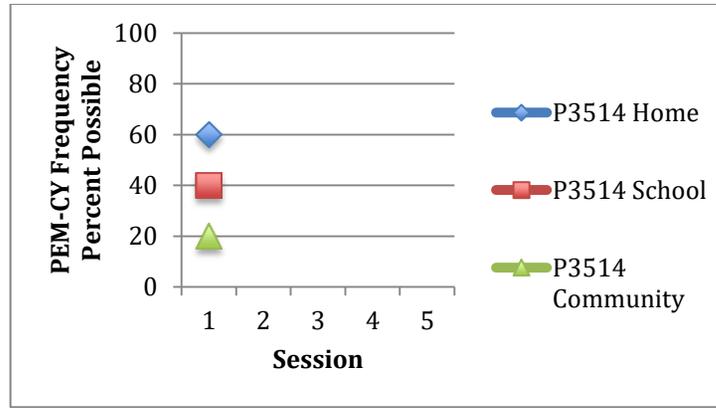
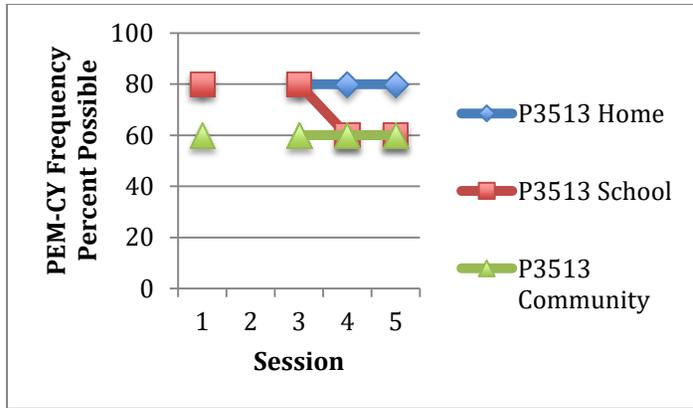
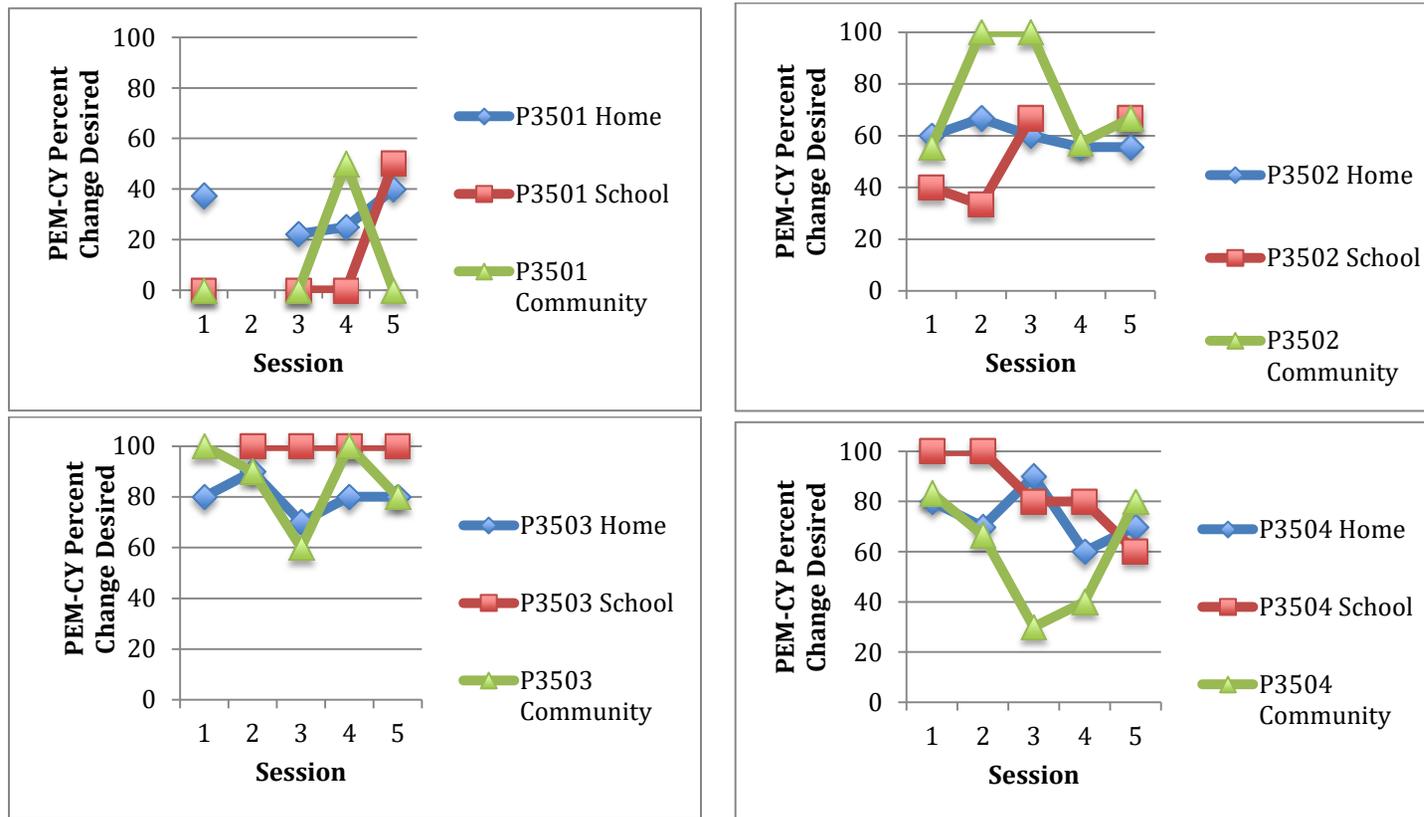
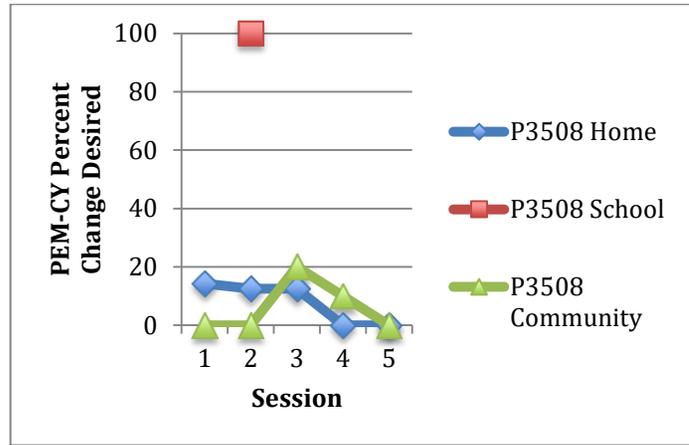
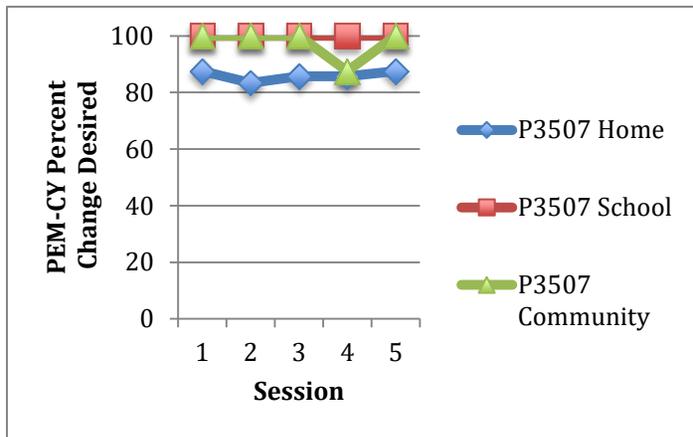
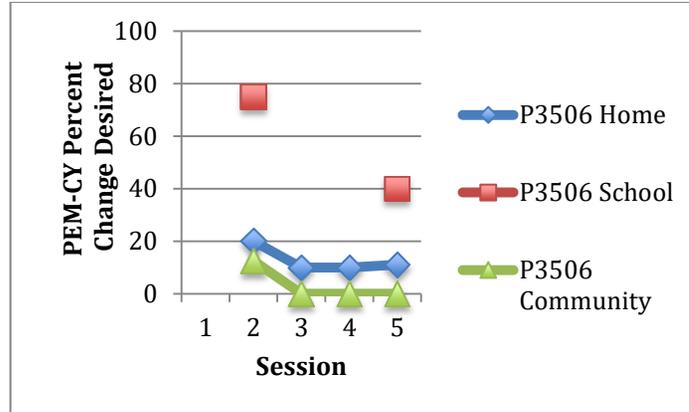
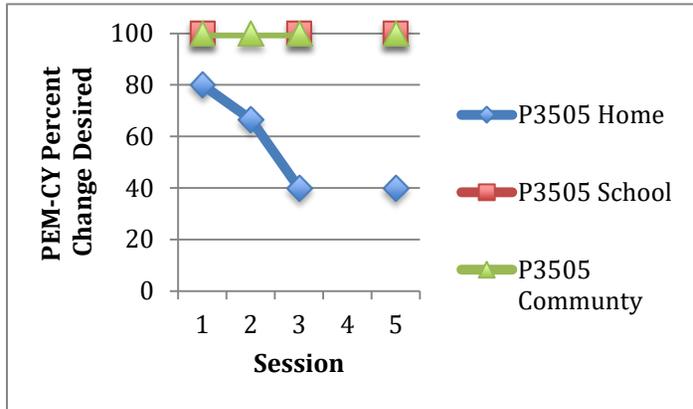
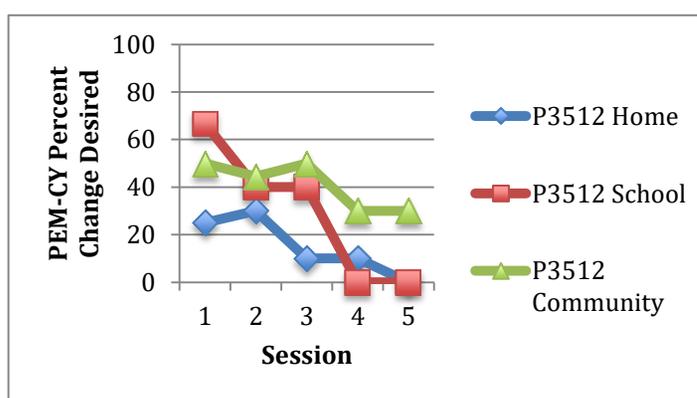
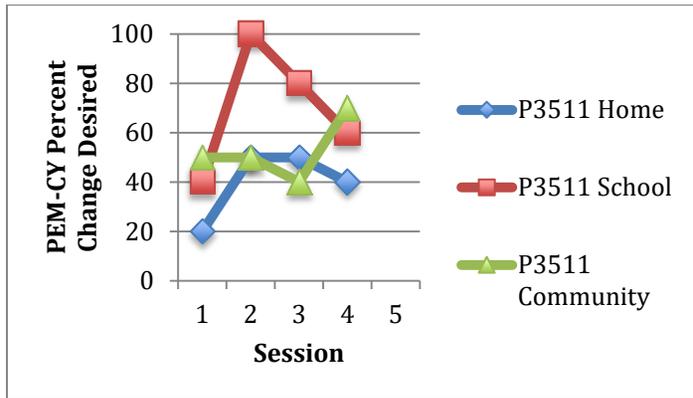
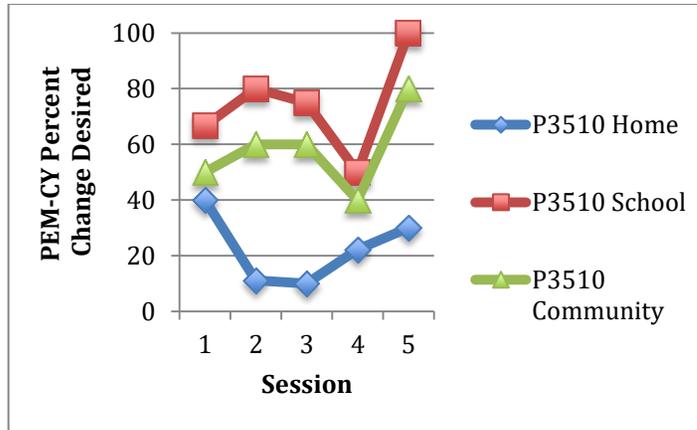
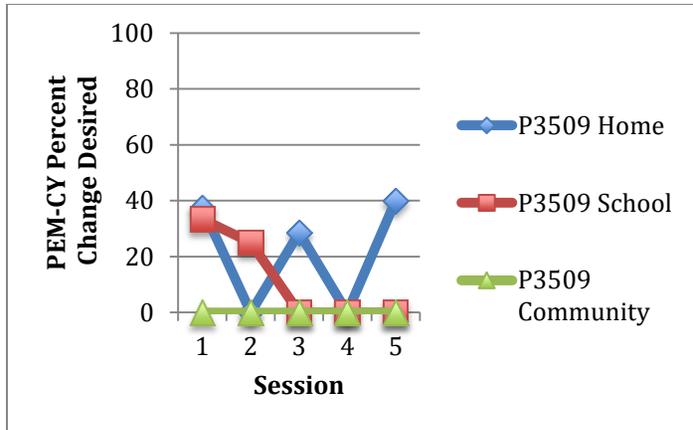


Figure 5.1(ii) Comparison of Individual Participants' PEM-CY¹⁷⁸ % Change Desired Summary Scores







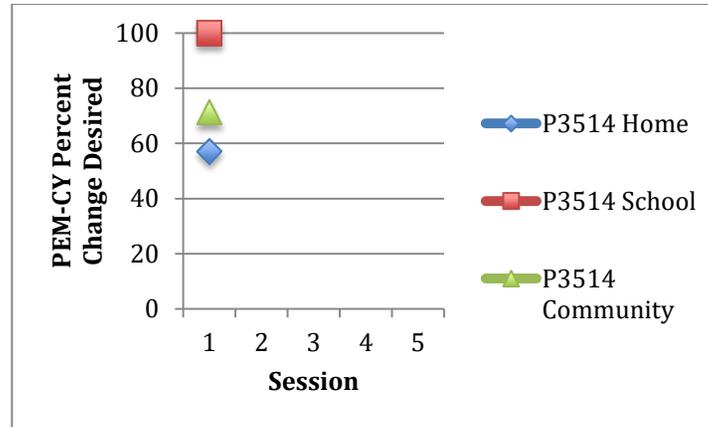
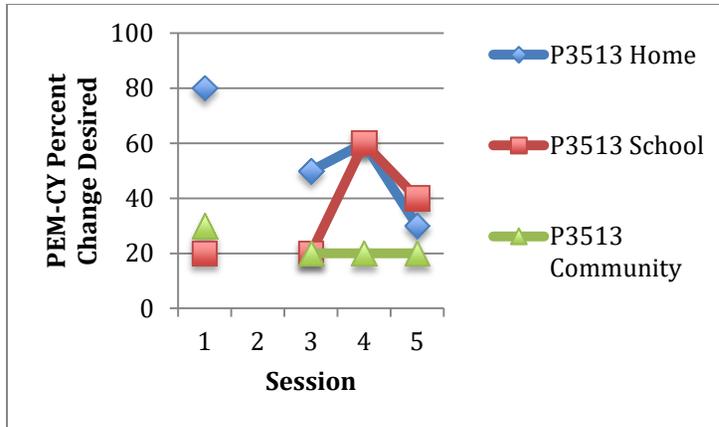
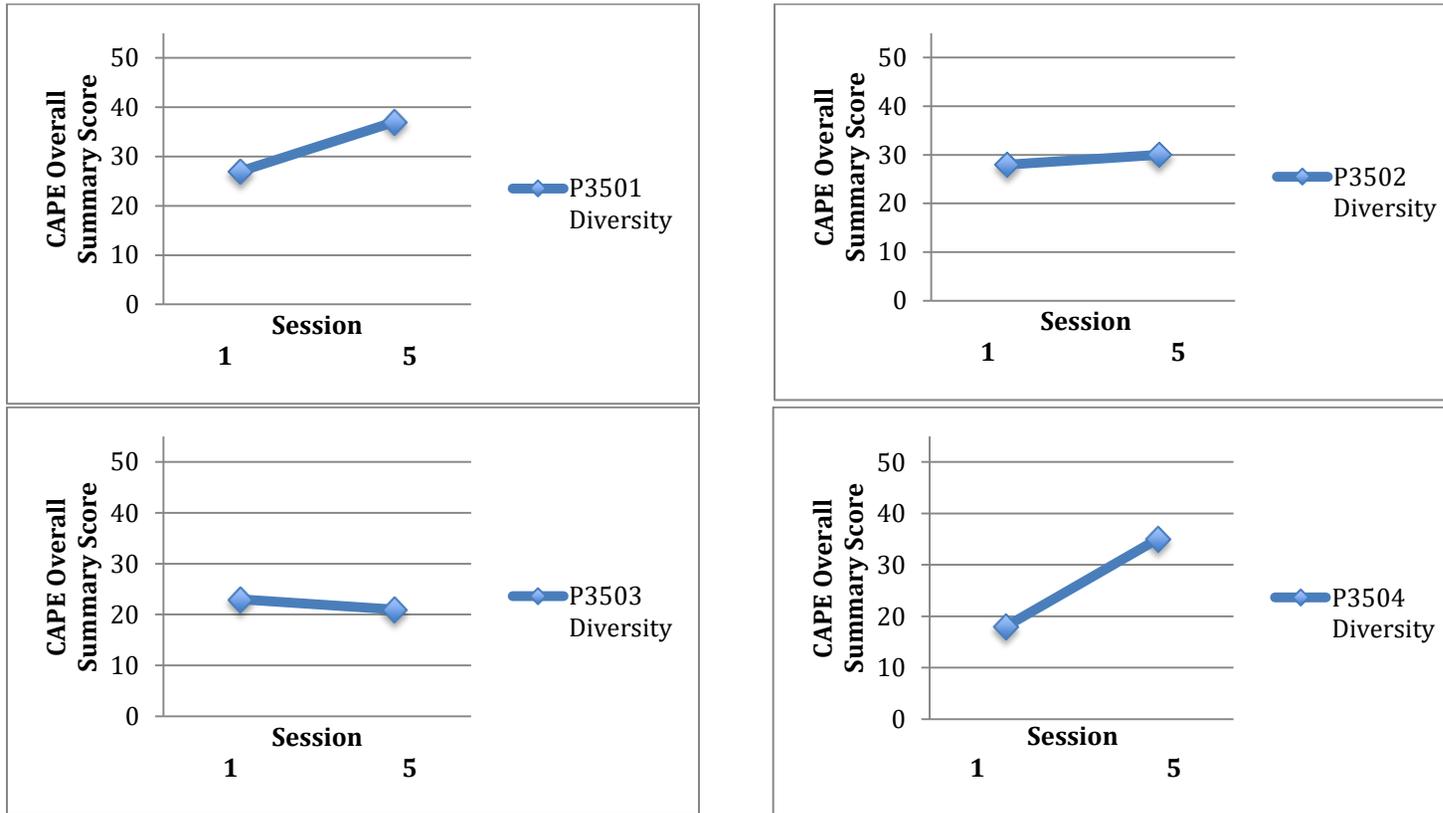
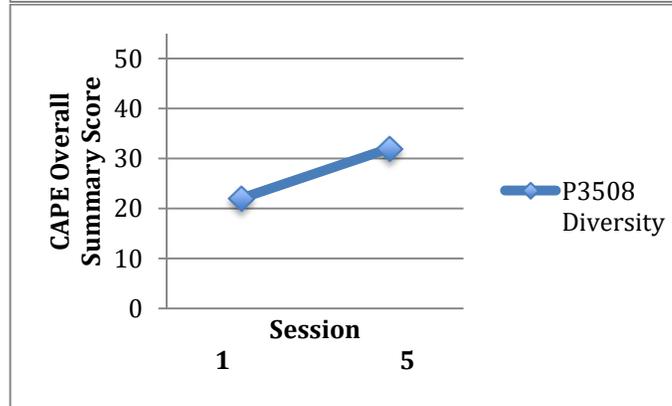
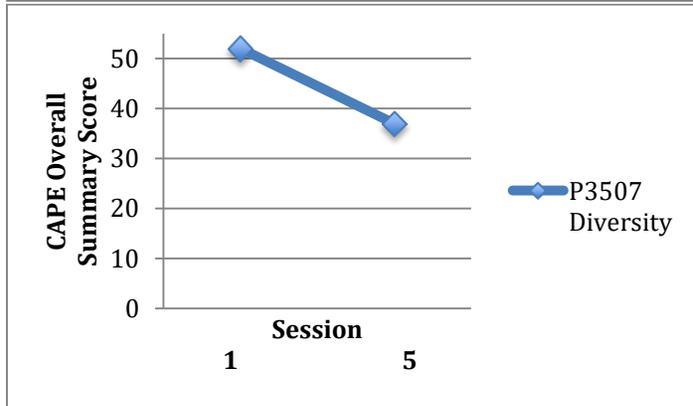
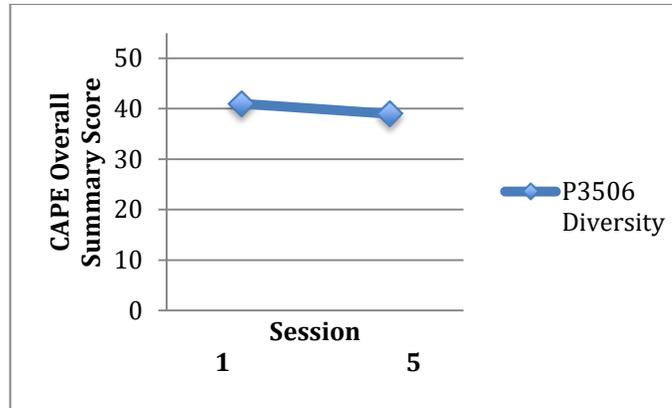
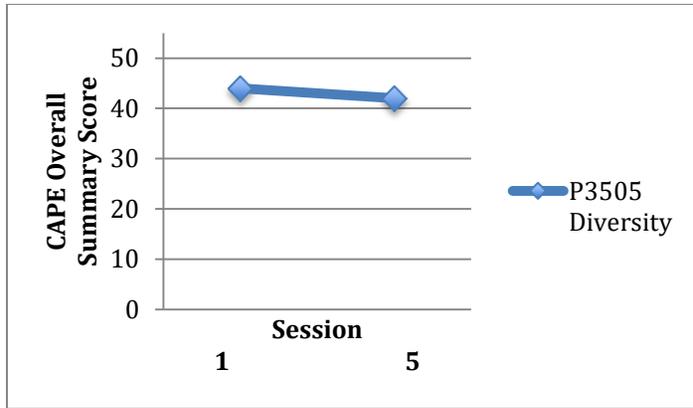
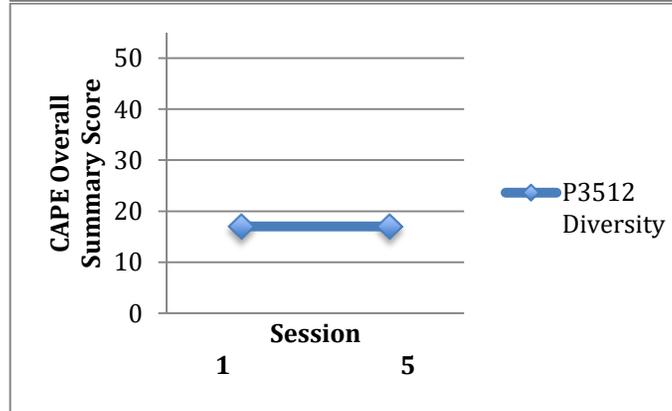
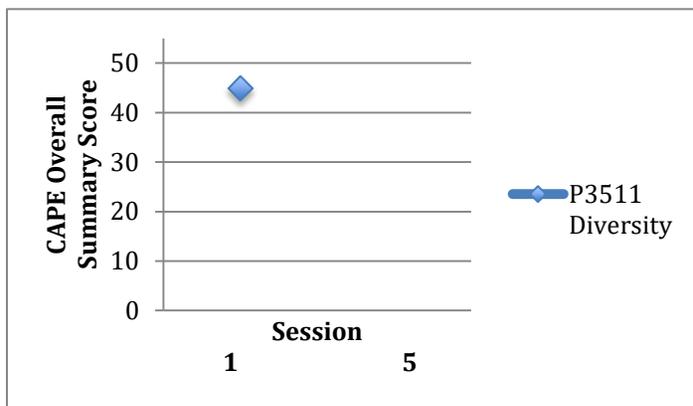
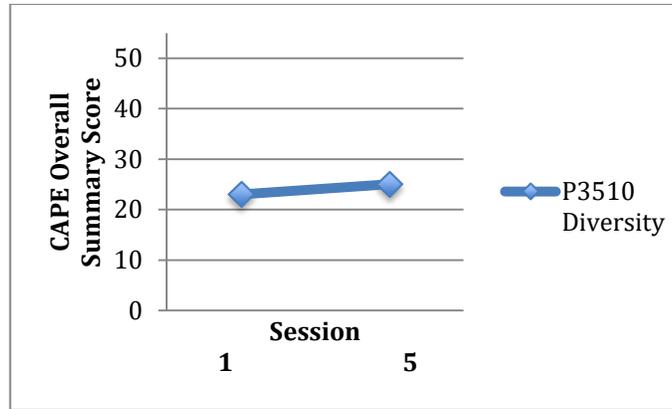
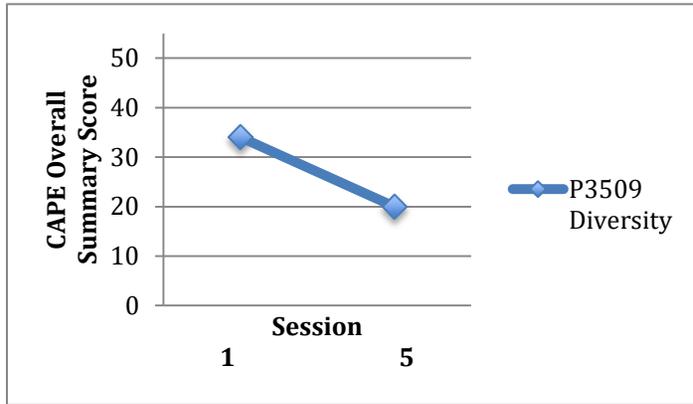


Figure 5.1(iii) Comparison of Individual Participants' CAPE ¹⁶⁶ Overall Diversity Summary Scores







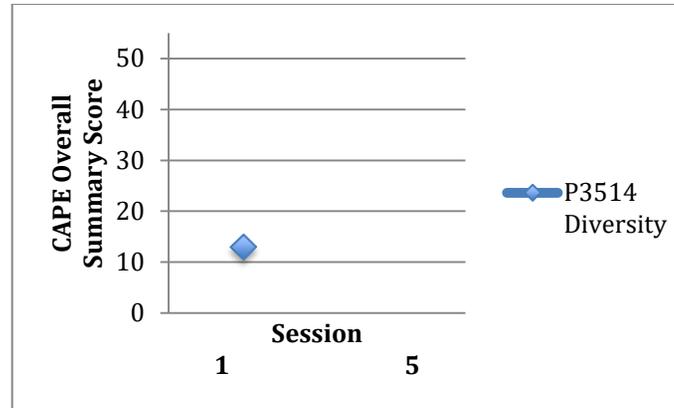
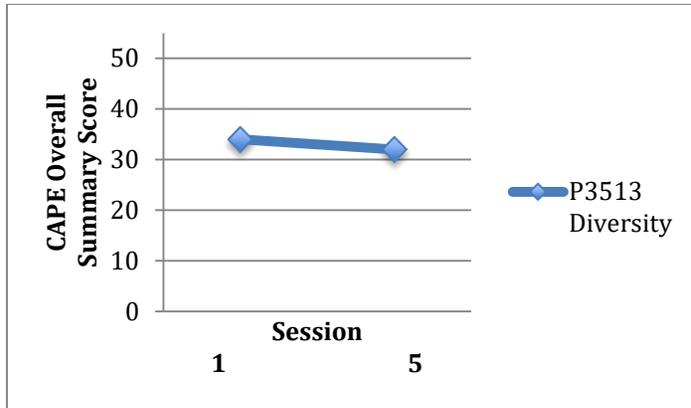
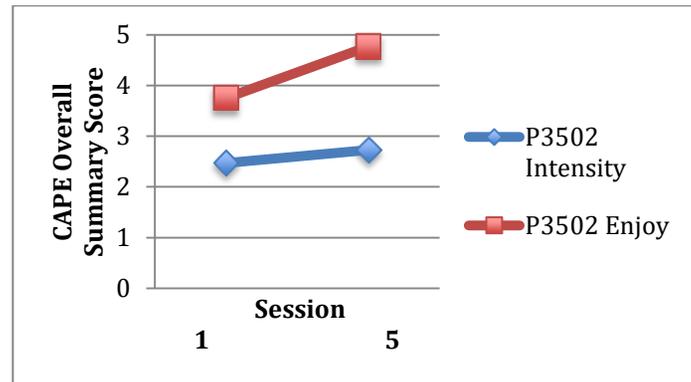
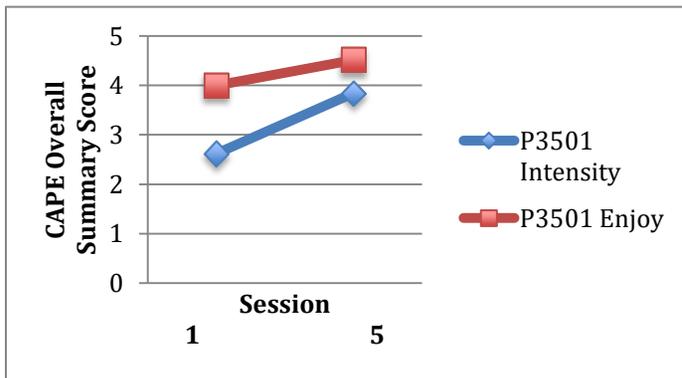
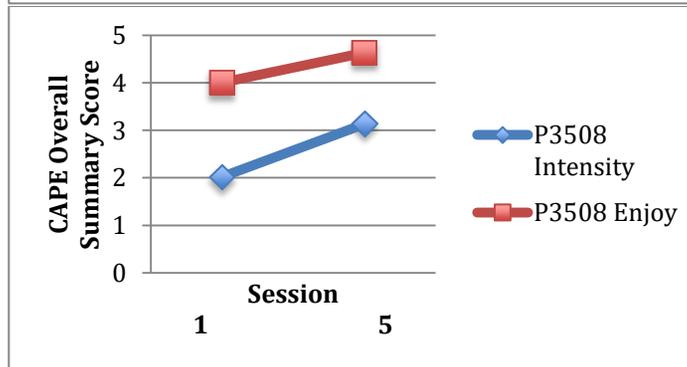
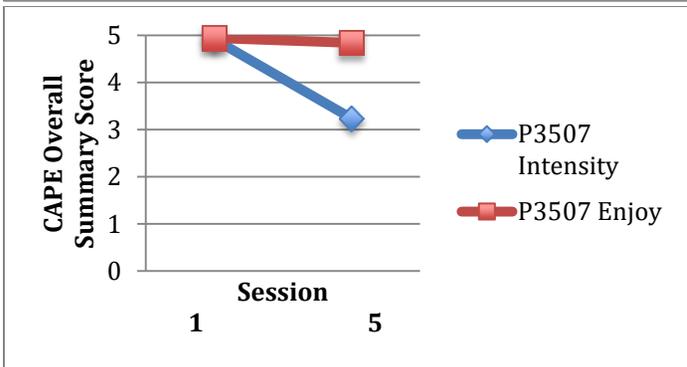
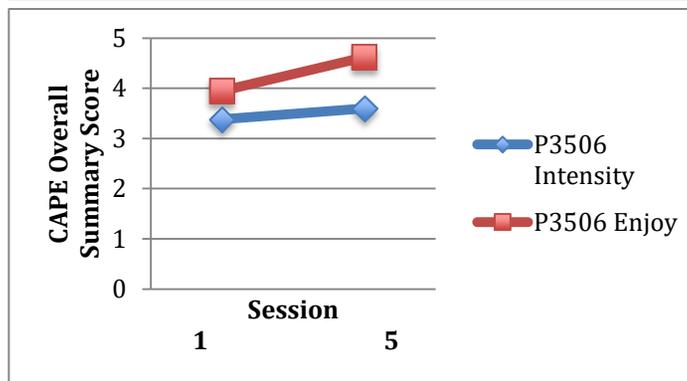
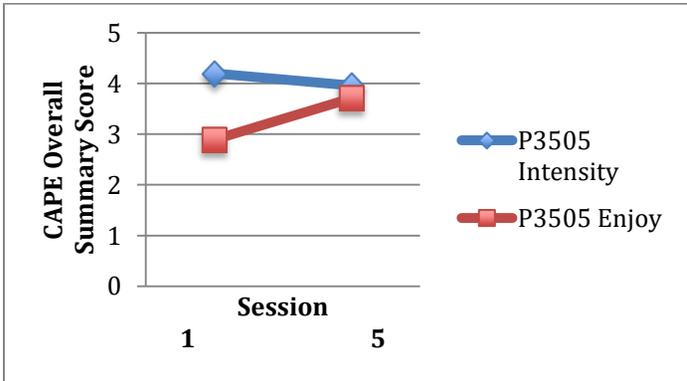
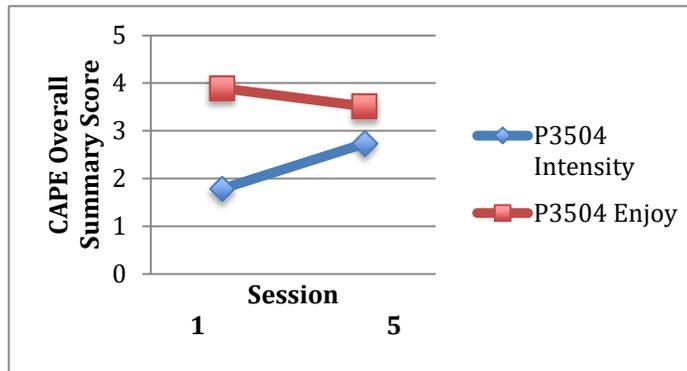
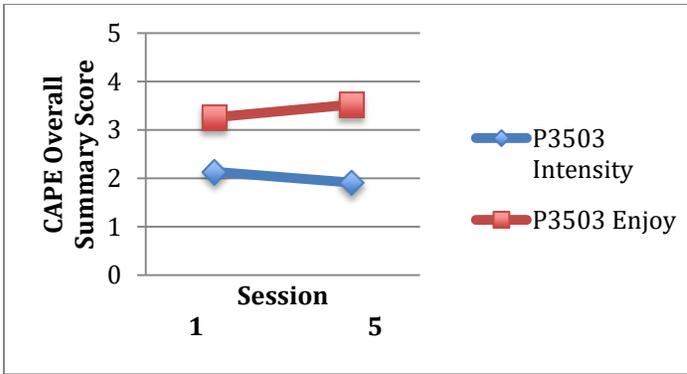
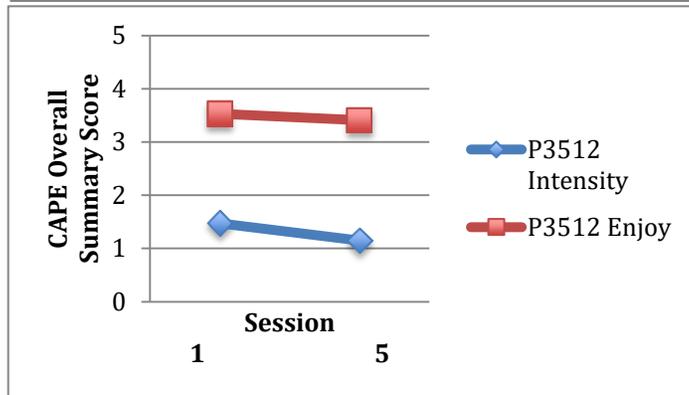
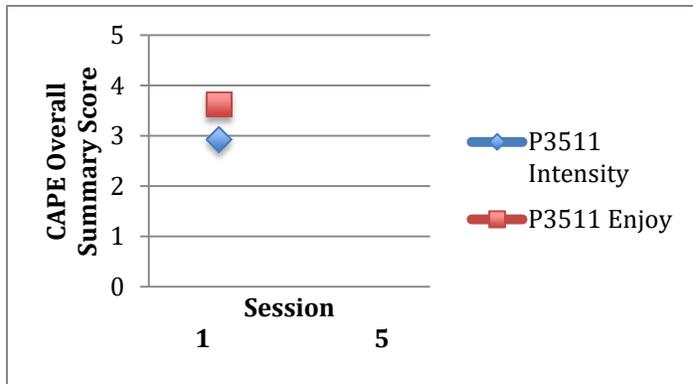
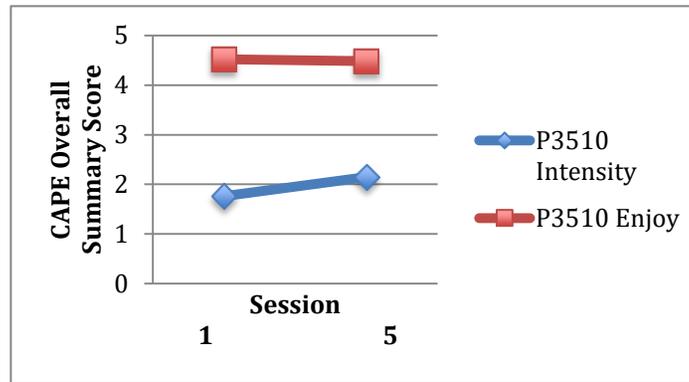
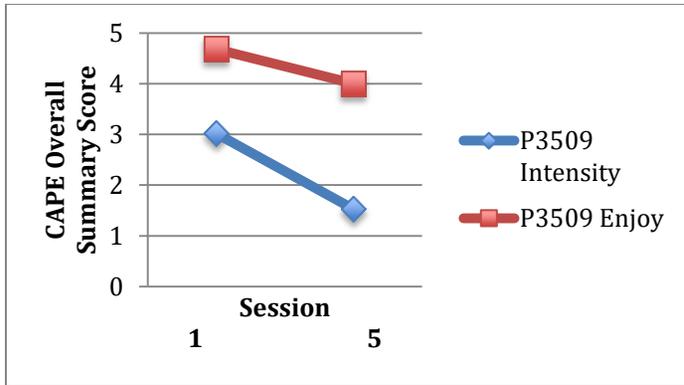


Figure 5.1(iv) Comparison of Individual Participants' CAPE¹⁶⁶ Overall Intensity and Enjoyment Summary Scores







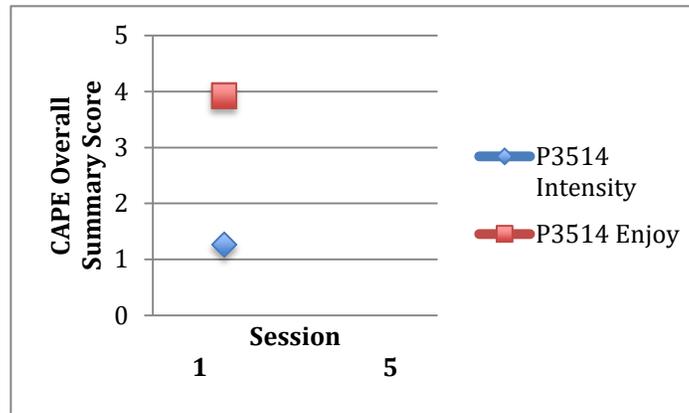
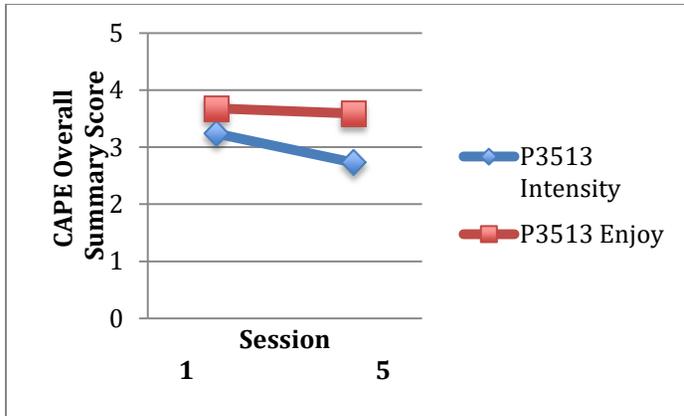
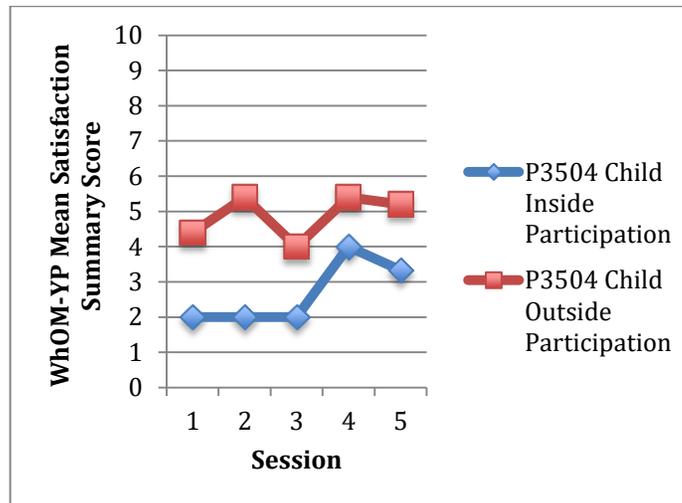
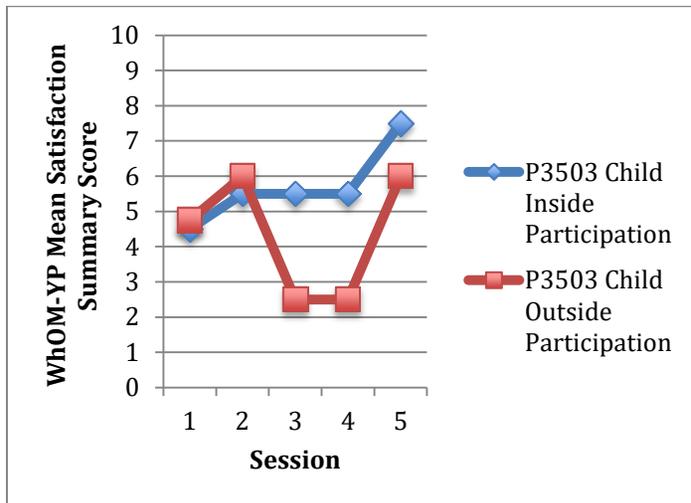
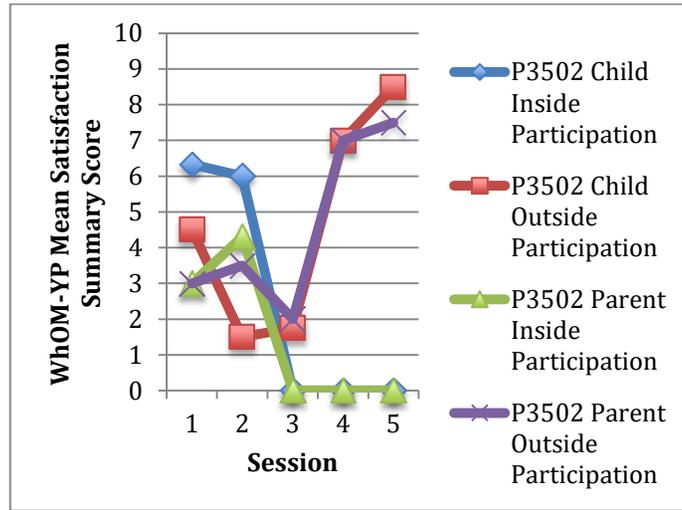
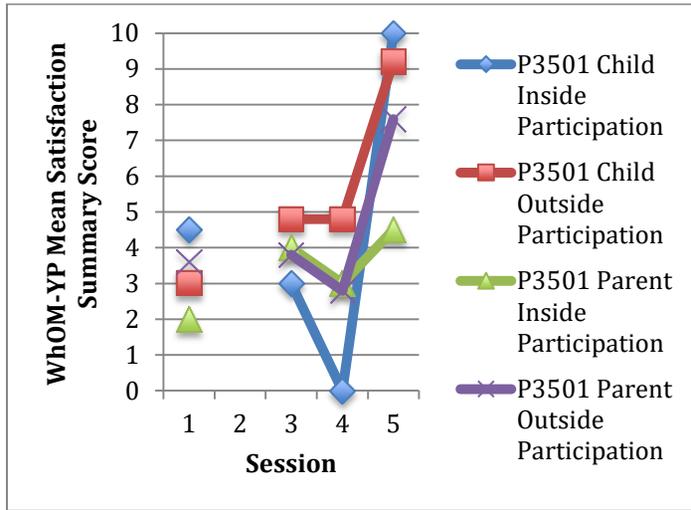
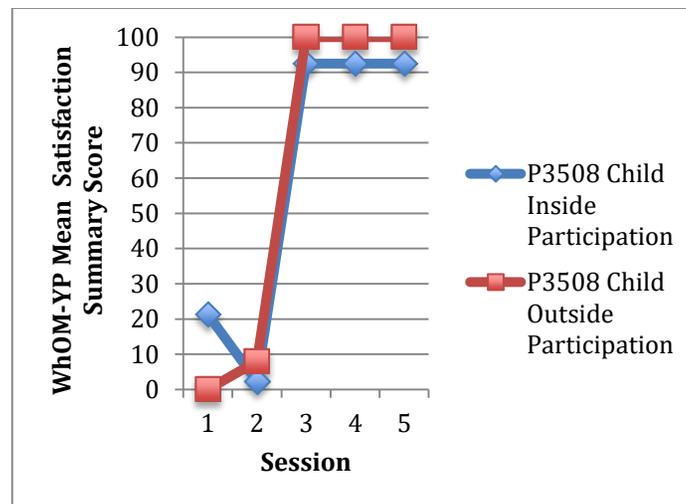
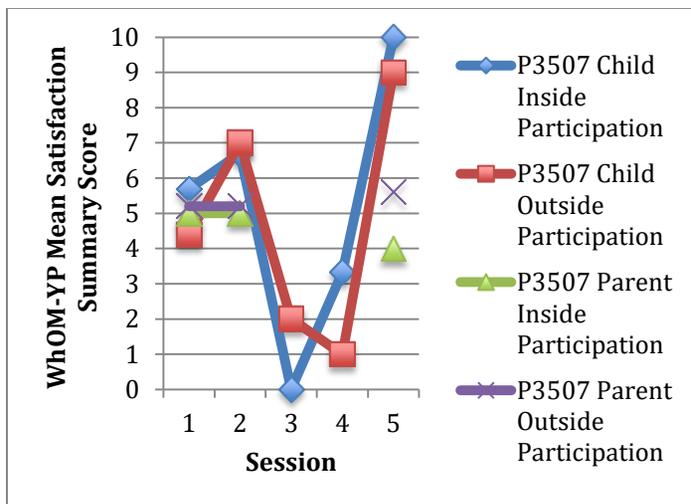
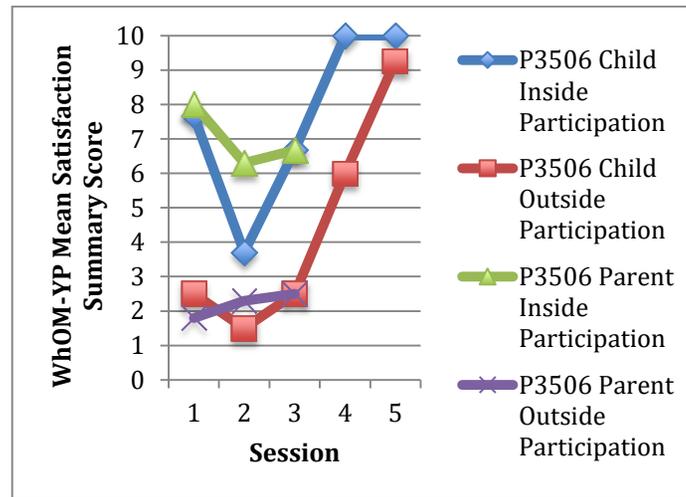
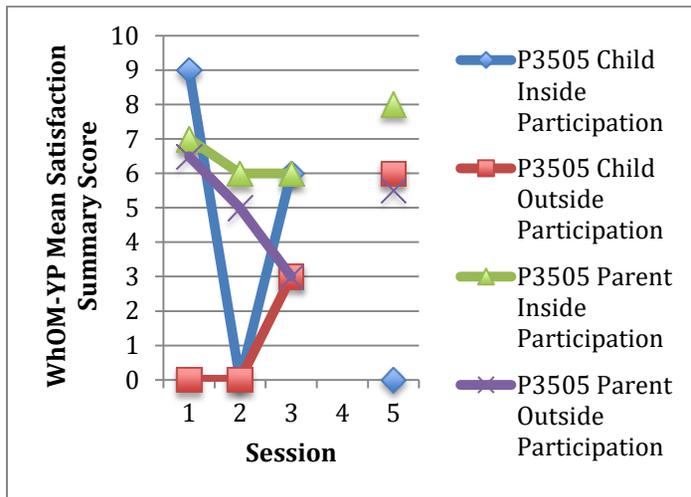
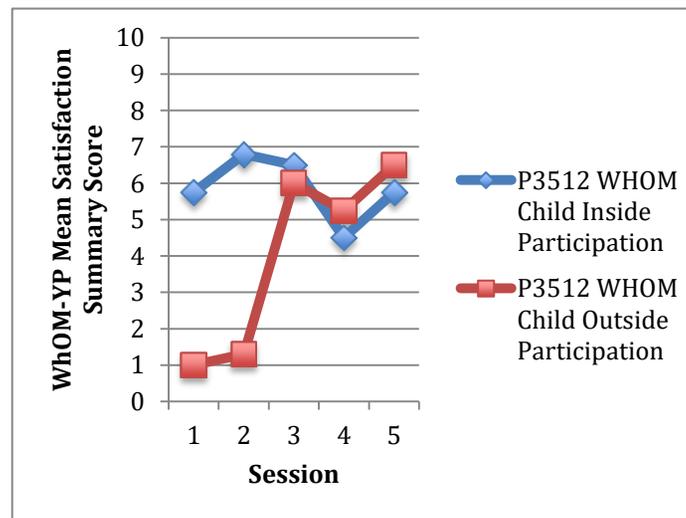
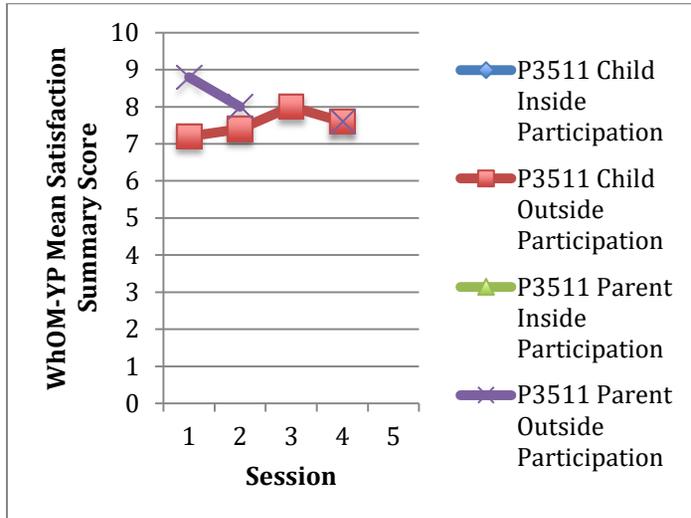
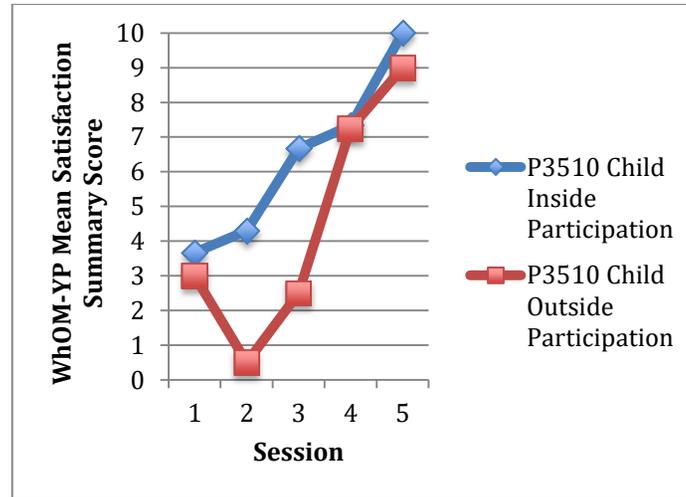
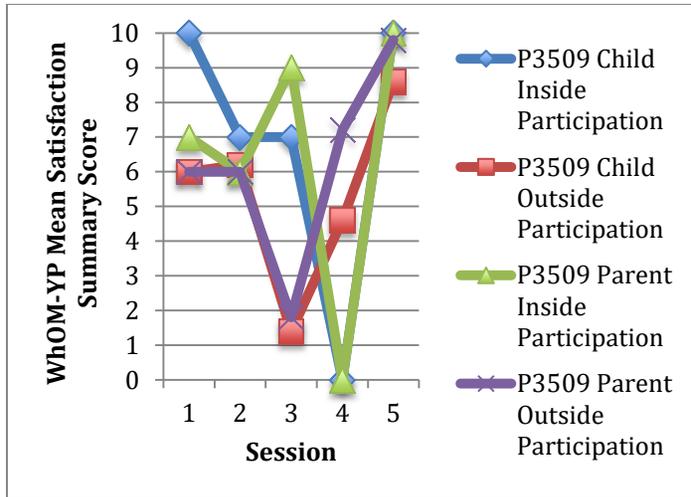


Figure 5.1(v) Comparison of Individual Participants' WhOM-YP Mean Satisfaction Summary Scores







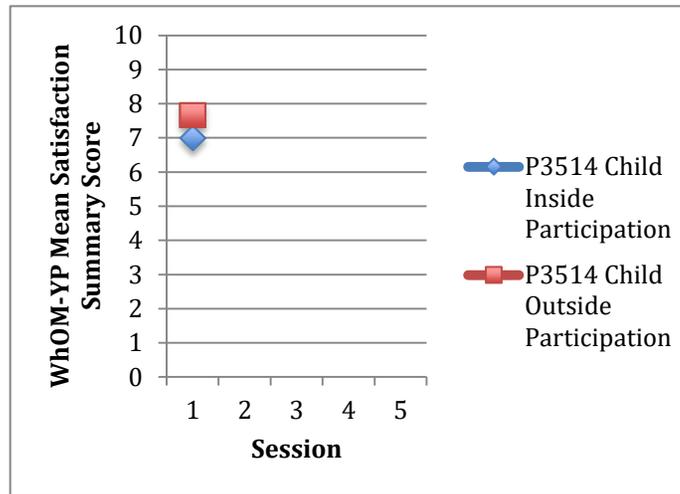
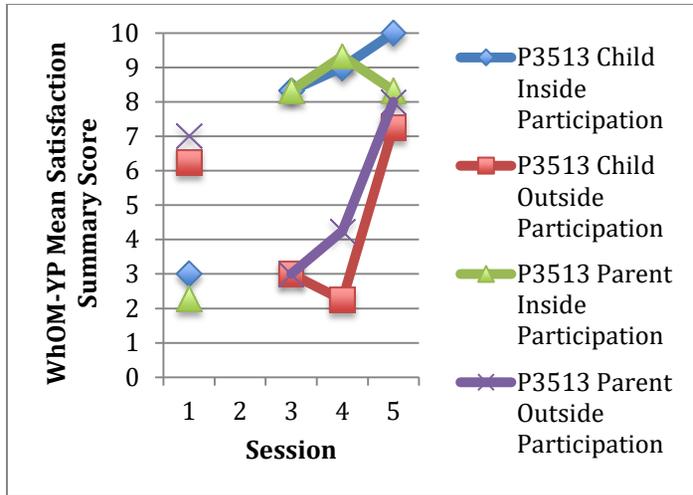


Table 5.3 Comparison of Summary Scores for New PM Group

	T1	T2	T3	T4	T5	◆ Friedman's Test**^ □ Wilcoxon's Test**^ <i>p</i> = 0.05 unless noted	Standardized Response Mean (SRM)
PEM-CY¹⁷⁸ Home participation Frequency % possible mean & SD [95% CI of mean] median min / max skewness; kurtosis	n=12/13 82.5 (15.5) (72.7, 92.3) 80 50 / 100 -0.5; 0.2	n=11 86.4 (14.3) (76.7, 96.0) 90 60 / 100 -0.7; -0.8	n=13 85.4 (12.7) (77.7, 93.0) 90 70 / 100 -0.1; -1.7	n=12 84.2 (11.7) (76.8, 91.6) 80 70 / 100 0.2; -1.4	n=12 86.7 (13.0) (78.4, 95.0) 85 70 / 100 -0.1; -1.9	◆ 0.35	0.51
PEM-CY¹⁷⁸ School participation Frequency % possible mean & SD [95% CI of mean] median min / max skewness; kurtosis	n=11/13 61.8 (22.7) (46.6, 77.1) 60 20 / 100 -0.2; -0.1	n=10 60.0 (18.9) (46.5, 73.5) 60 20 / 80 -1.0; 1.2	n=12 66.7 (15.6) (56.8, 76.6) 60 40 / 100 0.7; 0.9	n=11 61.7 (24.8) (45.9, 77.4) 60 0 / 100 -1.2; 3.1	n=11 67.3 (18.5) (54.9, 79.7) 60 40 / 100 1.0; 0.4	◆ 0.81	0.26
PEM-CY¹⁷⁸ Community participation Frequency % possible mean & SD [95% CI of mean] median min / max skewness; kurtosis	n=12/13 63.3 (13.0) (55.1, 71.6) 60 50 / 90 0.7; -0.1	n=11 69.1 (14.5) (59.4, 78.8) 70 50 / 90 0.2; -1.3	n=13 63.9 (12.6) (56.2, 71.5) 60 50 / 90 0.6; -0.2	n=12 61.7 (9.4) (55.7, 67.6) 60 50 / 80 1.2; 1.3	n=12 62.5 (16.0) (52.3, 72.7) 60 40 / 90 0.2; -0.9	◆ 0.70	-0.06
PEM-CY¹⁷⁸ Home participation % change desired mean & SD [95% CI of mean] median min / max skewness; kurtosis	n=12/13 53.5 (27.3) (36.2, 70.8) 50 14.3 / 88 -0.1; -1.8	n=11 45.5 (31.9) (24.1, 66.9) 50 0 / 90 -0.1 -1.7	n=13 41.5 (28.8) (24.1, 58.9) 40 10 / 90 0.4; -1.1	n=12 37.4 (30.4) (18.0, 56.7) 32.5 0 / 86 0.3, -1.4	n=12 40.3 (29.0) (21.9, 58.8) 40 0 / 88 0.2; -0.8	◆ 0.02^ □ 0.08 T3-T1 □ 0.05 T4-T1^ □ 0.02 T5-T1^ □ 0.39 T4-T3 □ 0.89 T5-T3 □ 0.34 T5-T4	-0.75

	T1	T2	T3	T4	T5	◆ Friedman's Test**^ □ Wilcoxon's Test**^ <i>p</i> = 0.05 unless noted	Standardized Response Mean (SRM)
PEM-CY¹⁷⁸ School participation % change desired mean & SD [95% CI of mean] median min / max skewness; kurtosis	n=10/13 56.7 (35.7) (31.1, 82.2) 53 0 / 100 -0.0; -1.2	n=10 75.5 (30.9) (53.2, 97.5) 90 25 / 100 -0.8; -1.3	n=11 60.2 (38.8) (34.1, 86.2) 75 0 / 100 -0.6; -1.2	n=9 50.0 (41.2) (18.3, 81.7) 60 0 / 100 -0.2; -1.6	n=11 59.7 (38.1) (34.1, 85.3) 60 0 / 100 -0.4; -1.0	◆ 0.70	0.08
PEM-CY¹⁷⁸ Community participation % change desired mean & SD [95% CI of mean] median min / max skewness; kurtosis	n=11/13 56.3 (36.9) (31.5, 81.1) 50 0 / 100 -0.3; -1.0	n=11 56.7 (39.3) (30.3, 83.1) 60 0 / 100 -0.4; -1.4	n=13 44.6 (37.8) (21.8, 67.4) 40 0 / 100 0.4; -1.2	n=12 42.1 (32.6) (21.3, 62.8) 40 0 / 100 0.4; -0.7	n=12 46.4 (41.7) (19.9, 72.3) 48.3 0 / 100 0.0; -2.0	◆ 0.82	-0.68
CAPE¹⁶⁶ Overall diversity mean & SD [95% CI of mean] median min / max skewness; kurtosis	n=13 31.4 (11.3) (24.6, 38.2) 28 17 / 52 0.5; -1.0				n=12 30.6 (8.1) (25.4, 35.8) 32 17 / 42 -0.4; -1.1	◆ 0.76	-0.09
CAPE¹⁶⁶ Overall intensity mean & SD [95% CI of mean] median min / max skewness; kurtosis	n=13 2.8 (1.0) (2.2, 3.4) 2.6 1.5 / 4.9 0.82; 0.28				n=12 2.7 (0.9) (2.2, 3.3) 2.7 1.2 / 4.0 -0.3; -0.8	◆ 1.00	-0.1
CAPE¹⁶⁶ Overall enjoy mean & SD [95% CI of mean] median min / max skewness; kurtosis	n=13 3.9 (0.6) (3.6, 4.2) 3.9 2.9 / 4.9 0.3; 0.1				n=12 4.1 (0.6) (3.8, 4.5) 4.2 3.4 / 4.8 -0.1; -2.0	◆ 1.00	0.40

	T1	T2	T3	T4	T5	◆ Friedman's Test**^ □ Wilcoxon's Test**^ <i>p</i> = 0.05 unless noted	Standardized Response Mean (SRM)
WhOM-YP Child Inside mean satisfaction mean & SD (95% CI of mean) median min / max skewness; kurtosis	n=12 5.4 (2.6) (3.7, 7.0) 5.10 2 / 10 0.5; -0.6	n=10 4.2 (2.7) (2.3, 6.1) 4.9 0 / 7 -0.7; -1.1	n=12 5.1 (3.2) (3.1, 7.2) 6.3 0 / 10 -0.5; -0.7	n=11 4.9 (3.9) (2.3, 7.5) 4.5 0 / 10 0.0; -1.4	n=12 7.2 (4.0) (4.7, 8.8) 10 0 / 10 -1.1; -0.3	◆ 0.04^ □□0.69 T3-T1 □□0.93 T4-T1 □□0.26 T5-T1 □□0.83 T4-T3 □□0.06 T5-T3 □□0.02 T5-T4^	0.35
WhOM-YP Child Outside mean satisfaction mean & SD (95% CI of mean) median min / max skewness; kurtosis	n=13 3.6 (2.3) (2.2, 5.0) 4.4 0 / 7 -0.3; -0.8	n=11 3.4 (2.9) (1.4, 5.4) 1.5 0 / 7.4 0.2; -2.1	n=13 4.0 (2.6) (2.4, 5.5) 3 1.4 / 10 1.4; 1.2	n=12 5.3 (2.5) (3.7, 6.9) 5.3 1 / 10 -0.0; -0.1	n=12 7.9 (1.6) (6.9, 8.9) 8.6 5.2 / 10 -0.5; -1.4	◆ 0.001^ □□0.94 T3-T1 □□0.24 T4-T1 □□0.002 T5-T1^ □□0.14 T4-T3 □□0.003 T5-T3^ □□0.007 T5-T4^	1.54
WhOM-YP Parent Inside mean satisfaction mean & SD (95% CI of mean) median min / max skewness; kurtosis	n=7/8 4.9 (2.5) (2.6, 7.2) 5 2 / 8 -0.0; -2.2	n=5/8 5.5 (0.8) (4.5, 6.6) 6 4.3 / 6.3 -0.8; -1.2	n=6/8 5.7 (3.3) (2.2, 9.1) 6.3 0 / 9 -1.1; 1.0	n=4/8 3.1 (4.4) (-3.9, 10.1) 1.5 0 / 9.3 1.4; 1.7	n=6/8 5.8 (3.7) (2.0, 9.7) 6.3 0 / 10 -0.6; -0.4	◆ 0.58	0.28
WhOM-YP Parent Outside mean satisfaction mean & SD (95% CI of mean) median min / max skewness; kurtosis	n=8/8 5.2 (2.3) (3.3, 7.2) 5.6 1.8 / 8.8 -0.1; -0.8	n=6/8 5.0 (2.0) (2.9, 7.1) 5.1 2.3 / 8.0 0.2; 0.2	n=6/8 2.7 (0.7) (1.9, 3.5) 2.8 1.8 / 3.8 0.3; -0.6	n=5/8 5.8 (2.1) (3.1, 8.4) 7 2.8 / 7.6 -0.8; -1.8	n=6/8 7.3 (1.6) (5.6, 9.0) 7.6 5.5 / 9.8 0.3; -0.3	◆ 0.04^ □□0.12 T3-T1 □□1.00 T4-T1 □□0.09 T5-T1 □□0.14 T4-T3 □□0.04 T5-T3^ □□0.07 T5-T4	0.92

Legend: CI = confidence interval; % = percentage; Friedman's Test = Friedman's Related Samples ANOVA by Ranks test; max = maximum value; min = minimum value; SD = standard deviation; T() = session number; Wilcoxon's Test = Wilcoxon's Related Sample Signed Rank Test; *pairwise deletion; ^ = statistically significant at *p*=0.05.

Chapter 6: Overall Discussion, Synthesis and Future Directions

Little is known about the participation in everyday life of children who use PM. This may be related to a lack of understanding of what participation dimensions are important to measure for children needing PM, what tools are available, or what the measurement properties are for those tools when used to evaluate participation of children using PM. Before the effectiveness of PM interventions on improving participation in everyday life can be evaluated, we first need to be confident that the measurement tools are suitable for use with the population, and that the research methods are practical. In this dissertation, we sought to understand how children using PM participate in everyday life situations and to establish feasible research methods with reliable and valid measurement tools to investigate the impact that PM has on participation in everyday life. Understanding children's participation in everyday life will improve therapeutic interventions, address outcomes of importance for children and their families, and will influence service delivery and policy decisions.

6.1 Justifying the Importance of Measuring Participation in Everyday Life for Children Using Power Mobility

Chapter 1 reviewed paediatric literature relevant to measuring participation of individuals with physical disabilities and discussed gaps in knowledge as we attempted to integrate that evidence into practice when working with children using PM. Although much has been learned about participation of children with physical disabilities and how it compares to children who are typically developing,^{37, 39-41, 45-49, 343} research is needed to understand participation in everyday

life with more precisely-defined populations, including those harder to engage in research or who have complex health needs⁶⁶ such as children needing PM. Chapter 1 also reviewed paediatric PM literature, with attention to current knowledge of PM's impact on participation. Knowledge gaps were identified providing justification for this dissertation's focus on measuring participation in everyday life for children using PM. As you may recall, 'children using PM' refer to those under 18 years of age with mobility limitations who may benefit from PM intervention; including those currently using PM along with those who do not yet have such equipment.

Significance: Most participation research in childhood disability has either lacked description about participants' mobility status, or focused on individuals who were ambulatory or walked with aids, making it difficult to generalize findings to children using PM. Paediatric PM research has primarily investigated mobility and developmental outcomes associated with PM use. Although qualitative studies suggest PM offers participation benefits for children with mobility limitations, quantifying participation outcomes for children using PM has received little focus to date. Questions remain about what dimensions of participation in everyday life are important to measure, what tools are available, and what the measurement properties are for those tools when used with children using PM.

6.2 Identifying Potential Participation Measurement Tools

Chapter 2 described a systematic review conducted to identify and critically appraise existing tools developed to measure children's participation in everyday life that may be potentially

useful for children with PM needs. We identified 20 participation tools that had some relevance for our population, although none of the reviewed studies specifically addressed children's mobility status in sufficient detail that we could be confident in using the participation tools with children using PM without further testing of measurement properties. We identified a large number of participation tools, each bringing a different perspective to measuring participation, including differences in children's ages, types and settings of life situations, participation dimensions, targeted responders and the tools' conceptual basis. Such choice is both encouraging and frustrating. Encouraging because it gives options when searching for a tool that measures a specific participation dimension for a particular age and stage of development, and because there is a diverse inventory of paediatric participation outcomes supported by research evidence. Frustrating because such choice can be overwhelming. It also makes it challenging to compare results from one study to another (when different tools with different foci are used) when attempting to reach conclusions about research evidence to inform clinical practice.

Significance: Our systematic review described potential participation tools and their measurement properties, and rated reliability and validity evidence associated with the tools' use. Our findings informed development of our modified Delphi survey, comprising the next phase of research within this dissertation. In addition, our resulting publication³⁴³ compiled findings in one document, offering a contemporary evidence-based resource for clinicians, other knowledge users and researchers. The review synthesis of findings identified measurement tools that could potentially meet a particular purpose when measuring participation of children with mobility limitations. Further, lessons learned in carrying out this study informed the development and implementation of another systematic review that identified and critically appraised a broad array

of outcomes related to PM use in children.¹⁰

6.3 Determining Elements Important to Measure for Children with Power Mobility Needs and Identification of Suitable Measurement Tools

Given the numerous participation tools uncovered in Chapter 2, we designed a study to seek the advice of key informants, including parents of children using PM, and therapists and researchers with paediatric PM and participation expertise, to assist with determining what information is of importance for children with PM needs.^{13, 240} We sought to define ‘elements of participation’ important to measure for children using PM, addressing the ‘who, what, where, and how’ of measuring participation in everyday life. This also facilitated an integrative knowledge exchange early on in our research, helping us stay grounded in what matters to our knowledge end-users.^{148, 237} Delphi surveys are valuable for establishing consensus based on practical experience and expert knowledge when research evidence is limited.²³⁷ Chapter 3 described the four-round, on-line, modified Delphi survey²³⁶ involving 74 parents, therapists, and researchers that advanced our understanding of what participation-related information was important to measure for children using PM. The first three rounds determined elements of participation important to measure for two age groups: (i) 18 months to 5 years and (ii) 6 to 12 years. In addition, panelists helped determine what measurement tools may be suitable for use with this population. In the fourth and final round, the panel compared existing tools against participation elements ranked most important for children in the two groups. Six participation tools demonstrated potential for inclusion in a measurement toolkit,²³² but only the Participation and Environment Measure for Children and Youth (PEM-CY)¹⁷⁸ reached our consensus level and only for school-aged

children. The POWER Mobility toolkit, with acronym POWER standing for the Paediatric Participation Outcomes for Wheelchair Evaluation in Rehabilitation, was developed to provide a selection of measurement tools suitable upon further testing for use with children using PM.

Significance: Consensus on elements of importance when measuring participation in everyday life provided guidance for tool selection for children using PM. These elements informed development of our final Delphi survey round, by providing context from which potential participation tools could be compared. These elements may also inform new tool development that might better reflect participation outcomes of importance for children using PM. Lessons learned in carrying out this study were shared with other researchers who used a similar research design to reach consensus on best clinical practice consideration when working with children using PM.^{21, 112} Findings from this chapter guided the next phase of research that evaluated key measurement properties of highly-rated participation tools.

6.4 Evaluating Measurement Properties of Three Participation Tools with Children Using Power Mobility

Further research was warranted given the lack of information about the measurement properties of participation tools used to measure outcomes for children using PM. We needed to establish that proposed measurement tools were appropriate for use with children needing PM, before going forward with research examining PM's impact on children's participation in everyday life. Chapter 4 investigated evidence of reliability and validity when using three participation tools with our population. Based on the first two sessions of an interrupted time series research design,

¹¹⁰ this imbedded methodological study was part of a larger feasibility study detailed in the next section. The three tools, each measuring different elements of participation deemed important in Chapter 3, were the PEM-CY, ¹⁷⁸ the Children's Assessment of Participation and Enjoyment (CAPE) ¹⁶⁶ and the Wheelchair Outcome Measure for Young People (WhOM-YP). The PEM-CY, ¹⁷⁸ a parent report, evaluated frequency, involvement and desired change in 25 categories of childhood participation across home, school and community settings. The CAPE, ¹⁶⁶ a child report of leisure participation in out-of-school settings, evaluated diversity, intensity and enjoyment of 55 discrete items, along with where and with whom the child participated. The WhOM-YP evaluated up to 10 individualized participation outcomes inside and outside the home impacted by wheeled mobility use, identified by the child and/or parent as being important.

Preliminary internal consistency evidence was within acceptable range for all three PEM-CY¹⁷⁸ 'desired change' summary scores and all five CAPE¹⁶⁶ overall summary scores (internal consistency was not appropriate for WhOM-YP). Test-retest reliability point estimates were within acceptable limits for PEM-CY ¹⁷⁸ '% desired change' scores, WhOM-YP outside participation mean satisfaction and mean [importance x satisfaction] scores for parents and children aged 5 to 17 years and similarly for WhOM-YP inside participation outcomes for parents and children aged 8-17 years. Test-retest reliability evidence for the CAPE ¹⁶⁶ was not calculated for pragmatic reasons.

Some of our hypothesized relationships between select PEM-CY, ¹⁷⁸ CAPE ¹⁶⁶ and WhOM-YP scores demonstrated statistically significant correlation coefficient estimates supporting validity evidence for relationships with other variables. Validity evidence for discriminating

between known groups was supported as hypothesized by a statistically significant difference in CAPE¹⁶⁶ overall intensity scores between those 12 years and older and those under 12 years, and in WhOM-YP outside mean [importance x satisfaction] summary scores between children who were new to PM versus those experienced with PM. Hypothesized differences on PEM-CY¹⁷⁸ school and community participation frequency % possible scores between two groups (one analysis based on age, another based on PM experience) were not supported, although our small and diverse sample may have influenced results.

Significance: This was the first study to provide reliability and validity evidence for PEM-CY,¹⁷⁸ CAPE¹⁶⁶ and WhOM-YP use with children needing PM. Our findings provide preliminary support for using select summary scores from each tool to measure participation with our population, depending on desired purpose and context for participation measurement.¹¹² Findings also detail participation in multiple dimensions and settings for children using PM and lend support to theoretical models suggesting participation in everyday life is multi-dimensional, complex,^{2, 3, 13} and influenced by children's age.^{5, 13, 38, 40, 51-54} Our results provide evidence of moderate associations between parent and child ratings of a child's participation,^{112, 169} suggesting that although the two perspectives are related, children may have different opinions from their parents in regards to their participation in everyday life. Additionally, minimum detectable difference values (MDD₉₅), calculated as further evidence of validity, may be of value in future studies using the three tools to investigate change in children's participation. Finally this is the first study to examine differences in participation between children needing PM and those who are using PM.

6.5 Establishing Feasible Methods of Conducting Longitudinal Research with Children Using Power Mobility

Having confidence that the measurement tools used are suitable when conducting participation-related research with children using PM is only part of the challenge advancing this field of research. The other challenge is establishing feasible and practical research methods. Chapter 5 reported on a feasibility study^{132, 133} that evaluated viability of conducting longitudinal research with children using PM involving an interrupted time series research design.^{110, 115} This design, useful for determining appropriate evaluation intervals,¹¹⁰ and addressing practical and ethical challenges when random sampling is not viable,^{115, 268} has a level of participant burden not associated with simpler research designs. Feasibility indicators related to specific processes, resources, management, and scientific parameters^{132, 133} were set *a priori* and collected throughout the study to inform future research efforts. End-of-study interviews contributed qualitative data and enhanced evaluation of feasibility.^{320, 321} Most feasibility indicators were evaluated using the full sample of 32 children aged 5 to 17 years and their parents. Eighteen children participated in the first two sessions only, as part of the reliability sample discussed in Chapter 4, while 14 of the 32 participated in three additional sessions evaluating change in participation after receiving a new PM device recommended by their therapist. The majority of our predetermined parameters were met, supporting the feasibility of our study design and methods.^{132, 133} Findings suggest that children using PM may be a ‘hard to reach’ population for research,⁶⁶ and may benefit from additional and more personalized efforts and resources for recruitment and retention.

Significance: Our study is the first to explore feasibility indicators when working with children using PM, their families, and service providers, detailing valuable information for future research planning. Findings support moving forward with a large, multi-site longitudinal study to further investigate participation in everyday life for children using PM. This study provided preliminary information about change in participation after receipt of a new PM device, as well as initial evidence supporting responsiveness of the three participation tools with our population. Calculated effect size values will be useful when determining sample sizes for future participation-focused studies.¹¹⁰

6.6 Limitations

Each chapter has discussed limitations of this dissertation in depth, however several are worth mentioning that may have affected the overall course of the dissertation and interpretation of the research findings. Restricting our initial investigations to peer-reviewed English-language sources of evidence might have inadvertently restricted our consideration of relevant studies and potential participation tools. Quality rating tools and their associated criteria for rating evidence may have influenced our findings and resulting conclusions. Similarly our inclusion and exclusion criteria and recruitment methods for our Delphi survey may have limited input of others who may have different (cultural) perspectives on children's participation worth considering. Our decision to not include a third teenage age group for the Delphi survey as well as not including participation tools designed for adults with mobility limitations^{123, 157, 233, 255} may have altered that study's outcomes, and the tools considered for further evaluation. However, future studies are planned to revisit these topics. Given the nature of our feasibility

study, we might not have had the power to detect statistically significant results and random measurement error might have influenced our analyses. Additionally, we were restricted in our ability to conduct in-depth analyses between subgroups of participants. As a result, generalizability is limited; our findings should be viewed cautiously^{112, 169} and be confirmed with larger samples. The fact that participants comprised a convenience sample, willingness to participate in research may have biased results, and along with other factors not accounted for in the analyses, may also limit generalizability. Future studies should attempt to include samples with people of more diverse cultural and socioeconomic backgrounds, although consideration on how to account for this variability is needed.

6.7 Final Thoughts and Future Directions

In the past, PM was considered an intervention of last resort. We are now recognizing the importance of using PM with children to increase independence and overall development, with clinical practice shifting to provide PM earlier in life. However, PM equipment can cost tens of thousands of dollars depending on complexity and need, and requires replacement as children grow or needs change. Funding is limited and consequently, health services and systems decision makers demand evidence to demonstrate that PM interventions are effective.

This dissertation presented the argument for and the evidence to support our increasing knowledge and understanding of participation outcomes associated with use of PM devices in everyday life by children with mobility limitations. Employing integrative knowledge exchange,

our findings identified participation elements that are important to measure for children using PM, and identified potential participation tools to explore outcomes relating to these elements for research and service applications. Our results presented preliminary evidence of three tools' measurement properties with children using PM, advanced our understanding of how children using PM participate in everyday life, and gathered new findings that suggested changes in participation outcomes following the receipt of a new PM device. This dissertation has provided foundational evidence on how children using PM participate in everyday life, and importantly provided a crucial underpinning for further discussions and investigations relevant to this topic.

However, this is just the beginning of a program of research investigating how PM can benefit the lives of children and their families. Further work is needed to confirm the value and utility of the three participation tools with larger samples, determine clinical importance of change scores, affirm elements of participation important to measure with children and other stakeholders, and examine elements of participation important to measure for youth. Future investigations may also include evaluating suitability of other participation tools identified in this dissertation (including those measuring participation for younger children and their families), modifying or developing more appropriate measurement tools for this population. Our intent is to provide appropriate measurement tools to investigate participation outcomes more systematically with larger samples to strengthen evidence of PM's value as a therapeutic intervention and its' impact on children's participation in everyday life. Developing and measuring strategies supporting knowledge exchange and implementation will be an important aspect of this work.

Additionally, more rigorous examination of contextual factors is needed that support or

restrict children's participation when using PM, such as children's personal characteristics and surrounding physical, social, attitudinal, institutional and societal influences. This information may be used to enhance, develop and evaluate resources and strategies directed at improving PM assessment and training to optimize children's participation in everyday life. This may be accomplished by exploring analyses developed to take into account the variability within and between individuals seen in our feasibility study. Finally another direction worthy of research is examining changes in brain functioning with independent PM mobility experiences (using functional magnetic resonance imaging and other such technologies) that promote development and contribute to engagement in meaningful life situations. Taken together, this research aims to demonstrate the value and effectiveness of PM as a key therapeutic intervention for improving developmental trajectories and life prospects for children with mobility limitations.

References

1. Lepage C, Noreau L, Bernard PM. Association between characteristics of locomotion and accomplishment of life habits in children with cerebral palsy. *Phys Ther* 1998;78(5):458-69.
2. Kang LJ, Palisano RJ, King GA, Chiarello LA. A multidimensional model of optimal participation of children with physical disabilities. *Disabil Rehabil Assist Technol* 2014;36:1735-41.
3. King G, Law M, King S, Rosenbaum P, Kertoy MK, Young NL. A conceptual model of the factors affecting the recreation and leisure participation of children with disabilities. *Phys Occup Ther Pediatr* 2003;23(1):63-90.
4. Law M. Participation in the occupations of everyday life. *Am J Occup Ther* 2002;56(6):640-9.
5. Dahan-Oliel N, Shikako-Thomas K, Majnemer A. Quality of life and leisure participation in children with neurodevelopmental disabilities: a thematic analysis of the literature. *Qual Life Res* 2012;21(3):427-39.
6. Lynch A, Ryu J, Agrawal S, Galloway JC. Power mobility training for a 7-month-old infant with spina bifida. *Pediatr Phys Ther* 2009;21(4):362-8.
7. May M, Rugg S. Electrically powered indoor/outdoor wheelchairs: Recipients' views of their effects on occupational performance and quality of life. *Br J Occup Ther* 2010;73(1):2-12.
8. Hardy P. Powered wheelchair mobility: An occupational performance evaluation perspective. *Aust Occup Ther J* 2004;51(1):34-42.
9. Rousseau-Harrison K, Rochette A. Impacts of wheelchair acquisition on children from a person-occupation-environment interactional perspective. *Disabil Rehabil Assist Technol* 2013;8(1):1-10.
10. Livingstone R, Field D. Systematic review of power mobility outcomes for infants, children and adolescents with mobility limitations. *Clin Rehabil* 2014;28(10):954-64.
11. Bray N, Noyes J, Edwards RT, Harris N. Wheelchair interventions, services and provision for disabled children: A mixed-method systematic review and conceptual framework. *BMC Health Services Research* 2014;14:309.
12. Majnemer A. Benefits of using outcome measures in pediatric rehabilitation. *Phys Occup Ther Pediatr* 2010;30(3):165-7.
13. Palisano RJ, Chiarello LA, King GA, Novak I, Stoner T, Fiss A. Participation-based therapy for children with physical disabilities. *Disabil Rehabil* 2012;34(12):1041-52.
14. Guerette P, Tefft D, Furumasu J. Pediatric powered wheelchairs: results of a national survey of providers. *Assist Technol* 2005;17(2):144-58.

15. Office of Disability Issues. Disability in Canada: A 2001 profile. Ottawa: Queens Printer; 2003. Available from <http://www.statcan.gc.ca/pub/89-577-x/index-eng.htm> Retrieved Jan 31, 2010.
16. Statistics Canada. Participation and Activity Limitation Survey 2006: A profile of assistive technology for people with disabilities in Canada. Ottawa: Statistics Canada; 2008. Report 89-628-X no. 005. Available from <http://www.statcan.gc.ca/pub/89-628-x/89-628-x2007002-eng.htm>. Retrieved Jan 31, 2010.
17. Wiart L, Darrach J, Cook A, Hollis V, May L. Evaluation of powered mobility use in home and community environments. *Phys Occup Ther Pediatr* 2003;23(2):59-75.
18. LaPlante MP, Kaye HS. Demographics and trends in wheeled mobility equipment use and accessibility in the community. *Assist Technol* 2010;22(1):3-17.
19. Routhier F, Vincent C, Desrosiers J, Nadeau S. Mobility of wheelchair users: a proposed performance assessment framework. *Disabil Rehabil* 2003;25(1):19-34.
20. Wiart L. Exploring mobility options for children with physical disabilities: A focus on powered mobility. *Phys Occup Ther Pediatr* 2011;31(1):16-8.
21. Livingstone R, Paleg G. Practice considerations for use and introduction of power mobility with children. *Dev Med Child Neurol* 2014;56(3):210-21.
22. Casey J, Paleg G, Livingstone R. Facilitating child participation through power mobility. *Br J Occup Ther* 2013;76(3):158-60.
23. Palisano RJ, Tieman BL, Walter SD, Bartlett DJ, Rosenbaum PL, Russell D, et al. Effect of environmental setting on mobility methods of children with cerebral palsy. *Dev Med Child Neurol* 2003;45(2):113-20.
24. Rodby-Bousquet E, Hagglund G. Use of manual and powered wheelchair in children with cerebral palsy: A cross-sectional study. *BMC Pediatrics* 2010;10(1):59.
25. Jones MA, McEwen IR, Neas BR. Effects of power wheelchairs on the development and function of young children with severe motor impairments. *Pediatr Phys Ther* 2012;24:131-40.
26. Assistive devices in Canada: ensuring inclusion and independence [Internet]; c2007 Available from: [http://www.archdisabilitylaw.ca/sites/all/files/ASSISTIVE%20DEVICES%20FINAL%20REPORT%20\(incl.%20exec%20summary\)%20-%20June%2029%202007%20-%20Text.txt](http://www.archdisabilitylaw.ca/sites/all/files/ASSISTIVE%20DEVICES%20FINAL%20REPORT%20(incl.%20exec%20summary)%20-%20June%2029%202007%20-%20Text.txt). Retrieved Jan 18, 2013.
27. Quay T, de Léséleuc L. Power mobility for preschool children. Ottawa: Canadian Agency for Drugs and Technologies in Health Ottawa ON: CADTH; 2016. (Environmental scan; no. 55) Available from <https://www.cadth.ca/power-mobility-technologies-children-six-years-under-disability-mobility-limitation>. Retrieved March 1, 2016.

28. Home AM, Ham R. Provision of powered mobility equipment to young children: the Whizz-Kidz experience. *Int J Ther Rehabil* 2003;10(11):511-7.
29. Rosenbaum P, King S, Law M, King G, Evans J. Family-centred service: A conceptual framework and research review. *Phys Occup Ther Pediatr* 1998;18(1):1-20.
30. Huhn K, Guarrera-Bowlby P, Deutsch JE. The clinical decision-making process of prescribing power mobility for a child with cerebral palsy. *Pediatr Phys Ther* 2007;19(3):254-60.
31. Scherer MJ, Glueckauf R. Assessing the benefits of assistive technologies for activities and participation. *Rehabil Psych* 2005;50(2):132-41.
32. Riemer-Reiss ML, Wacker RR. Factors associated with assistive technology discontinuance among individuals with disabilities. *J Rehabil* 2000;66(3):44-50.
33. World Health Organization. *International Classification of Functioning, Disability and Health (ICF)*. Geneva, Switzerland: World Health Organization; 2001.
34. World Health Organization. *International Classification of Functioning, Disability, and Health - Children and Youth*. Geneva, Switzerland: World Health Organization; 2007.
35. Coster W, Khetani MA. Measuring participation of children with disabilities: Issues and challenges. *Disabil Rehabil* 2008;30(8):639-48.
36. Adolfsson M, Malmqvist J, Pless M, Granulid M. Identifying child functioning from an ICF-CY perspective: Everyday life situations explored in measures of participation. *Disabil Rehabil* 2011;33(13-14):1230-44.
37. Galvin J, Froude EH, McAleer J. Children's participation in home, school and community life after acquired brain injury. *Aust Occup Ther J* 2010;57(2):118-26.
38. Ziviani J, Desha L, Feeney R, Boyd R. Measures of participation outcomes and environmental considerations for children with acquired brain injury: A systematic review. *Brain Impair* 2010;11(2):93-112.
39. King G, Petrenchik T, Law M, Hurley P. The enjoyment of formal and informal recreation and leisure activities: A comparison of school-aged children with and without disabilities. *Int J Disabil Dev Educ* 2009;56(2):109-30.
40. King G, Law M, Hurley P, Petrenchik T, Schwellnus H. A developmental comparison of the out-of-school recreation and leisure activity participation of boys and girls with and without physical disabilities. *Int J Disabil Dev Ed* 2010;57(1):77-107.
41. Engel-Yeger B, Jarus T, Anaby D, Law M. Differences in patterns of participation between youths with cerebral palsy and typically developing peers. *Am J Occup Ther* 2009;63(1):96-104.

42. Jarus T, Anaby D, Bart O, Engel-Yeger B, Law M. Childhood participation in after-school activities: what is to be expected? *Br J Occup Ther* 2010;73(8):344-50.
43. Almqvist L, Granlund M. Participation in school environment of children and youth with disabilities: A person-oriented approach. *Scand J Psychol* 2005;46(3):305-14.
44. Agnihotri S, Lynn Keightley M, Colantonio A, Cameron D, Polatajko H. Community integration interventions for youth with acquired brain injuries: A review. *Dev Neurorehabil* 2010;13(5):369-82.
45. McManus V, Corcoran P, Perry IJ. Participation in everyday activities and quality of life in pre-teenage children living with cerebral palsy in South West Ireland. *BMC Pediatr* 2008;8:50.
46. Bult M, Verschuren O, Jongmans M, Lindeman E, Ketelaar M. What influences participation in leisure activities of children and youth with physical disabilities? A systematic review. *Res Dev Disabil* 2011;32:1521-9.
47. Masse LC, Miller AR, Shen J, Schiariti V, Roxborough L. Comparing participation in activities among children with disabilities. *Res Dev Disabil* 2012;33:2245-54.
48. Shikako-Thomas K, Majnemer A, Law M, Lach L. Determinants of participation in leisure activities in children and youth with cerebral palsy: systematic review. *Phys Occup Ther Pediatr* 2008;28(2):155-69.
49. Rosenberg L, Jarus T, Bart O. Development and initial validation of the Children Participation Questionnaire (CPQ). *Disabil Rehabil* 2010;32(20):1633-44.
50. Law M, King G, King S, Kertoy M, Hurley P, Rosenbaum P, Young N, Hanna S. Patterns of participation in recreational and leisure activities among children with complex physical disabilities. *Dev Med Child Neurol* 2006;48(5):337-42.
51. Koster M, Pijl SJ, Nakken H, Van Houten E. Social participation of students with special needs in regular primary education in the Netherlands. *Int J Disabil Dev Ed* 2010;57(1):59-75.
52. King G, McDougall J, DeWit D, Petrenchik T, Hurley P, Law M. Predictors of change over time in the activity participation of children and youth with physical disabilities. *Children's Health Care* 2009;38(4):321-51.
53. Bendixen RM, Lott DJ, Senesac C, Mathur S, Vandenborne K. Participation in daily life activities and its relationship to strength and functional measures in boys with Duchenne muscular dystrophy. *Disabil Rehabil* 2014;36(22):1918-23.
54. Flanagan A, Kelly EH, Vogel LC. Psychosocial outcomes of children and adolescents with early-onset spinal cord injury and those with spina bifida. *Pediatr Phys Ther* 2013;25(4):452-9.
55. Ullenhag A, Bult MK, Nyquist A, Ketelaar M, Jahnsen R, Krumlinde-Sundholm L, Almqvist L, Granlund M. An international comparison of patterns of participation in leisure activities for

children with and without disabilities in Sweden, Norway and the Netherlands. *Dev Neurorehabil* 2013;15(5):369-85.

56. Heah T, Case T, McGuire B, Law M. Successful participation: The lived experience among children with disabilities. *Can J Occup Ther* 2007;74(1):38-47.
57. Law M, Anaby D, DeMatteo C, Hanna S. Participation patterns of children with acquired brain injury. *Brain Injury* 2011;25(6):587-95.
58. Anaby D, Law M, Hanna S, DeMatteo C. Predictors of change in participation rates following acquired brain injury: Results of a longitudinal study. *Dev Med Child Neurol* 2012; 54(4):339-46.
59. Hynes K, Galvin J, Howie L. Exploring the leisure experiences of young people with spinal cord injury or disease. *Dev Neurorehabil* 2012 15(5):361-8.
60. Johnson KA, Klaas SJ, Vogel LC, McDonald C. Leisure characteristics of the pediatric spinal cord injury population. *J Spinal Cord Med* 2004;27:S107-9.
61. Klaas SJ, Kelly EH, Gorzkowski J, Homko E, Vogel LC. Assessing patterns of participation and enjoyment in children with spinal cord injury. *Dev Med Child Neurol* 2010;52(5):468-74.
62. Imms C. Children with cerebral palsy participate: A review of the literature. *Disabil Rehabil* 2008;30(24):1867-84.
63. Palisano RJ, Chiarello LA, Orlin M, Oeffinger D, Polansky M, Maggs J, Bagley A, Gorton G. Determinants of intensity of participation in leisure and recreational activities by children with cerebral palsy. *Dev Med Child Neurol* 2011;53(2):142-9.
64. Chiarello LA, Palisano RJ, Bartlett DJ, McCoy SW. A multivariate model of determinants of change in gross-motor abilities and engagement in self-care and play of young children with cerebral palsy. *Phys Occup Ther Pediatr* 2011;31(2):150-68.
65. Palisano RJ, Kang LJ, Chiarello LA, Orlin M, Oeffinger D, Maggs J. Social and community participation of children and youth with cerebral palsy is associated with age and gross motor function classification. *Phys Ther* 2009;89(12):1304-14.
66. King G. Perspectives on measuring participation: Going forward. *Child Care Health Dev* 2013;39(4):466-9.
67. Bottos M, Bolcati C, Sciuto L, Ruggeri C, Feliciangeli A. Powered wheelchairs and independence in young children with tetraplegia. *Dev Med Child Neurol* 2001;43:769-77.
68. Butler C, Okamoto GA, McKay TM. Motorized wheelchair driving by disabled children. *Arch Phys Med Rehabil* 1984;65(2):95-7.

69. Dunaway S, Montes J, O'Hagen J, Sproule DM, Darryl C, Kaufmann P. Independent mobility after early introduction of a power wheelchair in spinal muscular atrophy. *J Child Neurol* 2012;28(5):576-582.
70. Jones MA, McEwen IR, Hansen L. Use of power mobility for a young child with spinal muscular atrophy. *Phys Ther* 2003;83(3):253-62.
71. Galloway JC, Ryu JC, Agrawal SK. Babies driving robots: self-generated mobility in very young infants. *Intel Serv Robotics* 2008;1(2):123-34.
72. Logan SW. Modified ride-on car use by children with complex medical needs. *Pediatr Phys Ther* 2016;28(1):100-107.
73. McGarry S, Moir L, Girdler S. The smart wheelchair: is it an appropriate mobility training tool for children with physical disabilities? *Disabil Rehabil Assist Technol* 2012;7(5):372-80.
74. Deitz J, Swinth Y, White O. Powered mobility and preschoolers with complex developmental delays. *Amer J Occup Ther* 2002;56(1):86-96.
75. Ragonesi CB, Chen X, Agrawal S, Galloway JC. Power mobility and socialization in preschool: follow-up case study of a child with cerebral palsy. *Pediatr Phys Ther* 2011;23(4):399-406.
76. Furumasu J, Guerette P, Tefft D. The development of a powered wheelchair mobility program for young children. *Technol Disabil* 1996;5:41-8.
77. Durkin J. Discovering powered mobility skills with children: 'Responsive partners' in learning. *Int J Ther Rehabil* 2009;16(6):331-41.
78. Nilsson L, Eklund M, Nyberg P. Driving to learn in a powered wheelchair: Inter-rater reliability of a tool for assessment of joystick-use. *Aust Occup Ther J* 2011;58(6):447-54.
79. Nilsson L, Durkin J. Assessment of learning powered mobility use—Applying grounded theory to occupational performance. *J Rehabil Research Dev* 2014;51(6):963-74.
80. Livingstone R, Field D. The child and family experience of power mobility: a qualitative synthesis. *Dev Med Child Neurol* 2015;57(4):317-27.
81. Henderson S, Skelton H, Rosenbaum P. Assistive devices for children with functional impairments: impact on child and caregiver function. *Dev Med Child Neurol* 2008;50(2):89-98.
82. Nicolson A, Moir L, Millsteed J. Impact of assistive technology on family caregivers of children with physical disabilities: a systematic review. *Disabil Rehabil Assist Technol* 2012;7(5):345-9.
83. CASP Checklists Oxford. CASP [Internet]; c2013. Available from: <http://www.casp-uk.net/#!casp-tools-checklists/c18f8>. Retrieved July 31, 2013.

84. Critical Appraisal Questionnaires. Amsterdam The Netherlands [Internet]; c2013. Available from: <http://www.cebma.org/frequently-asked-questions/what-is-critical-appraisal/>. Retrieved July 31, 2013.
85. Darrach J, Hickman R, O'Donnell M, Vogtle L, Wiart L. AACPDm methodology to develop systematic reviews of treatment interventions (revision 1.2). Milwaukee, WI: American Academy for Cerebral Palsy and Developmental Medicine 2008.
86. Tefft D, Guerette P, Furumasu J. The impact of early powered mobility on parental stress, negative emotions, and family social interactions. *Phys Occup Ther Pediatr* 2011;31(1):4-15.
87. Guerette P, Furumasu J, Tefft D. The positive effects of early powered mobility on children's psychosocial and play skills. *Assist Technol* 2013;25(1):39-48.
88. Kenyon LK, Farris JP, Gallagher C, Hammond L, Webster LM, Aldrich NJ. Power mobility training for young children with multiple, severe impairments: A case series. *Phys Occup Ther Pediatr* 2015;1-16.
89. Kenyon LK, Farris J, Brockway K, Hannum N, Proctor K. Promoting self-exploration and function through an individualized power mobility training program. *Pediatr Phys Ther* 2015;27(2):200-6.
90. Logan SW, Huang HH, Stahlin K, Galloway JC. Modified ride-on car for mobility and socialization: single-case study of an infant with Down syndrome. *Pediatr Phys Ther* 2014;26(4):418-26.
91. Huang HH, Ragonesi CB, Stoner T, Peffley T, Galloway JC. Modified toy cars for mobility and socialization: case report of a child with cerebral palsy. *Pediatr Phys Ther* 2014;26(1):76-84.
92. Benedict RE, Lee JP, Marrujo SK, Farel AM. Assistive devices as an early childhood intervention: Evaluating outcomes. *Technol Disabil* 1999;11(1/2):79-90.
93. Fougereyrollas P, Noreau L, Bergeron H, Cloutier R, Dion S, St-Michel G. Social consequences of long term impairments and disabilities: conceptual approach and assessment of handicap. *Int J Rehabil Res* 1998;21(2):127-41.
94. Haley SM, Coster W, Ludlow L, Haltiwanger J, Andrellos P. *Pediatric Evaluation of Disability Inventory (PEDI): Development, standardization and administration manual*. Boston MA: Trustees of Boston University; 1992.
95. Dumas HM, Fragala-Pinkham MA, Feng T, Haley SM. A preliminary evaluation of the PEDI-CAT mobility item bank for children using walking aids and wheelchairs. *J Pediatr Rehabil Med* 2012;5(1).
96. Law M, Baptiste S, McColl M, Opzoomer A, Polatajko H, Pollock N. The Canadian Occupational Performance Measure: An outcome measure for occupational therapy. *Can J Occup Ther* 1990;57(2):82-7.

97. Scherer M. Matching assistive technology & child (MATCH). A process and series of assessments for selecting and evaluating technologies used by infants and young children. Webster, NY: Institute for Matching Person & Technology; 1998.
98. Scherer MJ, Craddock G. Matching person & technology (MPT) assessment process. *Technol Disabil* 2002;14(3):125-31.
99. Hogan AE, Scott KG, Bauer CR. The Adaptive Social Behavior Inventory (ASBI): A new assessment of social competence in high-risk three-year-olds. *J Psychoed Assess* 1992;10(3):230-9.
100. Newborg J, Stock J, Wnek L, Guidubaldi J, Svincki J, Dickson J, Markley A. The Battelle Developmental Inventory: Examiner's manual. Allen, TX: DLM/Teaching Resources; 1988.
101. Zeitlin S, Williamson GG. Early Coping Inventory: a measure of adaptive behavior. Bensenville IL: Scholastic Testing Service; 1988.
102. Morgan GA, Busch-Rossnagel NA, Barrett KC, Wang J. The Dimensions of Mastery Questionnaire (DMQ): A manual about its development, psychometrics, and use. Fort Collins CO: Colorado State University 2009.
103. Narayanan UG, Fehlings D, Weir S, Knights S, Kiran S, Campbell K. Initial development and validation of the Caregiver Priorities and Child health Index of Life with Disabilities (CPCHILD). *Dev Med Child Neurol* 2006;48(10):804-12.
104. Sprigle S, Cohen L, Davis K. Establishing seating and wheeled mobility research priorities. *Disabil Rehabil Assist Technol* 2007;2(3):169-72.
105. King G, Wright V, Russell DJ. Understanding paediatric rehabilitation therapists' lack of use of outcome measures. *Disabil Rehabil* 2011;33(25-26):2662-71.
106. Guyatt GH, Kirshner B, Jaeschke R. Measuring health status: what are the necessary measurement properties? *J Clin Epidemiol* 1992;45(12):1341-5.
107. Messick S. Standards of validity and the validity of standards in performance assessment. *Ed Meas Issues Practice* 1995;14(4):5-8.
108. Küçükdeveci AA, Tennant A, Grimby G, Franchignoni F. Strategies for assessment and outcome measurement in physical and rehabilitation medicine: an educational review. *J Rehabil Med* 2011;43:661-72.
109. Morris C, Kurinczuk JJ, Fitzpatrick R. Child or family assessed measures of activity performance and participation for children with cerebral palsy: a structured review. *Child Care Health Dev* 2005;31(4):397-407.
110. Portney LG, Watkins MP. Foundations of clinical research: applications to practice. 3rd ed. Upper Saddle River, NJ: Pearson Education Inc.; 2009.

111. Schmitt N. Uses and abuses of coefficient alpha. *Psych Assess* 1996;8(4):350-3.
112. Streiner DL, Norman GR. Health measurement scales: a practical guide to their development and use. Oxford UK: Oxford University Press; 2008.
113. Chan EKH. Standards and guidelines for validation practices: Development and evaluation of measurement instruments. In: *Validity and validation in social, behavioral, and health sciences*. London, UK: Springer International Publishing; 2014, 9-24.
114. Zumbo BD. Validity as contextualized and pragmatic explanation, and its implications for validation practice. In: *The concept of validity: Revisions, new directions and applications* Charlotte NC: Information Age Publishing Inc.; 2009:65–82.
115. Stratford PW, Binkley FM, Riddle DL. Health status measures: strategies and analytic methods for assessing change scores. *Phys Ther* 1996;76(10):1109-23.
116. Hays RD. Responsiveness to change: An aspect of validity, not a separate dimension. *Qual Life Res* 1992;1(1):73-5
117. Beaton DE, Bombardier C, Katz JN, Wright JG. A taxonomy for responsiveness. *J Clin Epidemiol* 2001;54(12):1204-17.
118. Haley SM, Fragala-Pinkham MA. Interpreting change scores of tests and measures used in physical therapy. *Phys Ther* 2006;86(5):735-43.
119. Husted JA, Cook RJ, Farewell VT, Gladman DD. Methods for assessing responsiveness: a critical review and recommendations. *J Clin Epidemiol* 2000;53(5):459-68.
120. de Bruin AF, Diederiks JPM, de Witte LP, Stevens FCJ, Philipsen H. Assessing the responsiveness of a functional status measure: the Sickness Impact Profile versus the SIP68. *J Clin Epidemiol* 1997;50(5):529-40.
121. Sakzewski L, Boyd R, Ziviani J. Clinimetric properties of participation measures for 5- to 13-year-old children with cerebral palsy: a systematic review. *Dev Med Child Neurol* 2007;49(3):232-40.
122. McConachie H, Colver AF, Forsyth RJ, Jarvis SN, Parkinson KN. Participation of disabled children: how should it be characterised and measured? *Disabil Rehabil* 2006;28(18):1157-64.
123. Mortenson WB, Miller WC, Auger C. Issues for the selection of wheelchair-specific activity and participation outcome measures: a review. *Arch Phys Med Rehabil* 2008;89(6):1177-86.
124. Terwee CB, Mokkink LB, Knol DL, Ostelo RWJG, Bouter LM, de Vet HCW. Rating the methodological quality in systematic reviews of studies on measurement properties: A scoring system for the COSMIN checklist. *Qual Life Res* 2012;21:651-7.

125. Outcome Measures Rating Form Guidelines. [Internet]Hamilton,Canada: CanChild Centre for Childhood Disability Research; c2004. Available from: <http://www.canchild.ca/en/canchildresources/resources/measguid.pdf>. Retrieved July 9,2010.
126. McDougall J, Wright V, Rosenbaum P. The ICF model of functioning and disability: incorporating quality of life and human development. *Dev Neurorehabil* 2010;13(3):204-11.
127. Bedell GM, Khetani MA, Cousins MA, Coster WJ, Law MC. Parent perspectives to inform development of measures of children's participation and environment. *Arch Phys Med Rehabil* 2011;92(5):765-73.
128. Dijkers MP. Issues in the conceptualization and measurement of participation: an overview. *Arch Phys Med Rehabil* 2010;91(9):S5-16.
129. Chapparo C, Ranka J, editors. Occupational performance model (Australia). Monograph 1. Sydney NSW: Occupational Performance Network; 1997. Available from: <http://www.occupationalperformance.com/wp-content/uploads/2014/01/structure.pdf>. Retrieved January 31, 2010.
130. Palisano RJ, Shimmell LJ, Stewart D, Lawless JJ, Rosenbaum PL, Russell DJ. Mobility experiences of adolescents with cerebral palsy. *Phys Occup Ther Pediatr* 2009;29(2):133-53.
131. Butler C. Measuring participation for children with mobility limitations: a modified Delphi survey for those who use power mobility. *Dev Med Child Neurol* 2015;57(6):500.
132. Van Teijlingen ER, Rennie AM, Hundley V, Graham W. The importance of conducting and reporting pilot studies: the example of the Scottish births survey. *J Adv Nurs* 2001;34(3):289-95.
133. Thabane L, Ma J, Chu R, Cheng J, Ismaila A, Rios L, Robson R, Thabane M, Giangregorio L, Goldsmith C. A tutorial on pilot studies: the what, why and how. *BMC Medical Research Methodology* 2010;10(1):1.
134. Moore CG, Carter RE, Nietert PJ, Stewart PW. Recommendations for planning pilot studies in clinical and translational research. *Clin Translational Science* 2011;4(5):332-7.
135. Ragonesi CB, Chen X, Agrawal S, Galloway JC. Power mobility and socialization in preschool: a case study of a child with cerebral palsy. *Pediatr Phys Ther* 2010;22(3):322-29.
136. Nisbet PD. Assessment and training of children for powered mobility in the UK. *Technol Disabil* 2002;14(4):173-82.
137. Nisbet P, Craig J, Odor P, Aitken S. 'Smart' wheelchairs for mobility training. *Technol Disabil* 1996;5:49-62.
138. Everard L. The wheelchair toddler. *Health Visitor* 1984 Aug;57(8):241-2.
139. Gudgeon S, Kirk S. Living with a powered wheelchair: exploring children's and young people's experiences. *Disabil Rehabil Assist Technol* 2015;10(2):118-25.

140. Huang IC, Sugden D, Beveridge S. Children's perceptions of their use of assistive devices in home and school settings. *Disabil Rehabil Assist Technol* 2009;4(2):95-105.
141. Evans S, Neophytou C, de Souza L, Frank AO. Young people's experiences using electric powered indoor - outdoor wheelchairs (EPIOCs): Potential for enhancing users' development? *Disabil Rehabil* 2007;29(16):1281-94.
142. Wiart L, Darrah J, Hollis V, Cook A, May L. Mothers' perceptions of their children's use of powered mobility. *Phys Occup Ther Pediatr* 2004;24(4):3-21.
143. Skär L. Disabled children's perceptions of technical aids, assistance and peers in play situations. *Scand J Caring Sci* 2002;16(1):27-33.
144. Hoare P, Russell M. The quality of life of children with chronic epilepsy and their families: preliminary findings with a new assessment measure. *Dev Med Child Neurol* 1995;37(8):689-96.
145. Berry ET, McLaurin SE, Sparling JW. Parent/caregiver perspectives on the use of power wheelchairs. *Pediatr Phys Ther* 1996;8(4):146-50.
146. Douglas J, Ryan M. A preschool severely disabled boy and his powered wheelchair: a case study. *Child Care, Health Dev* 1987;13(5):303-9.
147. Williams G, Willmott C. Higher levels of mobility are associated with greater societal participation and better quality-of-life. *Brain Injury* 2012;26(9):1065-71.
148. Bedell G, Coster W. Measuring participation of school-aged children with traumatic brain injuries: considerations and approaches. *J Head Trauma Rehabil* 2008;23(4):220-9.
149. Rainey L, van Nispen R, van der Zee C, van Rens G. Measurement properties of questionnaires assessing participation in children and adolescents with a disability: a systematic review. *Qual Life Res* 2014;23:2793-808.
150. Chien C, Rodger S, Copley J, McLaren C. Measures of participation outcomes related to hand use for 2- to 12-year-old children with disabilities: a systematic review. *Child Care Health Dev* 2014;95:141-52.
151. Phillips RL, Olds T, Boshoff K, Lane AE. Measuring activity and participation in children and adolescents with disabilities: A literature review of available instruments. *Aust Occup Ther J* 2013;60(4):288-300
152. Dunford C, Bannigan K, Wales L. Measuring activity and participation outcomes for children and youth with acquired brain injury: an occupational therapy perspective. *Br J Occup Ther* 2013;76(2):67-76.
153. van Tol E, Gorter JW, DeMatteo C, Meester-Delver A. Participation outcomes for children with acquired brain injury: A narrative review. *Brain Injury* 2011(0):1-9.

154. Schiariti V, Klassen AF, Cieza A, Sauve K, O'Donnell M, Armstrong R, Mâsse LC. Comparing contents of outcome measures in cerebral palsy using the international classification of functioning (ICF-CY): A systematic review. *Eur J Paediatr Neurol* 2014;18(1):1-12.
155. Vargus-Adams J, Martin LK. Measuring what matters in cerebral palsy: a breadth of important domains and outcome measures. *Arch Phys Med Rehabil* 2009 12;90(12):2089-95.
156. McCauley SR, Wilde EA, Anderson VA, Bedell G, Beers SR, Campbell TF, Chapman SB, Ewing-Cobbs L, Gerring JP, Gioia GA. Recommendations for the use of common outcome measures in pediatric traumatic brain injury research. *J Neurotrauma* 2012;29(4):678-705.
157. Harris F. Conceptual issues in the measurement of participation among wheeled mobility device users. *Disabil Rehabil Assist Technol* 2007;2(3):137-48.
158. Kerfeld CI, Dudgeon BJ, Engel JM, Kartin D. Development of items that assess physical function in children who use wheelchairs. *Pediatr Phys Ther* 2013;25(2):158-66.
159. Assessing the quality and applicability of systematic reviews (AQASR). Austin, TX: SEDL, Center on Knowledge Translation for Disability and Rehabilitation Research [Internet]Austin, TX: SEDL, National Center for the Dissemination of Disability Research; c2013. Available from: http://www.ktdrr.org/ktlibrary/articles_pubs/ncddrwork/aqasr/index.html. Retrieved Nov 6, 2014.
160. Dijkers MP, Bushnik T, Heinemann AW, Heller T, Libin AV, Starks J, Sherer M, Vandergoot D. Systematic reviews for informing rehabilitation practice: an introduction. *Arch Phys Med Rehabil* 2012 5;93(5):912-8.
161. Moher D, Liberati A, Tetzlaff J, Altman DG, PRISMA Group. The Preferred Reporting Items for Systematic reviews and Meta-Analyses: The PRISMA statement. *BMJ* 2009;339:b2535,doi: 10.1136/bmj.b2535.
162. Law M, King G, Petrenchik T, Kertoy M, Anaby D. The assessment of preschool children's participation: internal consistency and construct validity. *Phys Occup Ther Pediatr* 2012;32(3):272-87.
163. Bourke-Taylor H, Law M, Howie L, Pallant JF. Development of the Assistance to Participate Scale (APS) for children's play and leisure activities. *Child Care Health Dev* 2009;35(5):738-45.
164. Simeonsson R,J., Carlson D, Huntington GS, Sturtz McMillen J, Lytle Brent J. Students with disabilities: A national survey of participation in school activities. *Disabil Rehabil* 2001;23(2):49-63.
165. Eriksson L. The relationship between school environment and participation for students with disabilities. *Dev Neurorehabil* 2005;8(2):130-9
166. King GA, Law M, King S, Hurley P, Hanna S, Kertoy M, Rosenbaum P. Measuring children's participation in recreation and leisure activities: construct validation of the CAPE and PAC. *Child Care Health Dev* 2006;33(1):28-39.

167. Ehrmann LC, Aeschleman SR, Svanum S. Parental reports of community activity patterns: A comparison between young children with disabilities and their nondisabled peers. *Res Dev Disabil* 1995;16(4):331-43.
168. Bedell GM. Developing a follow-up survey focused on participation of children and youth with acquired brain injuries after discharge from inpatient rehabilitation. *NeuroRehabil* 2004;19(3):191-205.
169. McDougall J, Bedell G, Wright V. The youth report version of the Child and Adolescent Scale of Participation (CASP): Assessment of psychometric properties and comparison with parent report. *Child Care Health Dev* 2013;39(4):512-22.
170. Chiarello LA, Palisano RJ, McCoy SW, Bartlett DJ, Wood A, Chang H, Kang L, Avery L. Child engagement in daily life: a measure of participation for young children with cerebral palsy. *Disabil Rehabil* 2014;36(21):1804-16.
171. Dunn L. Validation of the CHORES: A measure of school-aged children's participation in household tasks. *Scand J Occ Ther* 2004;11(4):179-90.
172. Cusick A, Lannin NA, Lowe K. Adapting the Canadian Occupational Performance Measure for use in a paediatric clinical trial. *Disabil Rehabil* 2007;29(10):761-6.
173. Keller J, Kafkes A, Kielhofner G. Psychometric characteristics of the Child Occupational Self-Assessment (COSA), part one: an initial examination of psychometric properties. *Scand J Occ Ther* 2005;12(3):118-27.
174. Michelsen SI, Flachs EM, Uldall P, Eriksen EL, McManus V, Parkes J, Parkinson KN, Thyen U, Arnaud C, Beckung E, Dickinson HO. Frequency of participation of 8-12-year-old children with cerebral palsy: A multi-centre cross-sectional European study. *Eur J Pediatr Neurol* 2009;13(2):165-77.
175. Malec JF, Moessner AM, Kragness M, Lezak MD. Refining a measure of brain injury sequelae to predict postacute rehabilitation outcome: rating scale analysis of the Mayo-Portland Adaptability Inventory. *J Head Trauma Rehabil* 2000;15(1):670-82.
176. Oddson B, Rumney P, Johnson P, Thomas-Stonell N. Clinical use of the Mayo-Portland Adaptability Inventory in rehabilitation after paediatric acquired brain injury. *Dev Med Child Neurol* 2006;48(11):918-22.
177. Washington LA, Wilson S, Engel JM, Jensen MP. Development and preliminary evaluation of a pediatric measure of community integration: The Pediatric Community Participation Questionnaire (PCPQ). *Rehabil Psychol* 2007;52(2):241-5.
178. Coster W, Bedell G, Law M, Khetani MA, Teplicky R, Liljenquist K, Gleason K, Kao YC. Psychometric evaluation of the participation and environment measure for children and youth. *Dev Med Child Neurol* 2011;53(11):1030-7.

179. Henry AD. Development of a measure of adolescent leisure interests. *Am J Occup Ther* 1998;52(7):531-9.
180. Berg C, LaVesser P. The preschool activity card sort. *OTJR Occupation, Participation Health* 2006;26(4):143-51.
181. Gronski MP, Niemann A, Berg C. Participation patterns of urban preschoolers attending head start. *OTJR: Occupation, Participation and Health* 2013;33(2):68-75.
182. Hayes RP, Vogtle LK, Allaire J, Jones AK, Blair AE. Development and preliminary validation of a measure of social functioning for adolescents with physical disabilities. *J Rehabil Outcomes Measurement* 1999;3(3):34-41.
183. Tuffrey C, Bateman BJ, Colver AC. The Questionnaire of Young People's Participation (QYPP): a new measure of participation frequency for disabled young people. *Child Care Health Dev* 2013;39(4):500-11.
184. Coster WJ, Mancini MC, Ludlow LH. Factor structure of the school function assessment. *Ed Psych Measurement* 1999;59(4):665-77.
185. Chiarello LA, Palisano RJ, Orlin MJ, Chang HJ, Begnoche D, An, M. Understanding participation of preschool-age children with cerebral palsy. *J Early Interv* 2012;34(1):3-19.
186. Kelly EH, Vogel LC. Overview of psychosocial health among youth with spinal cord injury. *Top Spinal Cord Inj Rehabil* 2013;19(2):129-41.
187. Bourke-Taylor H, Pallant JF. The Assistance to Participate Scale to measure play and leisure support for children with developmental disability: Update following Rasch analysis. *Child Care Health Dev* 2013;39(4):544-51.
188. King G, Law M, King S, Hurley P, Rosenbaum P, Hanna S, Kertoy M, Young N. Children's assessment of participation and enjoyment & preferences for activities of children: manual. San Antonio, TX: PsychCorp, Harcourt Assessment Inc; 2004.
189. Imms C. Review of the children's assessment of participation and enjoyment and the preferences for activity of children. *Phys Occup Ther Pediatr* 2008;28(4):386-401.
190. Bedell G. Further validation of the Child and Adolescent Scale of Participation (CASP). *Dev Neurorehabil* 2009;12(5):342-51.
191. Dunn L, Gardner J. Brief Report—Household task participation of children with and without physical disability. *Am J Occup Ther* 2013;67:e100-5.
192. Dunn L, Magalhaes LC, Mancini MC. Internal structure of the Children Helping Out: Responsibilities, Expectations, and Supports (CHORES) measure. *Am J Occup Ther* 2014;68:286-95.

193. McColl MA, Paterson M, Davies D, Doubt L, Law M. Validity and community utility of the Canadian Occupational Performance Measure. *Can J Occup Ther* 2000;67(1):22-30.
194. Bosch J. The reliability and validity of the COPM. unpublished master's thesis. McMaster University, Hamilton, ON;1995. referenced in McColl MA, Paterson M, davies D, Doubt, L, law, M. Validity and community utility of the Canadian Occupational Performance Measure. *Can J Occup Ther* 2000;67(1):22-30.
195. Law M, Stewart D. Test retest reliability of the COPM with children. unpublished manuscript, McMaster University, Hamilton ON;1996. referenced in McColl MA, Paterson M, davies D, Doubt, L, law, M. Validity and community utility of the Canadian Occupational Performance Measure. *Can J Occup Ther* 2000;67(1):22-30.
196. Carswell A, McColl MA, Baptiste S, Law M, Polatajko H, Pollock N. The Canadian Occupational Performance Measure: A research and clinical literature review. *Can J Occup Ther* 2004;71(4):210-22.
197. Keller J, Kielhofner G. Psychometric characteristics of the Child Occupational Self-Assessment (COSA), part two: Refining the psychometric properties. *Scand J Occ Ther* 2005;12(4):147-58.
198. Kramer JM, Kielhofner G, Smith EV. Validity evidence for the Child Occupational Self Assessment. *Am J Occup Ther* 2010;64(4):621-32.
199. Noreau L, Fougereyrollas P, Tremblay J. Measure of Life Habits (LIFE-H): User's manual. Lac St-Charles, QC: CQICIDH; 2005.
200. Coster W, Law M, Bedell G, Khetani M, Cousins M, Teplicky R. Development of the participation and environment measure for children and youth: Conceptual basis. *Disabil Rehabil* 2012;34(3):238-46.
201. Coster W, Law M, Bedell G, Liljenquist K, Kao YC, Khetani M, Teplicky R. School participation, supports and barriers of students with and without disabilities. *Child Care Health Dev* 2013;39(4):535-43.
202. Trottier AN, Brown GT, Hobson SJG, Miller W. Reliability and validity of the Leisure Satisfaction Scale (LSS–short form) and the Adolescent Leisure Interest Profile (ALIP). *Occup Ther Inter* 2002;9(2):131-44.
203. Coster WJ, Deeney TA, Haltiwanger JT, Haley SM. School Function Assessment. San Antonio, TX: Psychological Corp/Therapy Skill Builders; 1998.
204. Davies PL, Soon PL, Young M, Clausen-Yamaki A. Validity and reliability of the School Function Assessment in elementary school students with disabilities. *Phys Occup Ther Pediatr* 2004;24(3):23-43.
205. Mancini MC, Coster WJ. Functional predictors of school participation by children with disabilities. *Occup Ther Int* 2004;11(1):12-25.

206. Palisano RJ, Chiarello LA, McCoy SW, Bartlett D, An M. Use of the child engagement in daily life and ease of caregiving for children to evaluate change in young children with cerebral palsy. *Phys Occup Ther Pediatr* 2015;35(3):280-95.
207. Noreau L, Lepage C, Boissiere L, Picard R, Fougeryrollas P, Mathieu J, Desmarais G, Nadeau L. Measuring participation in children with disabilities using the Assessment of Life Habits. *Dev Med Child Neurol* 2007;49(9):666-71.
208. Bourke-Taylor H, Howie L, Law M. Impact of caring for a school-aged child with a disability: Understanding mothers' perspectives. *Aust Occup Ther J* 2010;57:127-36.
209. Shikako-Thomas K, Shevell M, Lach L, Law M, Schmitz N, Poulin C., Majnemer A, the QUALA group. Picture me playing—A portrait of participation and enjoyment of leisure activities in adolescents with cerebral palsy. *Research Dev Disabil* 2013;34:1001-10.
210. Parker DM, Sykes CH. A systematic review of the Canadian Occupational Performance Measure: a clinical practice perspective. *Br J Occup Ther* 2006;69(4):150-60.
211. Cusick A, McIntyre S, Novak I, Lannin N, Lowe K. A comparison of goal attainment scaling and the Canadian Occupational Performance Measure for paediatric rehabilitation research. *Pediatr Rehabil* 2006;9(2):149-57.
212. Novak I, Cusick A, Lannin N. Occupational therapy home programs for cerebral palsy: double-blind, randomized, controlled trial. *Pediatrics* 2009;124:e606-14.
213. Kramer J, Bowyer P, Kielhofner G, O'Brien J, Maziero-Barbosa V. Examining rater behavior on a revised version of the Short Child Occupational Profile (SCOPE). *OTJR Occupation Participation Health* 2009;29(2):88-96.
214. Kramer JM. Using mixed methods to establish the social validity of a self-report assessment: An illustration using the Child Occupational Self-Assessment (COSA). *J Mixed Method Research* 2011;5(1):52-76.
215. Parkes J, McCullough N, Madden A. To what extent do children with cerebral palsy participate in everyday life situations? *Health & Social Care in the Community* 2010;18(3):304-15.
216. Lepage C, Noreau L, Bernard PM, Fougeryrollas P. Profile of handicap situations in children with cerebral palsy. *J Rehabil Med* 1998;30(4):263-72.
217. Bedell G, Coster W, Law M, Liljenquist K, Kao YC, Teplicky R, Anaby D, Khetani MA. Community participation, supports and barriers of school age children with and without disabilities. *Arch Phys Med Rehabil* 2013;94:315-23.
218. Law M, Anaby D, Teplicky R, Khetani MA, Coster W, Bedell G. Participation in the home environment among children and youth with and without disabilities. *Br J Occup Ther* 2013;76(2):58-66.

219. Khetani M, Marley J, Baker M, Albrecht E, Bedell G, Coster W, Anaby D, Law M. Validity of the Participation and Environment Measure for Children and Youth (PEM-CY) for Health Impact Assessment (HIA) in sustainable development projects. *Disabil Health J* 2014;7:226-35.
220. Stoffel A, Berg C. Spanish translation and validation of the preschool activity card sort. *Phys Occup Ther Pediatr* 2008;28(2):171-89.
221. LaVesser P, Berg C. Participation patterns in preschool children with an autism spectrum disorder. *OTJR Occupation, Participation Health* 2011;31(1):33-9.
222. Michelsen SI, Flachs EM, Damsgaard MT, Parkes J, Parkinson K, Rapp M, Arnaud C, Nystrand M, Colver A, Fauconnier J, Dickinson HO. European study of frequency of participation of adolescents with and without cerebral palsy. *Eur J Pediatr Neurol* 2014;18(3):282-94.
223. Hwang JL, Davies PL, Taylor MP, Gavin WJ. Validation of School Function Assessment with elementary school children. *OTJR: Occupation, Participation and Health* 2002;22(2):48-58.
224. West S, Dunford C, Mayston MJ, Forsyth R. The School Function Assessment: identifying levels of participation and demonstrating progress for pupils with acquired brain injuries in a residential rehabilitation setting. *Child Care Health Dev* 2013;40(5):689-97.
225. Wright F, Boschen K, Jutai J. Exploring the comparative responsiveness of a core set of outcome measures in a school-based conductive education programme. *Child Care Health Dev* 2005;31(3):291-302.
226. Mancini MC, Coster WJ, Trombly CA, Heeren TC. Predicting elementary school participation in children with disabilities. *Arch Phys Med Rehabil* 2000;81(3):339-47.
227. Calley A, Williams S, Reid S, Blair E, Valentine J, Girdler S, Elliott C. A comparison of activity, participation and quality of life in children with and without spastic diplegia cerebral palsy. *Disabil Rehabil* 2012;34(15):1306-10.
228. Khetani MA. Reliability of the young children's participation and environment measure (YC-PEM) for pediatric research and practice. *Arch Phys Med Rehabil* 2014;95(10):e91.
229. Palisano R, Rosenbaum P, Walter S, Russell D, Wood E, Galuppi B. Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Dev Med Child Neurol* 1997;39(4):214-23.
230. Verkerk GJ, Wolf MJ, Louwers AM, Meester-Delver A, Nollet F. The reproducibility and validity of the Canadian Occupational Performance Measure in parents of children with disabilities. *Clin Rehabil* 2006;20(11):980-8.
231. Kramer JM, Smith Jr EV, Kielhofner G. Rating scale use by children with disabilities on a self-report of everyday activities. *Arch Phys Med Rehabil* 2009;90(12):2047-53.
232. Wright FV, Majnemer A. The concept of a toolbox of outcome measures for children with cerebral palsy why, what, and how to use? *J Child Neurol* 2014;29(8):1055-65.

233. Salminen AL, Brandt A, Samuelsson K, Töytäri O, Malmivaara A. Mobility devices to promote activity and participation: a systematic review. *J Rehabil Med* 2009;41(9):697-706.
234. Heinemann AW, Tulsy D, Dijkers M, Brown M, Magasi S, Gordon W, DeMark H. Issues in participation measurement in research and clinical applications. *Arch Phys Med Rehabil* 2010;91(9):S72-6.
235. Murphy MK, Black NA, Lamping DL, McKee CM, Sanderson CF, Askham J, Marteau T. Consensus development methods, and their use in clinical guideline development: A review. *Health Technol Assess* 1998;2(3):1-88.
236. Hasson F, Keeney S, McKenna H. Research guidelines for the Delphi survey technique. *J Adv Nurs* 2000;32(4):1008-15.
237. Sinha IP, Smyth RL, Williamson PR. Using the Delphi technique to determine which outcomes to measure in clinical trials: recommendations for the future based on a systematic review of existing studies. *PLoS Med*. 2011 Jan 25;8(1):e1000393.
238. Sumsion T. The Delphi technique: an adaptive research tool. *Brit J Occup Ther* 1998;61(4):153-6.
239. Hsu CC, Sandford BA. The Delphi technique: making sense of consensus. *Practical Assessment, Research and Evaluation* 2007;12(10):1531-7714.
240. Palisano RJ. Practice knowledge: The forgotten aspect of evidence-based practice. *Phys Occup Ther Pediatr* 2010;30(4):261-3.
241. Young NL, Yoshida KK, Williams JI, Bombardier C, Wright JG. The role of children in reporting their physical disability. *Arch Phys Med Rehabil* 1995;76(10):913-8.
242. Chide.it. Inc. FluidSurveys online survey tool; available at <http://fluidsurveys.com>. [computer program]. 2008.
243. Little RJ, D'Agostino R, Cohen ML, Dickersin K, Emerson SS, Farrar JT, Frangakis C, Hogan JW, Molenberghs G, Murphy SA. The prevention and treatment of missing data in clinical trials. *N Engl J Med* 2012;367(14):1355-60.
244. Microsoft Corporation. Microsoft Excel for Mac 2011. [computer program]. Version 14.4.3. 2011.
245. Coster W. Occupation-centered assessment of children. *Am J Occup Ther* 1998;52(5):337-44.
246. Young NL, Williams JI, Yoshida KK, Wright JG. Measurement properties of the activities scale for kids. *J Clin Epidemiol* 2000;53(2):125-37.
247. Bowyer PL, Kramer J, Kielhofner G, Maziero-Barbosa V, Girolami G. Measurement properties of the Short Child Occupational Profile (SCOPE). *Phys Occup Ther Pediatr* 2007;27(4):67-85.

248. McEwen IR, Arnold SH, Hansen LH, Johnson D. Interrater reliability and content validity of a minimal data set to measure outcomes of students receiving school-based occupational therapy and physical therapy. *Phys Occup Ther Pediatr* 2003;23(2):77-95.
249. Steenbeek D, Ketelaar M, Galama K, Gorter JW. Goal attainment scaling in paediatric rehabilitation: a critical review of the literature. *Dev Med Child Neurol* 2007;49(7):550-6.
250. Mackie PC, Jessen EC, Jarvis SN. The lifestyle assessment questionnaire: an instrument to measure the impact of disability on the lives of children with cerebral palsy and their families. *Child Care Health Dev* 1998;24:473-81.
251. Ottenbacher KJ, Taylor ET, Msall ME, Braun S, Lane SJ, Granger CV, Lyons N, Duffy LC. The stability and equivalence reliability of the functional independence measure for children (WeeFIM). *Dev Med Child Neurol* 1996;38(10):907-16
252. Chien C, Rodger S, Copley J, Skorka K. Comparative content review of children's participation measures using the international classification of functioning, disability and health—children and youth. *Arch Phys Med Rehabil* 2014;95(1):141-52.
253. Kenny S, Gowran RJ. Outcome measures for wheelchair and seating provision: a critical appraisal. *Br J Occup Ther* 2014;77(2):67-77
254. Sinha I, Jones L, Smyth RL, Williamson PR. A systematic review of studies that aim to determine which outcomes to measure in clinical trials in children. *PLoS Med* 2008;5(4):e96.
255. Hoenig H, Giacobbi P, Levy CE. Methodological challenges confronting researchers of wheeled mobility aids and other assistive technologies. *Disabil Rehabil Assist Technol* 2007;2(3):159-68.
256. Barlow I. Reliability and clinical utility of selected outcome measures with adult clients of seating clinics [master's thesis]. London ON: University of Western Ontario; 1998.
257. Giesbrecht EM, Ripat JD, Quanbury AO, Cooper JE. Participation in community-based activities of daily living: comparison of a pushrim-activated, power-assisted wheelchair and a power wheelchair. *Disabil Rehabil Assist Technol* 2009;4(3):198-207.
258. Mortenson WB, Miller WC, Miller-Pogar J. Measuring wheelchair intervention outcomes: development of the wheelchair outcome measure. *Disabil Rehabil Assist Technol* 2007;2(5):275-85.
259. Reid D, Rigby P, Ryan S. Functional impact of a rigid pelvic stabilizer on children with cerebral palsy who use wheelchairs: Users' and caregivers' perceptions. *Pediatr Rehabil* 1999;3(3):101-18.
260. Chiarello LA, Palisano RJ, Maggs JM, Orlin MN, Almasri N, Lin-Ju Kang, Hui-Ju Chang. Family priorities for activity and participation of children and youth with cerebral palsy. *Phys Ther* 2010;90(9):1254-64.

261. Brandao MB, Oliveiria RHS, Mancini MC. Functional priorities reported by parents of children with cerebral palsy: contribution to the pediatric rehabilitation process. *Braz J Phys Ther* 2014;18(6):563-71.
262. Gimeno H, Gordon A, Tustin K, Lin JP. Functional priorities in daily life for children and young people with dystonic movement disorders and their families. *Eur J Pediatr Neurol* 2013;17:161-8.
263. Livingston MH, Stewart D, Rosenbaum PL, Russell DJ. Exploring issues of participation among adolescents with cerebral palsy: what's important to them? *Phys Occup Ther Pediatr* 2011;31(3):275-87.
264. Mills TL, Holm MB, Schmeler M. Test-retest reliability and cross validation of the functioning everyday with a wheelchair instrument. *Assist Technol* 2007;19(2):61-77.
265. Kumar A, Schmeler MR, Karmarkar AM, Collins DM, Cooper R, Cooper RA, Shin H, Holm MB. Test-retest reliability of the functional mobility assessment (FMA): a pilot study. *Disabil Rehabil Assist Technol* 2014;8(3):213-9.
266. Field D, Miller WC. Development of the Wheelchair Outcome Measure for Adolescents. In: 28th International Seating Symposium. Vancouver BC: March 7-9, 2012, 185-86.
267. Corra H, Goodmanson H, Field D, Miller WC. Evaluating the clinical usefulness of the Wheelchair Outcome Measure for Young People. Presented at the Canadian Occupational Therapists Association 2015 conference; Winnipeg MB; May 28, 2015.
268. Anaby D, Lal S, Huszczyński J, Maich J, Rogers J, Law M. Interrupted time series design: A useful approach for studying interventions targeting participation. *Phys Occup Ther Pediatr* 2015;34(4):457-70.
269. Cohen P, Cohen J, Aiken LS, West SG. The problem of units and the circumstance for POMP. *Multivariate Behavioral Research* 1999;34(3):315-46.
270. Auger C, Demers L, Gelinas I, Routhier F, Mortenson WB, Miller WC. Reliability and validity of telephone administration of the wheelchair outcome measure for middle-aged and older users of power mobility devices. *J Rehabil Med* 2010;42(6):574-81.
271. Parvenah S, Mortenson WB, Miller WC. Validating the wheelchair outcome measure with residents of long term care. *Disabil Rehabil Assist Technol* 2014;9(3):209-12.
272. Miller WC, Garden J, Mortenson WB. Measurement properties of the wheelchair outcome measure in individuals with spinal cord injury. *Spinal Cord* 2011;49:995-1000.
273. Miller WC, Miller F, Miller Polgar J. The WhOM, the Wheelchair Outcome Measure manual version 2, 2007.

274. Morris C, Kurinczuk JJ, Fitzpatrick R, Rosenbaum PL. Who best to make the assessment? professionals' and families' classifications of gross motor function in cerebral palsy are highly consistent. *Arch Dis Child* 2006;91(8):675-9.
275. Palisano RJ, Hanna SE, Rosenbaum PL, Russell DJ, Walter SD, Wood EP, Raina PS, Galuppi BE. Validation of a model of gross motor function for children with cerebral palsy. *Phys Ther* 2000;80(10):974-85.
276. Palisano R, Rosenbaum P, Livingston M, Bartlett D. Gross motor function classification system: validation of a 12-18 year age band and revision of the 6-12 year age band. *Pediatr Phys Ther* 2008;20(1):120-1.
277. Wood E, Rosenbaum P. The gross motor function classification system for cerebral palsy: a study of reliability and stability over time. *Dev Med Child Neurol* 2000;42(5):292-6.
278. Rosenbaum PL, Palisano RJ, Bartlett DJ, Galuppi BE, Russell DJ. Development of the gross motor function classification system for cerebral palsy. *Dev Med Child Neurol* 2008;50(4):249-53.
279. Ryan SE, Sawatzky B, Campbell KA, Rigby PJ, Montpetit K, Roxborough L, McKeever PD. Functional outcomes associated with adaptive seating interventions in children and youth with wheeled mobility needs. *Arch Phys Med Rehabil* 2014;95(5):825-31.
280. King G, Batorowicz B, Rigby P, Pinto M, Thompson L, Goh F. The leisure activity settings and experiences of youth with severe disabilities. *Dev Neurorehabil* 2014;17(4):259-69.
281. Waninge A, Evenhuis IJ, van Wijck R, van der Schans CP. Feasibility and reliability of two different walking tests in people with severe intellectual and sensory disabilities. *J Applied Res Intellect Disabil* 2011;24:518-27.
282. Cunningham SD, Thomas PD, Warschausky S. Gender differences in peer relations of children with neurodevelopmental conditions. *Rehab Psychol* 2007;52:331-7.
283. Eliasson AC, Krumlinde-Sundholm L, Rösblad B, Beckung E, Arner M, Ohrvall AM, Rosenbaum P. The Manual Ability Classification System (MACS) for children with cerebral palsy: scale development and evidence of validity and reliability. *Dev Med Child Neurol* 2006;48(7):549-54.
284. Carnahan KD, Arner M, Hägglund G. Association between gross motor function (GMFCS) and manual ability (MACS) in children with cerebral palsy. A population-based study of 359 children. *BMC Musculoskelet Disord* 2007;8(1):1.
285. Morris C, Kurinczuk JJ, Fitzpatrick R, Rosenbaum PL. Reliability of the manual ability classification system for children with cerebral palsy. *Dev Med Child Neurol* 2006;48(12):950-3.
286. Reidy TG, Naber E, Viguers E, Allison K, Brady K, Carney J, Salorio C, Pidcock F. Outcomes of a clinic-based pediatric constraint-induced movement therapy program. *Phys Occup Ther Pediatr* 2012;32:355-67.

287. Cimolin V, Beretta E, Piccinini L, Turconi AC, Locatelli F, Galli M, Strazzer S. Constraint-induced movement therapy for children with hemiplegia after traumatic brain injury: A quantitative study. *J Head Trauma Rehabil* 2012;27:177-87.
288. Graham HK, Harvey A, Rodda J, Nattrass GR, Pirpiris M. The functional mobility scale (FMS). *J Pediatr Orthopedics* 2004;24(5):514.
289. Harvey A, Graham HK, Morris ME, Baker R, Wolfe R. The functional mobility scale: ability to detect change following single event multilevel event surgery. *Dev Med Child Neurol* 2007;49(8):603-7.
290. Harvey AR, Morris ME, Graham HK, Wolfe R, Baker R. Reliability of the functional mobility scale for children with cerebral palsy. *Phys Occup Ther Pediatr* 2012;30(2):139-49.
291. Fife SE, Roxborough LA, Armstrong RW, Harris SR, Gregson JL, Field D. Development of a clinical measure of postural control for assessment of adaptive seating in children with neuromotor disabilities. *Phys Ther* 1991;71(12):981-93.
292. Field DA, Roxborough LA. Responsiveness of the Seated Postural Control Measure and the Level of Sitting Scale in children with neuromotor disorders. *Disabil Rehabil Assist Technol* 2011;6(6):473-82.
293. Field DA, Roxborough LA. Validation of the relation between the type and amount of seating support provided and Level of Sitting Scale (LSS) scores for children with neuromotor disorders. *Dev Neurorehabil* 2012;15(3):202-8.
294. Gagnon B, Noreau L, Vincent C. Reliability of the seated postural control measure for adult wheelchair users. *Disabil Rehabil* 2005;27(24):1479-91.
295. Teng EI, Chui HC. The modified mini-mental state (3MS) examination. *J Clin Psychiatr* 1987;48:314-8.
296. Jain M, Passi GR. Assessment of a modified Mini-Mental Scale for cognitive functions in children. *Indian Pediatr* 2005;42:905-12.
297. Ouvrier RA, Goldsmith RF, Ouvrier S, Williams IC. The value of the Mini-Mental State Examination in childhood: a preliminary study. *J Child Neurol* 1993;8:145-8.
298. Besson PS, Labbé EE. Use of the modified mini mental state examination with children. *J Child Neurol* 1997;12:455-60.
299. SPSS Inc. IBM SPSS Statistics 23.[computer program]. Chicago, IL: 2010.
300. American Educational Research Association (AERA), American Psychological Association (APA) & National Council on Measurement in Education (NCME). Standards for educational and psychological testing. Washington DC: American Educational Research Association; 1999.

301. King GA, Law M, King S, Hurley H, Rosenbaum P, Hanna S. CAPE/PAC manual: Children's assessment of participation and enjoyment & preferences for activities of children. San Antonio TX: PsychCorp; 2004.
302. Nunnally JC, Bernstein IH. Psychometric theory. New York NY: McGraw-Hill; 1994.
303. Cieza A, Brockow T, Ewert T, Amman E, Kollerits B, Chatterji S, Ustun TB, Stucki G. Linking health-status measurements to the international classification of functioning, disability and health. *J Rehabil Med* 2002;34:205-10.
304. Cieza A, Geyh S, Chatterji S, Kostanjsek N, Ustun B, Stucki G. ICF linking rules: an update based on lessons learned. *J Rehabil Med* 2005;37:212-8.
305. Auger C, Demers L, Gelinas I, Jutai J, Fuhrer MJ, DeRuyter F. Powered mobility for middle-aged and older adults: systematic review of outcomes and appraisal of published evidence. *Am J Phys Med Rehabil* 2008;87(8):666-80.
306. Brandt A, Kreiner S, Iwarsson S. Mobility-related participation and user satisfaction: construct validity in the context of powered wheelchair use. *Disabil Rehabil Assist Technol* 2010;5(5):305-13.
307. Gray D, Hollingsworth HH, Stark SL, Morgan KA. PARTS/ M: psychometric properties of a measure of participation for people with mobility impairments and limitations. *Arch Phys Med Rehabil* 2006;87(2):189-97.
308. Carver J, Ganus A, Ivey JM, Plummer T, Eubank A. The impact of mobility assistive technology devices on participation for individuals with disabilities. *Disabil Rehabil Assist Technol* 2015(0):1-10.
309. Skär L, Tamm M. Disability and social network. A comparison between children and adolescents with and without restricted mobility. *Scand J Disabil Res* 2002;4(2):118-37.
310. Palisano RJ, Orlin M, Chiarello LA, Oeffinger D, Polansky M, Maggs J, Gorton G, Bagley A, Tylkowski C, Vogel L. Determinants of intensity of participation in leisure and recreational activities by youth with cerebral palsy. *Arch Phys Med Rehabil* 2011;92(9):1468-76.
311. Faul F, Erdfelder E, Lang AG, Buchner A. G* power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods* 2007;39(2):175-91.
312. Peterson RA. A meta-analysis of cronbach's coefficient alpha. *J Consumer Res* 1994;21(2):381-91.
313. Streiner DL. Being inconsistent about consistency: When coefficient alpha does and doesn't matter. *J Pers Assess* 2003;80(3):217-22.

314. Coster W, Law M, Bedell G, Anaby D, Khetani M, Teplicky R. PEM-CY user's guide (version 1.1). [Http://Canchild Ca/En/resourcesGeneral/TermsOfUse Pdf](http://Canchild.ca/En/resourcesGeneral/TermsOfUsePdf) 2014:1-27. Retrieved April 9, 2014.
315. Piskur B, Daniëls R, Jongmans MJ, Ketelaar M, Smeets RJEM, Norton M, Beurskens AJHM. Participation and social participation: are they distinct concepts? *Clin Rehabil* 2014;28(3):211-30.
316. Anaby D, Hand C, Bradley L, DiRezze B, Forhan M, DiGiacomo A, Law M. The effect of the environment on participation of children and youth with disabilities: a scoping review. *Disabil Rehabil* 2014;35(19):1589-98.
317. Ripat JD, Brown CL, Ethans KD. Barriers to wheelchair use in the winter. *Arch Phys Med Rehabil* 2015;96(6):1117-22.
318. Guyatt G, Walter S, Norman G. Measuring change over time: assessing the usefulness of evaluative instruments. *J Chronic Dis* 1987;40(2):171-8.
319. Hart T, Bagiella E. Design and implementation of clinical trials in rehabilitation research. *Arch Phys Med Rehabil* 2012;93(8 Suppl 2):S117-26.
320. Campbell NC, Murray E, Darbyshire J, Emery J, Farmer A, Griffiths F, Guthrie B, Lester H, Wilson P, Kinmonth AL. Designing and evaluating complex interventions to improve health care. *BMJ* 2007;334(7591):455-9.
321. Rauscher L, Greenfield BH. Advancements in contemporary physical therapy research: Use of mixed methods designs. *Phys Ther* 2009;89(1):91-100.
322. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res* 2005;15:1277-88.
323. Feise R. Do multiple outcome measures require p-value adjustment? *BMC Med Res Methodol* 2002;2(1):8.
324. Bender R, Lange S. Adjusting for multiple testing—when and how? *J Clin Epidemiol* 2001;54:343-9.
325. Cohen JW. *Statistical power analysis for the behavioral sciences*. 2nd ed. Hillsdale NJ: Lawrence Erlbaum Associates; 1988.
326. Law M, Anaby D, Imms C, Teplicky R, Turner L. Improving the participation of youth with physical disabilities in community activities: An interrupted time series design. *Aust Occup Ther J* 2015;62(2):105-15.
327. Blanton S, Morris DM, Prettyman MG, McCulloch K, Redmond S, Light KE, Wolf SL. Lessons learned in participant recruitment and retention: The EXCITE trial. *Phys Ther* 2006;86(11):1520-33.

328. Lin AC, DeMatteo CA. The challenges of loss to follow-up in longitudinal pediatric acquired brain injury research: one research team's experiences. *Pediatr Res Int J* 2013; 1-10.
329. Pyatak EA, Blanche EI, Garber SL, Diaz J, Blanchard J, Florindez L, Clark FA. Conducting intervention research among underserved populations: lessons learned and recommendations for researchers. *Arch Phys Med Rehabil* 2013;94(6):1190-8.
330. Bourke-Taylor H, Cotter C, Stephan R. Young children with cerebral palsy: families self-reported equipment needs and out-of-pocket expenditure. *Child Care Health Dev* 2014;40(5):654-62.
331. Camden C, Shikako-Thomas K, Nguyen T, Graham E, Thomas A, Sprung J, Morris C, Russell DJ. Engaging stakeholders in rehabilitation research: a scoping review of strategies used in partnerships and evaluation of impacts. *Disabil Rehabil* 2014(0):1-11.
332. Hemsley-Brown J, Sharp C. The use of research to improve professional practice: A systematic review of the literature. *Oxford Review of Education* 2003;29(4):449-71.
333. Kothari A, Armstrong R. Community-based knowledge translation: Unexplored opportunities. *Implement Sci* 2011;6(1):59.
334. Green SE. "We're tired, not sad": Benefits and burdens of mothering a child with a disability. *Soc Sci Med* 2007;64(1):150-63.
335. Kirk S, Glendinning C, Callery P. Parent or nurse? The experience of being the parent of a technology-dependent child. *J Adv Nurs* 2005;51(5):456-64.
336. MacDonald H, Callery P. Parenting children requiring complex care: A journey through time. *Child Care Health Dev* 2008;34(2):207-13.
337. Higginbotham DJ, Shane H, Russell S, Caves K. Access to AAC: Present, past, and future. *Augmentative and Alternative Communication* 2007;23(3):243-57.
338. Copley J, Ziviani J. Assistive technology assessment and planning for children with multiple disabilities in educational settings. *Brit J Occup Ther* 2005;68(12):559-66.
339. Feldman MA, Battin SM, Shaw OA, Luckasson R. Inclusion of children with disabilities in mainstream child development research. *Disabil Society* 2013;28(7):997-1011.
340. Frank AO, De Souza LH, Frank JL, Neophytou C. The pain experiences of powered wheelchair users. *Disabil Rehabil* 2012;34(9):770-8.
341. Nesselroade JR, Ram N. Studying intraindividual variability: What we have learned that will help us understand lives in context. *Research in Human Development* 2004;1(1-2):9-29.
342. Bult MK, Verschuren O, Kertoy MK, Lindeman E, Jongmans MJ, Ketelaar M. Psychometric evaluation of the Dutch version of the Assessment of Preschool Children's Participation (APCP): construct validity and test-retest reliability. *Phys Occup Ther in Pediatr* 2013;33(4):372-83.

343. Field DA, Miller WC, Ryan SE, Jarus T, Abundo A. Measuring participation for children and youth with power mobility needs: A systematic review of potential health measurement tools. *Arch Phys Med Rehabil* 2015 (early online).
344. Varni JW, Seid M, Kurtin PS. PedsQL (TM) 4.0: Reliability and validity of the Pediatric Quality of Life Inventory (TM) Version 4.0 Generic Core Scales in healthy and patient populations. *Med Care* 2001;39(8):800-12.
345. Sytsma SE, Kelley ML, Wymer JH. Development and initial validation of the child routines inventory. *J Psychopathol Behav Assess* 2001;23:241-51.
346. Kiresuk TJ, Sherman RE. Goal attainment scaling: A general method for evaluating comprehensive community mental health programs. *Community Ment Health J* 1968;4(6):443-53.
347. Ravens-Sieberer U, Gosch A, Rajmil L, Erhart M, Bruil J, Duer W, Auquier P, Power M, Abel T, Czemy L, Mazur J. KIDSCREEN- 52 quality-of-life measure for children and adolescents. *Expert Review of Pharmacoeconomics Outcomes Research* 2005;5(3):353-64.
348. Reilly PL, Simpson DA, Sprod R, Thomas L. Assessing the conscious level in infants and young children: a paediatric version of the Glasgow Coma Scale . *Child's Nerv Syst* 1988;4(1):30-3.
349. Walker LS, Greene JW. The functional disability inventory: measuring a neglected dimension of child health status. *J Pediatr Psych* 1991;16(1):39-58.
350. Beard JG, Ragheb MG. Measuring leisure satisfaction. *J Leisure Research* 1980;1:20-33.
351. Sparrow SS, Balla DA, Cicchetti DV, Harrison PL, Doll EA. Vineland adaptive behavior scales (interview edition). Circle Pines, MN: American Guidance Service; 1984.
352. Palisano RJ, Haley SM, Westcott SL, Hess A. Pediatric physical therapy outcomes management system. *Pediatr Phys Ther* 1999;11:220.
353. Department of National Health and Welfare and Canadian Association of Occupational Therapists. Guidelines for the client-centred practice of occupational therapy. H39-33/1983E ed. Ottawa ON: Department of National Health and Welfare; 1983.
354. Kielhofner G. A model of human occupation: Theory and application. Baltimore MD: Lippincott, Williams, & Wilkins; 2002.

Appendices

Appendix A Listing of Search Terms and Databases

Appendix A(i) Listing of Search Terms for CINAHL, PsycInfo, ERIC, Medline and EMBASE

Platform:		EBSCO	EBSCO	EBSCO	OvidSP	OvidSP
Database:		CINAHL	PsycInfo	ERIC	Medline	EMBASE
Concept	Keywords	Subject Headings	Subject Headings	Subject Headings	MeSH Headings	Subject Headings
Population						
child or children paediatric	Child* [Pediatic]	Child, disabled [Pediatic]		Child	Child Disabled children	Handicapped child
early childhood; young children; preschoolers;	Early childhood Preschool*	[Child,preschool]		Early childhood	Child, preschool	
school aged; students;	Student*	Students,disabled Special needs students		Student	Child	
adolescent or adolescence; teen; youth	Adolescen*	Adolescence+		Adolescen*	Adolescent Disabled persons	Disabled person
motor impairment movement disorder; (physical) disabilities; motor/neuromotor /neuromuscular/ musculoskeletal disorders, or disabilities; developmental/ neurodevelopmental disabilities;	Motor Movement Musculoskeletal Neuromuscular Developmental Physical Neurodevelopmental Neuromotor Disease* Disab* Impair*	Developmental disabilities Neuromuscular diseases+ Musculoskeletal diseases+ Movement disorders + Muscular atrophy & children Muscular dystrophy & children [Apraxia+]	Musculoskeletal disorders Bone disorders Joint disorders Movement disorders Apraxia Ataxia Athetosis Dyskinesia Dyspraxia Paralysis Spasms tremor Muscular disorders	Motor Movement Musculoskeletal Neuromuscular Developmental Physical Neurodevelopmental Neuromotor Disease* Disab* Impair*	Neuromuscular diseases Developmental disabilities	Motor dysfunction

Platform:		EBSCO	EBSCO	EBSCO	OvidSP	OvidSP
Database:		CINAHL	PsycInfo	ERIC	Medline	EMBASE
Concept	Keywords	Subject Headings	Subject Headings	Subject Headings	MeSH Headings	Subject Headings
			Developmental disabilities Neuromuscular disorders & children			
CP, BI, SCI, SB, MD, SMA, OI, Arthrogryposis, amputation	Cerebral palsy Brain inj* Head inj* Spinal cord inj* Spina bifida Muscular dystroph* (MD) Spinal muscular atrophy* (SMA) Osteogenesis imperfecta (OI) Arthrogryposis Amput* Quadripleg*	Cerebral palsy Brain injur* Head injur* Spinal cord injuri* Spina bifida Muscular dystrophy+ Osteogenesis imperfecta Arthrogryposis Amputation+ Quadriplegia	Cerebral palsy Traumatic brain injury Head injuries Spinal cord injuries Spina bifida Osteogenesis imperfecta Arthrogryposis Myopathy Muscular dystrophy	Cerebral palsy Brain inj* Head inj* Spinal cord inj* Spina bifida Muscular dystrophy Spinal muscular atrophy* (SMA) Osteogenesis imperfecta Arthrogryposis Amput* Quadripleg*	Brain injuries Osteogenesis Imperfecta Arthrogryposis Paralysis Muscular dystrophies Spinal cord injuries MD, Duchenne	Cerebral palsy Brain injury Head injury Spinal cord injury SMA MD Spinal dysraphism Spina bifida Osteogenesis imperfecta Arthrogryposis Quadriplegia
mobility limitations, disability or impairment; locomotor disability	[Mobility limit*] [Mobility impair*] [Mobilit* dis*] [Locomotor dis*]	[Physical mobility] [Locomotion+]	[Physical mobility]		[Mobility limitation] [Locomotion]	
Intervention						
Rehabilitation early intervention special needs	Special education needs Early intervention	Early childhood intervention [Rehabilitation] [Pediatric]	Occupational Therapy Physical Therapy Early intervention School based intervention [Habilitation] [Rehabilitation] [Neurorehab] [Psychosocial rehab]	Special needs Early intervention	Early Intervention (Education) Education, special+ [Rehabilitation] [School healthservice]	

Platform:		EBSCO	EBSCO	EBSCO	OvidSP	OvidSP
Database:		CINAHL	PsycInfo	ERIC	Medline	EMBASE
Concept	Keywords	Subject Headings	Subject Headings	Subject Headings	MeSH Headings	Subject Headings
Wheelchair (wheeled) Mobility aids	[Wheelchair]		[Mobility aids]			
participation; social, community, school, home	Home School Community Social participat* involve* life	Social participation [Home rehabilitation+] Role change [Community role] [Student role]	Involvement Community involvement Job involvement Parental involvement Student engagement Participation Athletic participation Group participation	Home School Community Social participat* involve* life	Social participation	Social participation
everyday life; daily life; daily routines; home, school or community life; family life	everyday life situation activ* [Life experience*] [Daily life] [Social life] [Daily activ*]	[Life experiences+]		everyday life situation activ*	[Social environment]	
Outcome						
measure* tool; instrument; assess* questionnaire outcome self-report	Assess* Measure* Question* Interview* Survey* Tool* [Instrument (comes	Weights & measures+ Clinical Assessment Tools+ OT assessment PT assessment [Measurement issues & assessment+]	Measurement+ Achievement measures Aptitude measures Attitude measures body sway testing Comprehension	Assess* Measure* Question* Interview* Survey* Tool*	Weights & measures [Treatment outcome] [Self report] [Psychometrics]	Questionnaire

Platform:		EBSCO	EBSCO	EBSCO	OvidSP	OvidSP
Database:		CINAHL	PsycInfo	ERIC	Medline	EMBASE
Concept	Keywords	Subject Headings	Subject Headings	Subject Headings	MeSH Headings	Subject Headings
parent-report	up as musical instrument; left off) [Outcome*] [Child report] [Parent report] [Self report]	[Research instruments+] [Health status indicators] [Outcome assessment] [Outcomes research] [Treatment outcomes] [Parents of disabled children] [Self Report]	tests Creativity measurement Criterion referenced tests Digit span testing group testing Individual testing Intelligence measures Inventories Multidimensional scaling Needs assessment Occupational interest measures Employment Testing		[Questionnaires]	

Legend: * = wild card; [] = not used in final search; + = exploded subject heading; & = and.

Appendix A(ii) Listing of Search Terms for OT Seeker, PEDro, Health and Psychosocial Instruments, EBM Reviews

Database:		OT Seeker	PEDro	Health and Psychosocial Instruments	EBM Reviews
Concept	Keywords				
child or children paediatric	Child* [Pediatric]	Child	Child	Child*	Child*
early childhood; young children; preschoolers;	Early childhood Preschool*			Preschool*	Preschool*
school aged; students;	Student*				Student* Special education
adolescent or adolescence; teen; youth	Adolescen*			Adolescen*	Adolescen*
motor impairment movement disorder; (physical) disabilities; motor/neuromotor /neuromuscular/ musculoskeletal disorders, or disabilities; developmental/ neurodevelopmental disabilities;	Motor Movement Musculoskeletal Neuromuscular Developmental Neurodevelopmental Neuromotor Physical Disease* Disab* Impair*			Motor Movement Musculoskeletal Neuromuscular Developmental Neurodevelopmental Neuromotor Physical Disease* Disab* Impair*	Motor Movement Musculoskeletal Neuromuscular Developmental Neurodevelopment* Neuromotor Physical Disease* Disab* Impair*
CP, BI, SCI, SB, MD, SMA, OI, Arthrogyposis, amputation	Cerebral palsy Brain inj* Head inj* Spinal cord inj* Spina bifida Musc* dystroph* Spinal muscular atrophy* Osteogenesis imperfecta Arthrogyposis Amput*			Cerebral palsy Brain inj* Head inj* Spinal cord inj* Spina bifida Muscular dystroph* Spinal muscular atrophy* Osteogenesis imperfecta Arthrogyposis	Cerebral pals* Brain injur* Head injur* Spinal cord injur* Spina bifida Muscular dystroph* Spinal muscular atrophy* Osteogenesis imperfecta Arthrogyposis

Database:		OT Seeker	PEDro	Health and Psychosocial Instruments	EBM Reviews
	Quadripleg*			Amputee* Quadripleg*	Amputee* Quadripleg*
Rehabilitation early intervention special needs	Special education needs Early intervention				Early intervention School therap*
Wheelchair (wheeled) Mobility aids (not used)	Wheelchair (not used)				
participation; social community school, home	Home School Community Social participat* involve* life everyday situation activ*	Participat*	Participat*	Home School Community Social participat* involve* life everyday situation activ*	Home School Community Social participat* involve* life everyday situation activ*
measure* tool; instrument; assess* questionnaire outcome self-report parent-report	Assess* Measure* Question* Interview* Survey* Tool* [Instrument (comes up as musical instrument; left off)] [Outcome*] [Child report] [Parent report] [Self report]	Measure*	Measure*		Assess* Measure* Question* Interview* Survey* Tool*

Legend: * = wild card; [] = not used in final search; + = exploded subject heading; & = and.

Appendix B Example of Search Strategy

Medline OVID SP Search
Strategy Set Search Results

1 exp Child/ 1542062
2 exp Child, Preschool/ 749806
3 exp Adolescent/ 1609336
4 child*.mp. 1894913 [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
5 adolescen*.mp. 1646836 [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
6 preschool*.mp. 753197 [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
007 or/1-6 [age group] 2731732
8 "Early Intervention (Education)"/ 1800
9 "early intervention*".mp. 12039
10 exp Education, Special/ 14212
11 or/8-10 [types of services] 25994
12 exp Disabled Persons/ 46547
13 exp Developmental Disabilities/ 14832
14 exp Neuromuscular Diseases/ 239467
15 exp Disabled Children/ 4116
16 "cerebral pals*".mp. 19597
17 Brain Injuries/ 42636
18 ((head or brain or spinal) adj3 injur*).mp. 120877 [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier] 019 "spina bifida".mp. 6984
20 "muscular dystroph*".mp. 23941
21 "spinal muscular atroph*".mp. 3633 [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
22 exp Osteogenesis Imperfecta/ 3819
23 "osteogenesis imperfecta".mp. 4476
24 exp Arthrogryposis/ 1441
25 arthrogryposis.mp. 1987
26 exp Paralysis/ 69256
27 (amputee* or quadripleg*).mp. 13233 [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
28 exp Muscular Dystrophies/ 21537
29 exp Spinal Cord Injuries/ 37628
30 Muscular Dystrophy, Duchenne/ 3298
31 ((movement or motor or musculoskeletal or neuromuscular or developmental or neurodevelopment or neuromotor or physical) adj3 (disease* or disab* or impair*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
32 or/12-31 [disability or diagnosis] 552849
33 7 and 32 [age and disability/diagnosis] 144648
34 33 and 11 [(age and disability/diagnosis) and service] 3679
35 exp Social Participation/ 550
36 ((home or school or community or social) adj (participat* or involve* or life)).mp. 9297 [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
37 ((everyday or life) adj (situation or activ*)).mp. 4102 [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier] 038 or/35-37 [participation terms] 13312

39 33 and 38 [age and disability/diagnosis and participation] 602
40 34 and 38 [age and disability/diagnosis and service and participation] 29
41 exp "Weights and Measures"/205005
42 (assess* or measure* or question* or interview* or survey* or tool*).mp. 4778702 [mp=title, abstract,
original title, name of substance word, subject heading word, keyword heading word, protocol supplementary
concept word, rare disease supplementary concept word, unique identifier]
43 41 or 42 [measurement terms] 4885739
44 38 and 43 [participation and measurement terms]8228
45 33 and 44 [age, disability/diagnosis and participation and measurement] 441
046 limit 45 to updaterrange="prnz(20140613124729-20140613124729] 0

Appendix C Reliability Evidence for Paediatric Participation Tools

Appendix C(i) Internal Consistency and Test-Retest Reliability Evidence for Paediatric Participation Tools

Measurement Tool	Internal Consistency	Test-Retest Reliability
Assessment of Preschool Children's Participation (APCP) ¹⁶²	<p><i>Law et al, 2012</i>¹⁶² (120 parents of children with CP, 2-5yrs) (Canada) Diversity Cronbach's α: 0.73 – 0.85 Intensity Cronbach's α: 0.52 – 0.70 Cronbach's test uses list-wise deletion for missing values, only 89 children were included in analysis for Active Physical Recreation, rest did not take part in activities</p> <p><i>Chiarello et al, 2012</i>¹⁸⁵ (reported on initial testing by <i>Petrinchik et al, 2005 unpublished report with 54 parents of children without developmental disabilities</i>)(US) all items Cronbach's α = 0.87 Activity Types range Cronbach's α range: 0.60 - 0.71</p> <p><i>Chiarello et al, 2012</i>¹⁸⁵ (also reported on their own study of 85 parents of preschoolers with CP)(US) all items Cronbach's α = 0.88</p> <p><i>Kelly et al, 2013</i>¹⁸⁶ (52 parents of children with SCI, 2-5yrs) (US) Diversity subscales Cronbach's α range: 0.58 - 0.67</p>	
Assistance to Participate Scale (APS) ¹⁶³	<p><i>Bourke-Taylor et al, 2009</i>¹⁶³ (152 mothers of children with disabilities, 5-18yrs)(Australia) APS-Home alone Cronbach's α = 0.85 APS-Community social Cronbach's α = 0.83 Total APS Cronbach's α = 0.88</p> <p><i>Bourke-Taylor & Pallant, 2013</i>¹⁸⁷ (152 mothers of children with disabilities aged 5-18 yrs)(Australia) Rasch Model Analysis of the eight APS items showed good internal consistency (PSI = 0.85)</p>	

Measurement Tool	Internal Consistency	Test-Retest Reliability
Availability and Participation scale (AvailabilityPS) ^{164, 165}	<i>Simeonsson et al, 2001</i> ^{164, 165} (1180 teachers)(US) Cronbach's $\alpha = 0.85$ (n=1180)	
Children's Assessment of Participation and Enjoyment (CAPE) ¹⁶⁶ and accompanying Preference for Activities of Children (PAC) ¹⁶⁶	<i>King et al, 2004</i> ¹⁸⁸ (n=427 children & youth with disabilities, 6-14 yrs using 49 item version)(Canada) referenced in <i>King et al, 2006</i> , ¹⁶⁶ <i>Imms, 2008</i> ¹⁸⁹ CAPE Frequency scores Formal domain Cronbach's α range: 0.35 – 0.42 Informal domain Cronbach's α range: 0.76 – 0.77 PAC Preference scores Formal domain Cronbach's α range: 0.76 – 0.78 Informal domain Cronbach's $\alpha = 0.84$ Activity Types Cronbach's α range: 0.67 – 0.77 CAPE Frequency scores Cronbach's α range: 0.30-0.62 (referenced in <i>Ziviani et al. 2010</i> ³⁸ & <i>Sakzewski et al. 2007</i>) ¹²¹ <i>Kelly et al, 2013</i> ¹⁸⁶ (410 children with SCI, 2-18yrs)(USA) CAPE Diversity scores Overall Cronbach's α : 0.77-0.81 Formal domain: 6-12-yrs Cronbach's $\alpha = 0.61$ (n=135) 13-15-yrs Cronbach's $\alpha = 0.60$ (n=80) 16-18-yrs Cronbach's $\alpha = 0.42$ (n=129) Informal domain: Cronbach's α range: 0.73-0.78	<i>King et al, 2004</i> ¹⁸⁸ (n=48 children & youth with disabilities, 6-14 yrs, using 49 item version)(Canada) referenced in <i>Imms, 2008</i> ¹⁸⁹ 3 weeks apart CAPE Overall Participation: Diversity ICC = 0.75 Intensity ICC = 0.72 Enjoyment ICC = 0.65 Formal & Informal Diversity & Intensity: ICC range: 0.67 - 0.86 Enjoyment ICC range: 0.64 - 0.65 Activity Type Diversity ICC range: 0.67 - 0.78 Intensity ICC range: 0.72 - 0.81 Enjoyment ICC range: 0.12 - 0.73 Enjoyment scores may be influenced by recency effects
Community Activities Questionnaire (CAQ) ¹⁶⁷	<i>Ehrmann, 1995</i> ¹⁶⁷ (Parents of children, 2-5 yrs, 82 with disabilities, 132 typically developing)(US) Cronbach's $\alpha = 0.60$	
Child and Adolescent Scale of Participation (CASP) ^{168, 169}	<i>Bedell, 2004</i> ¹⁶⁸ (60 caregivers of children with ABI, 4 mo-21 yrs)(US) Cronbach's $\alpha = 0.98$ (n=21) Cronbach's $\alpha = 0.95$ (n=60) -missing values replaced with mean <i>Bedell, 2009</i> ¹⁹⁰ (caregivers of 313 children with disabilities, 3-22 yrs)(US, Canada, Australia, Israel) Cronbach's $\alpha = 0.96$	<i>Bedell, 2004</i> ¹⁶⁸ (33 caregivers of children with ABI, 4 mo-21 yrs)(US) interval not specified ICC = 0.94

Measurement Tool	Internal Consistency	Test-Retest Reliability
	<p><i>McDougall et al, 2013</i>¹⁶⁹ (409 parents & youth with disabilities, 11-17 yrs) Youth self-report total score Cronbach's $\alpha = 0.87$ subscales Cronbach's α range: 0.67-0.80 Parent-report total score Cronbach's $\alpha = 0.95$ subscales Cronbach's α range: 0.86-0.90 [subscales based on factor analysis]</p>	
Child Engagement in Daily Life Measure (CEDL) ¹⁷⁰	<p><i>Chiarello et al, 2014</i>¹⁷⁰ (429 parents & children with CP, 110 parents & children typically developing)(US & Canada) Frequency Cronbach's $\alpha = 0.86$ Enjoyment Cronbach's $\alpha = 0.91$</p>	<p><i>Chiarello et al, 2014</i>¹⁷⁰ (33 parents & children with CP, parents & children typically developing)(US & Canada) 23 days apart on average Frequency $ICC_{(2,1)} = 0.70$ (CI₉₅: 0.47 – 0.84) Enjoyment $ICC_{(2,1)} = 0.70$ (CI₉₅: 0.47 – 0.84) Part I dimension $ICC_{(2,1)} = 0.61$ (CI₉₅: 0.34 – 0.79)</p>
Children Helping Out: Responsibilities Expectations and Supports (CHORES) ¹⁷¹	<p><i>Dunn, 2004</i>¹⁷¹ (32 parents of children aged 6-11 yrs 13 with & 19 without disabilities)(US) Total Performance Cronbach's $\alpha = 0.96$ Self-care Performance Cronbach's $\alpha = 0.92$ Family-care Performance Cronbach's $\alpha = 0.95$ [missing data (items indicated not expected to do) replaced with relative mean value for each item to determine internal consistency]</p> <p><i>Dunn & Garner, 2013</i>¹⁹¹ (46 children, 6-14 yrs, 23 with physical disabilities & 23 children & youth without disabilities, matched for age, gender & ethnicity)(US) Total Performance Cronbach's $\alpha = 0.93$</p> <p><i>Dunn et al, 2014</i>¹⁹² (132 children, 6-14 yrs, in three groups: 65 developing typically, 44 with cognitive or behavioral disorders & 23 with physical disabilities, matched for age, gender & ethnicity)(US) Self-care performance Cronbach's $\alpha = 0.96$ Family-care performance Cronbach's $\alpha = 0.98$</p>	<p><i>Dunn, 2004</i>¹⁷¹ (21 parents of children aged 6-11 yrs 10 with & 11 without disabilities)(US) 2-3 weeks apart Performance $ICC_{(3,1)} = 0.93$ Pearson correlations between $ICC_{(3,1)}$ scores from each administration: Total Performance $r = 0.92$ (CI₉₅ 0.82 - 0.97) Self-care Performance $r = 0.92$ (CI₉₅ 0.82 - 0.97) Family Care Performance $r = 0.90$ (CI₉₅ 0.76 - 0.96) Total Assistance $r = 0.88$ (CI₉₅ 0.73 - 0.95) Self-care assistance $r = 0.93$ (CI₉₅ 0.84 - 0.97) Family Care assistance $r = 0.84$ (CI₉₅ 0.65 - 0.93)</p> <p>Weighted percentage of maximum possible (WPOMP) scores calculated to examine variance in parents' assistance scores & to calculate intraclass coefficients (ICCs) for test-retest reliability</p>

Measurement Tool	Internal Consistency	Test-Retest Reliability
Canadian Occupational Performance Measure (COPM) ^{96, 172}	<p><i>McColl et al, 2000</i>¹⁹³ referenced <i>Bosch, 1995</i>¹⁹⁴ a study with adults</p> <p><i>Cusick et al, 2007</i>¹⁷² (42 parents of children with CP, 2-7yrs)(Australia) <i>modified COPM for paediatric use (proxy)</i> (214 items generated) performance Cronbach's $\alpha = 0.86$ satisfaction Cronbach's $\alpha = 0.88$</p>	<p><i>McColl et al, 2000</i>¹⁹³ referenced 2 adult studies along with <i>Law & Stewart, 1996</i>¹⁹⁵ (children)(unpublished manuscript) performance reliability = 0.79 satisfaction reliability = 0.75</p> <p><i>Carswell et al, 2004</i>¹⁹⁶ systematic review referenced 3 test-retest studies with adults in addition to initial testing 1 week apart by authors</p>
Child Occupational Self Assessment (COSA) ¹⁷³	<p><i>Keller et al, 2005a</i>¹⁷³ (62 children 8-17yrs, 31 receiving OT, 31 children not receiving OT)(US) Rasch analysis established</p> <ul style="list-style-type: none"> • Competence item reliability: 0.74 Person reliability: 0.72 • Value item reliability: 0.78 Person reliability: 0.80 <p><i>Keller & Kielhofner, 2005b</i>¹⁹⁷ (43 children 8-17yrs, receiving OT) After revision to items & response scale, Rasch analysis repeated</p> <ul style="list-style-type: none"> • Competence item reliability 0.85 • Person reliability 0.88 • Value item reliability 0.82 • Person reliability 0.91 <p><i>Kramer et al, 2010</i>¹⁹⁸ (502 children with disabilities 6-17 yrs)</p> <ul style="list-style-type: none"> • Competence item reliability: 0.97 (n = 502) Person reliability: 0.83 • Value item reliability: 0.94 (n = 496) Person reliability: 0.85 	

Measurement Tool	Internal Consistency	Test-Retest Reliability
Frequency of Participation Questionnaire (FPQ) ^{45,174}	<i>McManus et al, 2008</i> ⁴⁵ (98 children with CP, 448 children TD, 8-12yrs)(Republic of Ireland) Overall participation Cronbach's $\alpha = 0.63$	
Assessment of Life Habits (LIFE-H) ⁹³	<i>Bedell & Coster, 2008</i> ¹⁴⁸ referencing <i>Noreau et al, 2005 administration manual</i> ¹⁹⁹ $\alpha \geq 0.82$ for daily activities and social roles domain as well as life habit category scores <i>Morris et al, 2005</i> ¹⁰⁹ reported, source not referenced Each domain Cronbach's α : $0.73 < 0.90$ except interpersonal relationships Cronbach's $\alpha = 0.40$	<i>Fougeyrollas et al, 1998</i> ⁹³ (24 parents of children with myelodysplasia 6-14 yrs & 25 adults with SCI, 29 yrs+) (Canada)(child results only) 2 weeks apart total score long form ICC= 0.73 total score short form ICC= 0.67 10/12 life habits categories ICC range: 0.44 - 0.76 except interpersonal relations (not statistically significant) & work (not applicable) <i>Morris et al, 2005</i> ¹⁰⁹ reported, source not referenced ICC range: 0.64-0.96
MayoPortland Adaptability Index (MPAI) ^{175, 176}		<i>Oddson et al, 2006</i> ¹⁷⁶ (children with ABI, 0-19 yrs) (Canada) Spearman's correlations ($p < 0.001$) between MPAI-2 scores & First outpatient visit ~ 1 yr post injury (early recovery) (n=230): Everyday activity $r_s = 0.67$ Behaviour $r_s = 0.46$ Cognition $r_s = 0.55$ Emotion $r_s = 0.48$ Physical $r_s = 0.73$ Social $r_s = 0.45$ Total $r_s = 0.72$ Spearman's correlations ($p < 0.001$) between MPAI-2 scores & Second outpatient visit ~ 2 yr post injury (late recovery) (n=45): Everyday activity $r_s = 0.88$ Behaviour $r_s = 0.52$ Cognition $r_s = 0.80$ Emotion $r_s = 0.63$ Physical $r_s = 0.84$ Social $r_s = 0.79$ Total $r_s = 0.93$

Measurement Tool	Internal Consistency	Test-Retest Reliability
Pediatric Community Participation Questionnaire (PCPQ) ¹⁷⁷	<i>Washington et al, 2007</i> ¹⁷⁷ (105 youth with physical disabilities, 8-20 yrs)(US) Cronbach's α : = 0.92	
Participation and Environment Measure for Children and Youth (PEM-CY) ¹⁷⁸	<i>Coster et al, 2011</i> ¹⁷⁸ (576 parents of children with & without disabilities, 5-17 yrs)(Canada & US) Participation frequency Home Cronbach's α : = 0.59 School Cronbach's α : = 0.61 Community Cronbach's α : = 0.70 Involvement Home Cronbach's α : = 0.83 School Cronbach's α : = 0.72 Community Cronbach's α : = 0.75 Environment Cronbach's α : = 0.80 for all but: School-Resources Cronbach's α : = 0.73 Home-Supportiveness Cronbach's α : = 0.67	<i>Coster et al, 2011</i> ¹⁷⁸ (34 parents of children with & without disabilities, 5-17 yrs)(Canada & US) 1- 4 weeks apart Home total ICC _(2,1) = 0.84 Home items ICC _(2,1) : 0.68 - 0.96 School total ICC _(2,1) = 0.58 School items ICC _(2,1) : 0.73 - 0.91 Community ICC _(2,1) = 0.79 Community items: 0.73 - 0.93 'Per cent participates ever' Home ICC _(2,1) = 0.92 School ICC _(2,1) = 0.82 Community ICC _(2,1) = 0.66 Participation involvement Home ICC _(2,1) = 0.71 School ICC _(2,1) = 0.76 Community ICC _(2,1) = 0.69 Desire for change-all ICC _(2,1) > 0.75 Environment Supportiveness totals (n=24-29): home ICC _(2,1) = 0.76 school ICC _(2,1) = 0.87 community ICC _(2,1) = 0.96 <i>Coster et al, 2013</i> ²⁰¹ (30 to 34 parents of children with disabilities & children without disabilities, 5-17 yrs)(US & Canada) Percent agreement range: individual school participation items: 0.72 - 1.00 all environment items: 0.70 - 1.00 except for Attitudes (0.61)

Measurement Tool	Internal Consistency	Test-Retest Reliability
Paediatric Interest Profiles - Adolescent Leisure Interest Profile (ALIP) ¹⁷⁹	<p><i>Henry, 1998</i>¹⁷⁹ (28 youth without disabilities, 14-19 yrs) (US) Study 1 How interested total score Cronbach's $\alpha = 0.92$ subscales range Cronbach's α: 0.58 - 0.81</p> <p><i>Henry, 1998</i>¹⁷⁹ (88 youth with disabilities; 27 with psychiatric disabilities, 33 with learning disabilities, 28 with physical disabilities, 12-21yrs) Study 2 How interested total score Cronbach's $\alpha = 0.93$ subscales range Cronbach's α: 0.59 - 0.80</p> <p><i>Trottier et al, 2002</i>²⁰² (37 teens without impairments, 13-17 yrs)(Canada) How interested total Cronbach's $\alpha = 0.93$ subscales range Cronbach's α: 0.58 - 0.84 How often total Cronbach's $\alpha = 0.87$ subscales range Cronbach's α: 0.24 - 0.81</p>	<p><i>Henry, 1998</i>¹⁷⁹ (28 youth without disabilities, 14-19 yrs) (US) 1 week apart Pearson correlations ($p < 0.05$): How interested total $r = 0.85$ subscales range r: 0.53 - 0.89 How often total $r = 0.83$ subscales range r: 0.46 - 0.90 Why total $r = 0.61$ subscales range r: 0.83 - 0.98 (4/10 statistically significant) How well total $r = 0.61$ subscales range r: 0.48 - 0.76 (5/10 statistically significant) How much enjoy total $r = 0.73$ subscales range r: 0.47 - 0.69 (5/10 statistically significant) Others or alone total $r = 0.53$ subscales range r: 0.49 - 0.83 (4/10 statistically significant)</p> <p><i>Henry, 1998</i>¹⁷⁹ (88 youth with disabilities, 12-21 yrs) (US) 1-2 weeks apart Pearson correlations ($p < 0.05$): How interested total $r = 0.78$ subscales range r: 0.48 - 0.78 How often total $r = 0.77$ subscales range r: 0.38 - 0.80 Why total $r = 0.62$ subscales range r: 0.36 - 0.63 (7/10 statistically significant) How well total $r = 0.74$ subscales range r: 0.40 - 0.73 How much enjoy total $r = 0.68$ subscales range r: 0.33 - 0.68 Others or alone total $r = 0.78$ subscales range r: 0.47 - 0.71 (9/10 statistically significant)</p>

Measurement Tool	Internal Consistency	Test-Retest Reliability
		<p>Trottier et al, 2002²⁰² (30 teens without impairments) (Canada) 7-17 days apart</p> <p>Pearson correlations ($p < 0.05$):</p> <p>How interested total $r = 0.93$ subscale range $r: 0.68 - 0.91$</p> <p>How often total $r = 0.83$ subscale range $r: 0.43 - 0.83$</p> <p>Why total $r = 0.89$ subscale range $r: 0.57 - 0.84$</p> <p>How well total $r = 0.91$ subscale range $r: 0.51 - 0.86$</p> <p>How much enjoy total $r = 0.93$ subscale range $r: 0.48 - 0.92$</p> <p>Others or alone total $r = 0.85$ subscale range $r: 0.40 - 0.90$</p>
<p>Preschool Activity Card Sort (Preschool ACS)^{180, 181}</p>	<p>Gronski et al, 2013¹⁸¹ (81 parents of able-bodied preschoolers 3-6 yrs, 52 children enrolled in Head Start, 29 children not enrolled) Version 2 (85 items)</p> <p>Rasch Analyses reliability coefficient</p> <ul style="list-style-type: none"> • Self care 0.85 (n=59) • Social interaction 0.96 (n=69) • Domestic chores, 0.90 (n=63) • Education 0.97 (n=79) • Sedentary leisure 0.85 (n=35) • Vigorous leisure 0.94 (n=66) <p>Community mobility 0.91 (n=74)</p>	<p>Gronski et al, 2013¹⁸¹ (20 parents of preschoolers with or without disabilities, 3-6 yrs)(US)</p> <p>1 week apart</p> <p>Version 2 (85 items)</p> <p>ICC_(3,1) = 0.93</p>
<p>Quality of Social Functioning Scale and Index (QOSF)¹⁸²</p>	<p>Hayes et al, 1999¹⁸² (50 adolescents 11-21 yrs, 48% using a wheelchair)(US)</p> <p>Part A: How often do you do: Cronbach's $\alpha = 0.79$</p> <p>Part B: How often would you like to do</p> <p>Cronbach's $\alpha = 0.78$</p> <p>QOSF Index (difference Part A & Part B)</p> <p>Cronbach's $\alpha = 0.82$</p>	
<p>Questionnaire of Young People's Participation (QYPP)¹⁸³</p>	<p>Tuffrey et al, 2013¹⁸³ (107 young people 13-21 yrs)(UK) (69 self-report, 38 proxy report)</p> <p>internal consistency used to remove items not affecting content validity: Home life Cronbach's $\alpha = 0.83$</p> <p>Getting on with people Cronbach's $\alpha = 0.75$</p> <p>Educational life Cronbach's $\alpha = 0.49$</p>	<p>Tuffrey et al, 2013¹⁸³ (52 young people 13-21 yrs)(UK) (36 self-report, 16 proxy report)</p> <p>2 weeks apart</p> <p>Home life ICC = 0.97 (CI₉₅ 0.95 – 0.99)</p> <p>Getting on with people ICC = 0.96 (CI₉₅ 0.93 – 0.98)</p>

Measurement Tool	Internal Consistency	Test-Retest Reliability
	Work life Cronbach's $\alpha = 0.80$ Recreation & leisure Cronbach's $\alpha = 0.63$ Autonomy Cronbach's $\alpha = 0.86$ Preparing for the future Cronbach's $\alpha = 0.6$	Educational life ICC = 0.83 (CI ₉₅ 0.67 – 0.91) Work life ICC = 0.92 (CI ₉₅ 0.87 – 0.96) Recreation & leisure ICC = 0.91 (CI ₉₅ 0.84 – 0.95) Autonomy ICC = 0.98 (CI ₉₅ 0.97 – 0.99) Preparing for the future ICC = 0.90 (CI ₉₅ 0.82 – 0.94)
School Function Assessment (SFA) ¹⁸⁴ Part I Participation Part II Physical Task & Cognitive/Behavioral Task Supports Part III Physical Task & Cognitive/Behavioral Performance	<i>1998 SFA manual (Coster et al²⁰³) referenced in</i> <ul style="list-style-type: none"> • <i>Coster & Mancini, 1999</i>¹⁸⁴ <i>Part III</i> Activity Performance scales for both Tryout & Standardization versions were Cronbach's α range: ≥ 0.90 • <i>Davies et al, 2004</i>²⁰⁴ <i>Parts I, II, III</i> Cronbach's α range: 0.92 - 0.98 • <i>Bedell & Coster, 2008</i>¹⁴⁸ <i>Part I</i> Cronbach's $\alpha \geq 0.95$ • <i>Ziviani et al, 2010</i>³⁸ (n=363) <i>Part I</i> regular class Cronbach's α: 0.92 <i>Part I</i> special ed class Cronbach's α: 0.93 <i>Mancini & Coster, 2004</i> ²⁰⁵ (23 children with disabilities) <i>Part I & III</i> Cronbach's $\alpha \geq 0.94$	<i>SFA manual (Coster et al, 1998</i> ²⁰³ <i>) referenced in:</i> <ul style="list-style-type: none"> • <i>Coster & Mancini, 1999</i>¹⁸⁴ <i>Part III</i> Activity Performance scale: Tryout edition r range: 0.82 - 0.98 n=266 Standardization edition r range: 0.92 - 0.99 n=341 • <i>Davies et al, 2004</i>²⁰⁴ <i>Parts I, II, III</i> reliability coefficients range: 0.82 - 0.98 <i>Mancini & Coster, 2004</i> ²⁰⁵ (23 children with disabilities) <i>Part I</i> participation r range: 0.79 - 0.98 (mean r = 0.92) <i>Part III</i> physical tasks r range: 0.41 - 0.95 (mean r = 0.78) <i>Part III</i> cognitive tasks r range: 0.61 - 0.88 (mean r = 0.77)

Legend: α = alpha; CP = cerebral palsy; CI₉₅ = 95 percent confidence interval; et al, = and colleagues; ICC = Intraclass correlation coefficient; n = sample size; *p* = level of significance; r = Pearson's correlation coefficient; OT = occupational therapy; r_s = Spearman's rank correlation coefficient; SCI = spinal cord injury; SD = standard deviation; UK = United Kingdom; US = United States; vs = versa; yrs = years; & = and; = = equal to; + = plus; ~ = approximately; / = out of; % = percentage; - = to; \geq = greater or equal to; \leq = less than or equal to.

Appendix C(ii) Interrater, Intrarater Reliability and Measurement Error Evidence for Paediatric Participation Tools

Measurement Tool	Interrater Reliability	Intrarater Reliability and Measurement Error
Assessment of Preschool Children's Participation (APCP) ¹⁶²		
Assistance to Participate Scale (APS) ¹⁶³		
Availability and Participation scale (AvailabilityPS) ^{164, 165}		
Children's Assessment of Participation and Enjoyment (CAPE) ¹⁶⁶ and accompanying Preference for Activities of Children (PAC) ¹⁶⁶	<i>King et al, 2004</i> ¹⁸⁸ (n=56 children & youth with disabilities, 6-14 yrs, using 49 item version)(Canada) referenced in <i>Imms, 2008</i> ¹⁸⁹ Interviewer vs Self administered: Intensity range: 0.82 – 0.99 Enjoyment range: 0.47 – 0.78	
Community Activities Questionnaire (CAQ) ¹⁶⁷		
Child and Adolescent Scale of Participation (CASP) ^{168, 169}		
Child Engagement in Daily Life Measure (CEDL) ¹⁷⁰		<i>Palisano et al, 2014</i> ²⁰⁶ (33 parents & children with CP) 23 days apart on average Minimal Detectable Change for Part I = 13.2
Children Helping Out: Responsibilities Expectations and Supports (CHORES) ¹⁷¹		<i>Dunn et al, 2014</i> ¹⁹² (parents of 132 children, 6-14 yrs, 44 with cognitive/behavioural disabilities, 23 with physical disabilities & 65 children without disabilities)(US) 1 time assessment Standard error for each item Self-care range: 0.08- 0.13 Family-care range: 0.09-0.21
Canadian Occupational Performance Measure (COPM) ^{96, 172}		
Child Occupational Self Assessment (COSA) ¹⁷³		
Frequency of Participation Questionnaire (FPQ) ^{45, 174}		

Measurement Tool	Interrater Reliability	Intrater Reliability and Measurement Error
Assessment of Life Habits (LIFE-H) ⁹³	<p><i>Noreau et al, 2007</i>²⁰⁷ (80 parents of children with disabilities, 5-13 yrs)(Canada) 10-14 days apart Daily activities dimension: Communication ICC= 0.91 (CI₉₅ 0.87 – 0.94) Personal care ICC= 0.92 (CI₉₅ 0.88 – 0.95) Housing ICC = 0.93 (CI₉₅ 0.89 – 0.96) Mobility ICC= 0.88 (CI₉₅ 0.81 – 0.92) Nutrition ICC= 0.82 (CI₉₅.74 – 0.88) Fitness ICC= 0.80 (CI₉₅ 0.72 – 0.87) Social roles dimension: Recreation ICC= 0.87 (CI₉₅ 0.80 – 0.91) Responsibility ICC= 0.91 (CI₉₅ 0.86 – 0.94) Education ICC= 0.82 (CI₉₅ 0.73 – 0.88) Community life ICC= 0.78 (CI₉₅ 0.67 – 0.87) (n=60–66) Interpersonal relationships ICC=0.63 (CI₉₅ 0.48 – 0.74)</p> <p><i>Morris et al, 2005</i>¹⁰⁹ reported, source not referenced ICC range: 0.62-0.91 Also stated reliability between child and parent report</p>	<p><i>Noreau et al, 2007</i>²⁰⁷ (91 parents of children with disabilities, 5-13 yrs)(Canada) 10-14 days apart Intrater reliability Daily activities dimension: Communication ICC= 0.95 (CI₉₅ 0.93 – 0.97) Personal care ICC= 0.94 (CI₉₅ 0.91 – 0.96) Housing ICC= 0.93 (CI₉₅ 0.89 – 0.95) Mobility ICC= 0.91 (CI₉₅ 0.86 – 0.94) Nutrition ICC= 0.86 (CI₉₅ 0.80 – 0.91) Fitness ICC= 0.83 (CI₉₅ 0.75 – 0.88) Social roles dimension: Recreation ICC= 0.92 (CI₉₅ 0.88 – 0.95) Responsibility ICC= 0.90 (CI₉₅ 0.85 – 0.93) Education ICC= 0.90 (CI₉₅ 0.86 – 0.94) Community life ICC= 0.78 (CI₉₅ 0.66 – 0.86) (n=60–66) Interpersonal relationships ICC= 0.58 (CI₉₅ 0.42 – 0.70)</p>
MayoPortland Adaptability Index (MPAI) ^{175, 176}	<p><i>Oddson et al, 2006</i>¹⁷⁶ (22 children with ABI, 0-19 yrs) (Canada) clinician & assistant administered MPAI-3 independently (MPAI-3 similar to MPAI-2 + 4 questions) ICC = 0.84 (CI₉₅ 0.66 – 0.93)</p>	
Pediatric Community Participation Questionnaire (PCPQ) ¹⁷⁷		
Participation and Environment Measure for Children and Youth (PEM-CY) ¹⁷⁸		
Paediatric Interest Profiles - Adolescent Leisure Interest Profile (ALIP) ¹⁷⁹		

Measurement Tool	Interrater Reliability	Intrarater Reliability and Measurement Error
Preschool Activity Card Sort (Preschool ACS) ^{180, 181}	<i>Gronski et al, 2013</i> ¹⁸¹ (20 parents of preschoolers with or without disabilities, 3-6 yrs)(US) Version 2 (85 items) ICC _(3,1) = 0.91	
Quality of Social Functioning Scale and Index (QOSF) ¹⁸²		
Questionnaire of Young People's Participation (QYPP) ¹⁸³		
School Function Assessment (SFA) ¹⁸⁴ Part I Participation	<i>Davies et al, 2004</i> ²⁰⁴ (16 teacher/ OT pairs for elementary students; 5 with learning disabilities, 8 with autism & 3 with traumatic brain injury)(US) OT completed SFA within 1 month of teacher rating <ul style="list-style-type: none"> • participation ICC_(1,1) = 0.70 • task supports ICC_(1,1) = 0.68 • activity performance ICC_(1,1) = 0.73 Hypothesis supported	

Legend: α = alpha; CP = cerebral palsy; CI₉₅ = 95 percent confidence interval; et al, = and colleagues; ICC = Intraclass correlation coefficient; n = sample size; p = level of significance; r = Pearson's correlation coefficient; OT = occupational therapy; r_s = Spearman's rank correlation coefficient; SCI = spinal cord injury; SD = standard deviation; UK = United Kingdom; US = United States; vs = versa; yrs = years; & = and; = = equal to; + = plus; ~ = approximately; / = out of; % = percentage; - = to; \geq = greater or equal to; \leq = less than or equal to.

Appendix D Validity and Applicability Evidence for Paediatric Participation Tools

Appendix D(i) Validity Evidence for Paediatric Participation Tools

Tool	Construct Validity
Assessment of Preschool Children's Participation (APCP)¹⁶²	<p><i>Law et al, 2012¹⁶² (120 kids with CP, 2-5yrs)(Canada)</i></p> <p>Differences between groups (with effect sizes reported & further analyzed controlling for other variables, with similar results):</p> <ul style="list-style-type: none"> • by age (under 4 yrs vs over 4 yrs) for all intensity & diversity scores except intensity & diversity of active physical recreation and intensity of play • by Gross Motor Function Classification System (GMFCS)²²⁹ level (Levels I-III vs IV-V) for all intensity & diversity scores • by family income level (below \$60,000 annual income vs above \$60,000 annual income [\$60,000 median Canadian income from 2006 census]) for all diversity scores & play and skill development intensity scores • by sex (girls vs boys) for intensity of play, social and total activities & diversity in play, active physical recreation and total activities <p>Some but not all hypotheses supported</p> <p>Pearson's correlations ($p=0.01$ & $p=0.001$) between all APCP¹⁶² intensity & diversity scores and:</p> <ul style="list-style-type: none"> • number of additional health conditions (range: -0.27 to -0.41) • PEDI⁹⁴ self-care and mobility domains (functional skill & caregiver assistance) range: 0.51 to 0.78
Assistance to Participate Scale (APS)¹⁶³	<p><i>Bourke-Taylor et al, 2009¹⁶³ (152 mothers of children with disabilities, 5-18 yrs)(Australia)</i></p> <p>Exploratory Factor Analysis using Principal Component Analysis revealed two factors</p> <p>Spearman's correlations ($p<0.01$) between APS¹⁶³ scores and:</p> <ul style="list-style-type: none"> • PEDI⁹⁴ caregiver assistance range r_s: 0.59 to 0.77 • PedsQL³⁴⁵ parent report total score and health summary scores range r_s: 0.34 to 0.64 (correlations with PedsQL³⁴⁵ social function & school function scaled scores poor) • # assistive devices used by children r_s: = -0.62 <p>Differences between groups for total APS¹⁶³ and both subscale scores based on:</p> <ul style="list-style-type: none"> • school class type (typical vs spec ed) • frequency of child lifting required • disability type (4 different types) <p>Confirming all hypotheses</p>

Tool	Construct Validity
	<p><i>Bourke-Taylor & Pallant, 2013¹⁸⁷ (152 mothers of children with disabilities, 5-18 yrs)(Australia)</i> Rasch Model Analysis of the eight APS¹⁶³ items showed good fit to model (P = 0.51) No evidence of differential item functioning across groups based on mothers' age, education level or child's age</p>
Availability and Participation scale (AvailabilityPS)^{164, 165} Participation Index	<p><i>Simeonsson et al, 2001¹⁶⁴ (US)(English version national teachers' survey n=1180)</i> Exploratory Factor Analysis using Principal Component Analysis revealed 6 factors Confirmatory Factor Analysis confirmed 6 factors</p>
Children's Assessment of Participation and Enjoyment (CAPE)¹⁶⁶ and accompanying Preference for Activities of Children (PAC)¹⁶⁶	<p><i>King et al, 2006¹⁶⁶ (427 children with physical disabilities, 6-14 yrs)(Canada)</i> Pearson correlations ($p < 0.01$) for relationships between</p> <ul style="list-style-type: none"> • CAPE¹⁶⁶ activity type participation intensity scores & child, family and other environmental variables range: $r: 0.13$ to 0.42 and $r: -0.17$ to -0.21 [of 33 significant correlations, 23 (69.7%) were predicted, all predictions were supported, hypotheses confirmed] • CAPE¹⁶⁶ enjoyment & PAC¹⁶⁶ preference scores with self-perception of athletic, scholastic & social competence variables range $r: 0.15$ to 0.24 [of 6 significant correlations, 4 (66.7%) were predicted; 2 predictions were not supported, hypotheses partially confirmed] Other variables assessed using nine other standardized measures <p>Predicted differences that mean intensity, enjoyment and preference scores for the five types of activities would differ depending on children's sex and age were supported [for all but the recreational activities type for sex differences] using ANOVA ($p < 0.05$)</p> <p><i>King et al, 2004¹⁸⁸ (n=427 children & youth with disabilities, 6-14 yrs)(Canada) referenced in Imms, 2008¹⁸⁹</i> Principal Component Analysis of PAC¹⁶⁶ items revealed 5 factors (did not use CAPE¹⁶⁶ scores because not all children responded to all CAPE¹⁶⁶ items)</p> <ul style="list-style-type: none"> • conducted PCA 2x with 2 sets of data <p><i>Shikako-Thomas et al, 2013²⁰⁹ (175 adolescents with CP, 12-20 yrs)(Canada)</i> Difference in CAPE¹⁶⁶ group mean scores for:</p> <ul style="list-style-type: none"> • age - Older adolescents (≥ 16 yrs) engaged in fewer recreational activities, & less often ($p < 0.05$) • sex - Girls had greater intensity & diversity in self-improvement activities than boys ($p < 0.01$) • school setting - those attending regular school setting had higher diversity & intensity scores in physical active, social and self improvement activities than those attending special school settings ($p < 0.001$) • motor function - Diversity & intensity scores between ambulatory vs non-ambulatory adolescents, as well as those with mild vs severe manual ability limitations across physical active, social & self improvement activities as well as diversity scores across recreational activities ($p < 0.001$)

Tool	Construct Validity
	<p>Numerous studies provide evidence that CAPE¹⁶⁶ scores identified differences in participation between groups of children based on age, sex, type or level of impairment.</p>
<p>Community Activities Questionnaire (CAQ)¹⁶⁷</p>	<p><i>Ehrmann, 1995</i>¹⁶⁷ (<i>Parents of children 82 with disabilities, 132 typically developing, 2-5 yrs</i>)(US) Difference in groups between overall frequency of activities by ability (those with disabilities vs TD) using ANOVA ($p < 0.001$) Multivariate test of four factors by disability status resulted in overall significance ($p < 0.001$) Univariate ANOVAs ($p < 0.01$) revealed significant differences only on family enrichment factor; confirmed after adjust for social economic status Principal Component Analysis revealed four factors</p>
<p>Child and Adolescent Scale of Participation (CASP)^{168, 169}</p>	<p><i>Bedell, 2004</i>¹⁶⁸ (<i>60 caregivers of children with ABI, 4 months-21 yrs</i>)(US) Correlations ($p < 0.01$) between CASP¹⁶⁸ summary scores & PEDI⁹⁴ Functional Skills subscales:</p> <ul style="list-style-type: none"> • self-care $r = 0.72$ • social function $r = 0.65$ • mobility $r = 0.51$ <p>Exploratory Factor Analysis using Principal Components Analysis revealed two factors Rasch Model Analysis showed fit to model but somewhat large standard errors; 3 items deviated from model</p> <p><i>Bedell, 2009</i>¹⁹⁰ (<i>caregivers of 313 children with disabilities, 3-22 yrs</i>)(US, Canada, Australia, Israel) Differences in scores ($p < 0.001$) related to:</p> <ul style="list-style-type: none"> • disability groups (Those without disabilities had higher and less variable CASP¹⁶⁸ scores than all other groups. Those with developmental disabilities had lower CASP¹⁶⁸ scores than the other groups) <p>Pearson correlations ($p < 0.001$) between CASP¹⁶⁸ scores and:</p> <ul style="list-style-type: none"> • Child and Adolescent Factors Inventory (CAFI)¹⁶⁸ scores $r = -0.66$ • Child and Adolescent Scale of Environment (CASE)¹⁶⁸ scores $r = -0.43$ <p>Exploratory Factor Analysis using Principal Components analysis revealed three factors Rasch Model Analysis supported unidimensionality; 2 items deviated from model</p> <p><i>McDougall et al, 2013</i>¹⁶⁹ (<i>409 parents & youth with disabilities, 11-17 yrs</i>)(Canada) Moderate agreement between CASP^{168, 169} mean youth total scores & CASP¹⁶⁸ mean parent total scores ICC = 0.63, CI₉₅: 0.41 - 0.75 youth score significantly higher than parent score on t-test: $t = 10.93$ ($p < 0.0001$) Exploratory Factor Analysis using Principal Components analysis revealed three factors [confirms Bedell 2009¹⁹⁰]</p>

Tool	Construct Validity
<p>Child Engagement in Daily Life Measure¹⁷⁰</p> <p>Part I Family and recreational activities dimension</p>	<p><i>Chiarello et al, 2014</i>¹⁷⁰ (429 parents & children with CP, 110 parents & children typically developing) (US & Canada)</p> <p>Differences found for children's frequency of participation in family & recreational activities by:</p> <ul style="list-style-type: none"> • age (younger than 31 months participate less often than older) • gross motor ability (children without CP vs children with CP across all GMFCS²²⁹ level groupings) <p>Differences found for children's <i>enjoyment</i> of participation in family and recreational activities by:</p> <ul style="list-style-type: none"> • age • gross motor ability <p>Differential item functioning for 8/11 items across GMFCS²²⁹ level groupings</p> <p>Rasch analysis supports suitability of 5-point rating scale structure, unidimensionality of Part I & II, item selection & order</p>
<p>Children Helping Out: Responsibilities Expectations and Supports (CHORES)¹⁷¹</p>	<p><i>Dunn, 2004</i>¹⁷¹ (32 parents of children, 6-11 yrs, 13 with disabilities & 19 without disabilities)(US)</p> <p>Pearson correlation between:</p> <ul style="list-style-type: none"> • CHORES¹⁷¹ performance score & Child Routine Inventory³⁴⁶ household responsibility factor r = 0.38, p<0.05 • CHORES¹⁷¹ total performance scores on self-care & family-care subscales r = 0.64, p<0.01 • CHORES¹⁷¹ total assistance scores on self-care & family-care subscales r = 0.70, p<0.01 <p>Hypotheses supported</p> <p><i>Dunn & Garner, 2013</i>¹⁹¹ (46 children, 6-14 yrs, 23 with physical disabilities (PD) & 23 children without disabilities (TD) matched for age, gender & ethnicity)(US)</p> <p>Differences between groups by:</p> <ul style="list-style-type: none"> • age (6-10 yrs vs 11-14 yrs) for number of household items performed younger children did fewer tasks PD group: t (21)=2.16 p=0.04 TD group: t (21)=4.11 p=0.00 Effect size: PD group d=0.94 TD group d=1.79 • ability (PD vs TD) for amount of assistance required to participate children with PD have more assistance PD group: t (21)=2.77 p=0.01 TD group: t (21)=5.53 p=0.00 Effect size: PD group d=1.13 TD group d=2.33 • parent rating of importance of child's participation in household tasks TD group > importance PD group t (44)=2.38, p=0.02

Tool	Construct Validity
	<p><i>Dunn et al, 2014¹⁹² (132 children, 6-14 yrs, in three groups: 65 developing typically, 44 with cognitive or behavioral disorders & 23 with physical disabilities, matched for age, gender & ethnicity)(US)</i> Rasch analysis supports:</p> <ul style="list-style-type: none"> • unidimensionality of self-care & family-care subscales • use of summed subscale scores rather than total score for measuring children's assistance with household task
<p>Canadian Occupational Performance Measure (COPM)^{96, 172}</p>	<p><i>Carswell et al, 2004¹⁹⁶ systematic review</i> identified 11 studies addressing concurrent & content validity; 1/11 paediatric focus</p> <ul style="list-style-type: none"> • referenced numerous studies, at least 12 including children & youth with disabilities • used as criterion for testing other tools <p><i>Parker & Sykes, 2006²¹⁰ systematic review</i> Review stated 3 paediatric studies, referenced 4 studies including children & youth with disabilities</p> <p><i>Cusick et al, 2007¹⁷² (42 parents of children with CP, 2-7 yrs)(Australia)</i> <i>modified COPM^{96, 172} for pediatric use (proxy)</i> Spearman's correlations ($p < 0.05$) between modified COPM^{96, 172} change in total performance scores & change in Goal Assessment Scaling (GAS)³⁴⁷ scores: $r_s = 0.35-0.49$ with 214 items</p> <p><i>Cusick et al, 2006²¹¹ (41 parents of children with CP, 2-7 yrs) (Australia) modified COPM¹⁷² for pediatric use (proxy)</i> COPM^{96, 172} scores not significantly correlated with GAS³⁴⁷ scores; suggested explanation-difference in goal identification</p> <p><i>McColl et al, 2000¹⁹³ (details of participants not described, but adults only assumed by choice of measurement tools, results & discussion)</i> Multivariate analyses for evaluation of construct & criterion validity of COPM⁹⁶ with other tools measuring:</p> <ul style="list-style-type: none"> • Independent living • Life satisfaction • Perceived problems • Utility from consumer perspective
<p>Child Occupational Self Assessment (COSA)¹⁷³</p>	<p><i>Keller et al, 2005a¹⁷³ (31 children receiving OT 31 children not receiving OT, 8-17yrs)(US)</i> Rasch Rating Scale Model (RSM) supported 2 unidimensional constructs:</p> <ul style="list-style-type: none"> • competence (all items fit model) range: -0.79 to 1.15 • importance (all but 1 item fit model) range: -0.59 to 1.42 • ceiling effect with several respondents clustered $+2SD > \text{mean}$

Tool	Construct Validity
	<p><i>Keller & Kielhofner, 2005b</i>¹⁹⁷ (43 children receiving OT services, 8-17yrs)(US) After revision to items & response scale, Rasch analysis repeated:</p> <ul style="list-style-type: none"> • Competence item measures range: -0.92 to 0.84 • Value item measures range -1.33 to 0.58 <p>RSM with Principal Component Analysis demonstrated:</p> <ul style="list-style-type: none"> • unidimensionality with similar item hierarchies to those in first study • no ceiling or floor effects observed. <p><i>Kramer et al, 2009</i>²³¹ (407 children diagnosed with disability or received occupational therapy services, 6-17 years)(US & Europe) Mixed Rasch Model revealed competence scores best fit 2 class solution: class 1 used 4 point rating scale as intended (n=212/407) & class 2 unable to distinguish between lower rating options, but used 2 point rating consistently (n=195/407) Two point scale more common for those younger or with intellectual disabilities</p> <p><i>Kramer et al, 2010</i>¹⁹⁸ (502 children with disabilities 6-17 yrs)(US & Europe)</p> <ul style="list-style-type: none"> • Rasch Partial Credit model demonstrated similar hierarchical structure, to previous studies. • All Competence items fit model & 24/25 Value items fit model, providing support for content, structural &, substantive validity • Support for external validity mixed with differences found across country, translated version & administrative method/format used • Younger children & those with intellectual disabilities have greater chance of unexpected response patterns <p><i>Kramer, 2011</i>²¹⁴ (502 children with disabilities + 5 children with CP (not part of larger study), 6-17 yrs)(US & Europe) Concurrent triangulation design to corroborate findings across multiple methods to conduct a comprehensive evaluation of social validity resulted in varied results & considerations</p>
Frequency of Participation Questionnaire (FPQ) ^{45, 174}	<p><i>McManus, 2008</i>⁴⁵ (98 children with CP, 448 children TD, 8-12yrs)(Republic of Ireland) Multiple linear regression found:</p> <ul style="list-style-type: none"> • increased impairment associated with decreased participation, independent of age & gender • overall participation frequency significantly associated with 3 KIDSCREEN³⁴⁸ quality of life domains (Physical well-being, Social support and peers & Moods and emotions) <p><i>Michelsen et al, 2009</i>¹⁷⁴ (813 children with CP, 2939 children without disabilities, 8-12yrs)(9 regions of 7 European countries) Multivariable logistic regressions found participation differences between:</p> <ul style="list-style-type: none"> • ability groups (CP vs no disability) • regions for both ability groups

Tool	Construct Validity
	<ul style="list-style-type: none"> • impairment levels for those with CP <p><i>Parkes et al, 2010²¹⁵ (102 children with CP (Northern Ireland) + 827 children without disabilities (Republic of Ireland & England), 8-12 yrs)</i></p> <ul style="list-style-type: none"> • Item floor & ceiling effects present both for those with CP & those without disabilities • Differences between children with CP compared to normative sample using Mann–Whitney U-test
Assessment of Life Habits (LIFE-H)⁹³	<p><i>Lepage et al, 1998a²¹⁶ (98 children with CP 5-13 yrs)(Canada)</i> Differences in accomplishment of 10 life habits scores & LIFE-H⁹³ total score by impairment type & severity</p> <p><i>Lepage et al, 1998b¹ (children with CP 5-13 yrs, 62 walked, 34 used wheelchairs)(Canada)</i></p> <ul style="list-style-type: none"> • Differences ($p < 0.001$) in Life-H⁹³ total score & each category score between those who walked & those who used a wheelchair • Differences ($p < 0.001$) using ANOVA in Life-H⁹³ total score & all category scores among 4 locomotion types <p><i>Noreau et al, 2007²⁰⁷ (94 children with disabilities & their parents)(Canada)</i> <i>LIFE-H⁹³ 5-13 yr old short form version</i> Hypotheses regarding convergent & divergent validity supported. Pearson correlations ($p < 0.05$):</p> <ul style="list-style-type: none"> • LIFE-H⁹³ Personal care with PEDI⁹⁴ Self care functional skills $r = 0.79$ & caregiver assistance $r = 0.88$ • LIFE-H⁹³ Personal care with PEDI⁹⁴ Mobility functional skills $r = 0.82$ & caregiver assistance $r = 0.80$ • LIFE-H⁹³ Communication with PEDI⁹⁴ Social function- functional skills $r = 0.81$ & PEDI⁹⁴ Social function- caregiver assistance $r = 0.79$ • LIFE-H⁹³ Responsibility with PEDI⁹⁴ Social function- functional skills $r = 0.80$ & PEDI⁹⁴ Social function- caregiver assistance $r = 0.76$ • LIFE-H⁹³ Housing with PEDI⁹⁴ Mobility functional skills $r = 0.88$ & PEDI⁹⁴ Mobility caregiver assistance $r = 0.84$ • LIFE-H⁹³ Housing & Personal care with WeeFIM²⁵¹ Self-care, range $r: 0.90 - 0.94$ • LIFE-H⁹³ Communication with WeeFIM²⁵¹ communication $r = 0.89$ <p>In contrast,</p> <ul style="list-style-type: none"> • LIFE-H⁹³ Mobility with WeeFIM²⁵¹ communication $r = 0.43$ & WeeFIM²⁵¹ social cognition $r = 0.49$ • Remaining LIFE H⁹³ dimensions with remaining PEDI⁹⁴ functional skill range $r: 0.40 - 0.79$ & PEDI⁹⁴ caregiver assistance $r: 0.32 - 0.75$ for <p>Differences ($p < 0.05$) between diagnostic group LIFE-H⁹³ accomplishment scores</p>

Tool	Construct Validity
	<p><i>Calley et al, 2012²²⁷ (19 children with CP & 19 children age & sex matched without CP, 5-12yrs) (Australia)</i></p> <p>Differences ($p < 0.05$) in 10/12 LIFE-H⁹³ category scores (not relationships or work) between CP & TD</p>
<p>MayoPortland Adaptability Index (MPAI) ^{175, 176}</p> <p>Participation Index</p>	<p><i>Oddson et al, 2006¹⁷⁶ (335 children with ABI, 0-19 yrs)(Canada)</i></p> <p>For Inpatients, Spearman's correlations between MPAI-2¹⁷⁶ total scores:</p> <ul style="list-style-type: none"> • age at injury: $r_s = 0.23, p = 0.023$ (n=102) (older children showed more impairment) • Glasgow Coma Scale (GCS)³⁴⁹ scores: $r_s = -0.36, p = 0.002$, (n=72) (more serious injury associated with higher disability) • days of Posttraumatic amnesia: $r_s = 0.44, p < 0.001$ (n=57) • number of days requiring ventilation: $r_s = 0.44, p < 0.001$ (n=98) <p>For Outpatients, Spearman's correlations ($p < 0.001$) between first outpatient visit MPAI-2¹⁷⁵ total scores:</p> <ul style="list-style-type: none"> • GCS³⁴⁹ scores $r_s = -0.33$ (n=195) • days require ventilation: $r_s = 0.22$ (n=320) <p>Spearman's correlations ($p < 0.001$) between MPAI-2 Domain scores at first outpatient visit & self & family reports of ABI-related issues (n=335):</p> <ul style="list-style-type: none"> • Everyday activity: low endurance $r_s = 0.21$ • Cognition: slowed processing $r_s = 0.42$ • Cognition: limited attention & concentration $r_s = 0.39$ • Emotion: frustration $r_s = 0.52$ • Emotion: anger severity $r_s = 0.35$ • Physical: using a mobility device $r_s = 0.45$
<p>Pediatric Community Participation Questionnaire (PCPQ)¹⁷⁷</p>	<p><i>Washington et al, 2007¹⁷⁷ (105 youth with physical disabilities (CP, MD, SB) 8-20 yrs)(US)</i></p> <p>Pearson's correlation ($p < 0.001$) between PCPQ¹⁷⁷ & Functional Disability Index³⁵⁰ $r = 0.69$</p> <p>Differences ($p < 0.001$) between ambulatory vs. non-ambulatory groups</p>
<p>Participation and Environment Measure for Children and Youth (PEM-CY)¹⁷⁸</p>	<p><i>Coster et al, 2011¹⁷⁸ (282 children with disabilities, 294 children without disabilities, 5-17 yrs) (US & Canada)</i></p> <p>two-way analyses of variance determined</p> <ul style="list-style-type: none"> • statistically significant effect of disability across all settings & variables • significant effect of age group for 'Participation involvement' in home & school settings, but not community setting <p>Negative correlations between 'Desire for change' & total Environmental support:</p> <ul style="list-style-type: none"> • home $r = -0.42$ • school $r = -0.59$ • community $r = -0.53$

Tool	Construct Validity
	<p data-bbox="541 241 1556 302">Coster et al, 2013²⁰¹ (282 children with disabilities, 294 children without disabilities, 5-17 yrs) (US & Canada)</p> <p data-bbox="541 305 1524 331">Differences ($p < 0.01$) in school participation between those with disabilities & those without.</p> <p data-bbox="541 334 842 360">Elementary school students:</p> <ul data-bbox="562 363 1178 459" style="list-style-type: none"> • frequency of getting together with peers outside of class • involvement across 4/5 areas of school participation • desire for change in child's participation in all five areas <p data-bbox="541 462 831 488">Secondary school students:</p> <ul data-bbox="562 492 1247 618" style="list-style-type: none"> • frequency for school-sponsored teams, clubs and organizations • frequency of getting together with peers outside of class. • involvement across all five areas of school participation • desire for change in all five areas <p data-bbox="541 651 1549 711">Bedell et al, 2013²¹⁷ (282 children with disabilities, 294 children without disabilities, 5-17 yrs) (US & Canada)</p> <p data-bbox="541 714 1633 774">Differences ($p < 0.01$) in community participation between those with disabilities & those without using both ANOVA & ANCOVA (age & income category adjusted):</p> <ul data-bbox="562 777 1115 904" style="list-style-type: none"> • frequency • involvement • desired change in child's community participation • overall environmental supportiveness <p data-bbox="541 937 1528 997">Law et al, 2013²¹⁸ (282 children with disabilities, 294 children without disabilities, 5-17 yrs) (US & Canada)</p> <p data-bbox="541 1000 1629 1060">Differences ($p < 0.001$) in home participation between those with disabilities & those without, using a 2 way ANOVA with 4 block design:</p> <ul data-bbox="562 1063 1010 1252" style="list-style-type: none"> • number of activities done at home • frequency of participation • level of involvement • desire for change in child's participation • number of barriers in the home • number of supports in the home <p data-bbox="541 1284 1587 1344">Khetani et al, 2014²¹⁹ (89 caregivers of children and youth with disabilities residing in non-urban communities)(US & Canada)(66 from study above + 23)</p> <p data-bbox="541 1347 1476 1373">Group differences ($p < 0.001$) in summary scores according to annual household income:</p> <ul data-bbox="562 1377 972 1403" style="list-style-type: none"> • participating in community activities

Tool	Construct Validity
	<ul style="list-style-type: none"> • environmental supports
Paediatric Interest Profiles (PIP)- Adolescent Leisure Interest Profile (ALIP) ¹⁷⁹	<p><i>Henry, 1998</i>¹⁷⁹ (28 youth without disabilities, 14-19 yrs + 88 youth with disabilities (27 with psychiatric disabilities, 33 with learning disabilities, 28 with physical disabilities), 12-21 yrs)(US) Analysis of covariance, controlling for age, detected differences ($p < 0.01$) in mean total scores between the 4 groups (3 diagnostic groups + those without disabilities) for:</p> <ul style="list-style-type: none"> • How interested? • How often? • How much enjoy? <p><i>Trottier et al, 2002</i>²⁰² (37 teens without impairments, 13-17 yrs)(Canada)</p> <ul style="list-style-type: none"> • Pearson correlations ($p < 0.05$) between ALIP¹⁷⁹ ‘How often’ subscale scores & Leisure Satisfaction Scale³⁵¹ total score & subscale scores r range: -0.39-0.68 • 13/70 correlations statistically significant • Authors stated concurrent validity between two tools not supported
Preschool Activity Card Sort (Preschool ACS) ¹⁸⁰	<p><i>Stoffel et al, 2008</i>²²⁰ English (Preschool AC) & Spanish versions (TAP)(26 Spanish speaking parents & 11 English speaking parents of pre-schoolers without disabilities, 3-6 yrs) Differences ($p < 0.01$) between 4 subgroups of children based on language & time in US Spearman’s correlations ($p < 0.01$) with PEDI⁹⁴ self care scaled score: $r_s = 0.53$ for TAP²²⁰ $r_s = 0.73$ for PAC¹⁸⁰</p> <p><i>LaVesser & Berg 2011</i>²²¹ (parents of 103 children with autism spectrum disorder (ASD) & 41 children typically developing (TD), 3-6 yrs)(US) Version 1 (79 items) Differences ($p < 0.001$) between children who are TD vs those with Autism Spectrum Disorder across</p> <ul style="list-style-type: none"> • self-care • social interaction • domestic chores • education • sedentary leisure • vigorous leisure • community mobility <p><i>Gronski et al, 2013</i>¹⁸¹ version 2 (85 items)(81 parents of able-bodied preschoolers, 52 enrolled child in Head Start program, 29 not enrolled)(US) Version 2 (85 items) Differences ($p < 0.007$ - adjusted for multiple analyses) between 2 groups in domain scores:</p> <ul style="list-style-type: none"> • self-care

Tool	Construct Validity
	<ul style="list-style-type: none"> • community mobility • social interaction • education <p>Comparison of median scores indicate participation difference for only community mobility domain Rasch analysis used to establish internal validity</p>
Quality of Social Functioning Scale and Index (QOSF)¹⁸²	<p><i>Hayes et al, 1999¹⁸² (50 adolescents 11-21 yrs, 48% using a wheelchair)(US)</i></p> <p>Pearson's correlations ($p < 0.05$) between QOSF Index¹⁸² &</p> <ul style="list-style-type: none"> • age: $r = 0.37$ • anger or frustration about not being able to do things because of disability: $r = -0.29$ • think others stay away because of disability: $r = -0.63$ • compare their social life to peers: $r = 0.34$ • compare outlook on life now to outlook on life 1 year ago: $r = 0.35$ <p>Difference ($p < 0.05$) in QOSF Index¹⁸² between those who are ambulatory and those using wheelchairs</p>
Questionnaire of Young People's Participation (QYPP)¹⁸³	<p><i>Tuffrey et al, 2013¹⁸³ (107 young people with CP, 13-21 yrs)(UK)</i></p> <p>Spearman's correlations ($p < 0.01$) between QYPP¹⁸³ & impairment scores:</p> <p>Home life $r_s = -0.79$ Getting on with people $r_s = -0.33$ ($p < 0.05$) Educational life $r_s = -0.46$ Recreation & leisure $r_s = -0.58$ Autonomy $r_s = -0.66$ Preparing for the future $r_s = -0.50$</p> <p>Difference ($p < 0.01$) for all domains between those with disabilities vs without disabilities using Mann-Whitney U-test</p> <p>Categorical Principal Components Analysis using a two-factor model found</p> <ul style="list-style-type: none"> • first factor accounted for 13.2% of variance • second factor accounted for 4.3% of variance • suggests larger sample needed for comprehensive analyses <p><i>Michelsen et al, 2014²²² (667 young people with CP or parent proxy & 4666 young people from general population, 12-18 yrs)(Europe)</i></p> <p>Confirmatory Factor Analysis for 3/7 QYPP¹⁸³ domains revealed:</p> <p>Satisfactory fit: Autonomy Getting on with people</p> <p>Poor fit: Community recreation (other domains not enough items for analyses)</p> <p>Differential Item Functioning: Getting on with people - satisfactory Community recreation - satisfactory</p>

Tool	Construct Validity
	<p>Autonomy: interaction between region & severity Difference in frequency of participation varied by type & severity of impairment, & some regions: Those with CP spent time less time with friends, played sports less often, were more sedentary & felt less autonomous in everyday life, than those in the general population. Less social contact & autonomy associated with more severe impairment.</p>
<p>School Function Assessment (SFA)¹⁸⁴</p> <p>Part I Participation Part II Physical Task & Cognitive/Behavioral Task Supports Part III Physical Task & Cognitive/Behavioral Performance</p>	<p><i>Coster & Mancini, 1999</i>¹⁸⁴ (Sample 1 n=266 Sample 2 n=341 Grade 1-6 elementary school children with disabilities)</p> <p>Two separate exploratory factor analyses on total scores from 18 Activity Performance scales (Part III only) revealed 2 factors; one with Tryout edition (n=266) and one with Standardization edition (n=341) Also referenced SFA manual (Coster et al, 1998)²⁰³ Rasch analyses with Try out edition data (n = 266)</p> <p><i>Mancini & Coster, 2000</i>²²⁶ (n=341 Grade 1-6 elementary school children with disabilities)(US) Part I and Part III only Secondary analysis using Rasch and CART analyses Classification & regression tree (CART) analysis used to classify individuals using cut-off criterion score on Part I into:</p> <ul style="list-style-type: none"> • Full participation group (those able to participate independently or with intermittent assistance) (n=224) • Limited participation (those needing constant supervision or assistance to participate)(n=117) • Cross validation technique used to select predictive models • those in Limited participation group mostly students with physical disabilities who used wheelchairs -classified as severe impairment • in absence of functional information (from Part III), severity of impairment was selected over type of impairment to classify children into groups • impairment by itself can't adequately specify likely functional outcomes • interaction between physical capabilities & social competence was the major pathway associated with full participation <p><i>Hwang et al, 2002</i>²²³ (29 students without disabilities, 18 with learning disabilities & 17 with CP)(US) Differences ($p < 0.01$) between:</p> <ul style="list-style-type: none"> • all subsection scores (those with CP vs without disabilities) • participation, physical task performance & physical task support (those with CP vs learning disabilities) <p>Spearman's correlations ($p < 0.01$) range between SFA¹⁸⁴ & VABS³⁵² Classroom edition scores: Students with disabilities r_s: 0.56 - 0.72 Students without disabilities r_s: 0.37 - 0.65</p>

Tool	Construct Validity
	<p><i>Davies et al, 2004</i>²⁰⁴ (35 elementary students; 11 with learning disabilities (LD), 15 with autism & 9 with traumatic brain injury (TBI))(US) Differences using Kruskal-Wallis ANOVA; ($p=0.002$) between 3 diagnostic groups across 4/5 parts of SFA including Part I (Autism vs LD, but not TBI group) hypotheses partially supported Two discriminant classification analyses showed high correct classification of students with autism & LD, but TBI classification much less accurate, suggesting students with TBI do not clearly display consistent patterns of physical & cognitive/ behavioral abilities</p> <p><i>Mancini & Coster, 2004</i>²⁰⁵(secondary analysis of data reported in SFA manual for 266 elementary students with disabilities (Coster et al, 1998)²⁰³ Multiple regression analyses to examine association between participation score (SFA, Part I) & setting-relevant task scores (SFA, Part III) found:</p> <ul style="list-style-type: none"> • ‘best’ predictors differed for each setting • combination of physical & cognitive/behavioural tasks included • & of ‘definition’ of function in each setting highlighted by different order in which common tasks entered models • greater variance accounted for when in combination than when separate <p>Supports ICF model: activity & participation are context dependent <i>West et al, 2013</i>²²⁴(70 students with acquired brain injury (ABI) evaluated upon admission & discharge from residential rehabilitation program, 4-17 yrs)(UK) Differences ($p < 0.05$) using Linear mixed effects modeling between group admission & discharge scores for Part I, II & III</p>

Legend: ABI = acquired brain injury; ANOVA = Analysis of variance; ANCOVA = analysis of co-variance; CP = cerebral palsy; $CI_{(95)}$ = (95 percent) confidence interval; et al, = and colleagues; GMFCS = Gross Motor Function Classification System; ²²⁹ MCID = minimal clinically important difference; MDC_{95} = minimal detectable change (based on 95 percent confidence interval); n = sample size; p = level of significance; r = Pearson’s correlation coefficient r_s = Spearman’s correlation coefficient rho; RSM = Rasch Rating Scale Model; SCI = spinal cord injury; OT = occupational therapy; SD = standard deviation; SDC = smallest detectable change; SEM = standard error of measurement’ SRM = standard response mean; UK = United Kingdom; US = United States; vs = versa; yrs = years; & = and; = = equal to; + = plus; ~ = approximately; / = out of; % = percentage; - = to; \geq = greater or equal to; \leq = less than or equal to.

Appendix D(ii) Validity Evidence for Paediatric Participation Tools (Continued)

Tool	Content/Face Validity	Responsiveness	Applicability
Assessment of Preschool Children's Participation (APCP) ¹⁶²	<p><i>Law et al, 2012</i>¹⁶² (Canada)</p> <ul style="list-style-type: none"> • literature review of child development & existing measures including CAPE¹⁶⁶ • pilot testing with 57 parents of children typically developing 		<p>administration time <i>Law et al, 2012</i>¹⁶² approx 30–40 minutes</p> <p>cross cultural use Dutch version Norwegian version Chinese version (Taiwan)</p>
Assistance to Participate Scale (APS) ¹⁶³	<p><i>Bourke-Taylor, 2009</i>¹⁶³</p> <ul style="list-style-type: none"> • researcher expertise in childhood occupations • review of other tools <p><i>Bourke-Taylor et al, 2010</i>²⁰⁸</p> <ul style="list-style-type: none"> • item generation informed by semi-structured interviews with 4 mothers of children with disabilities & 4 health professionals 		<p>interpretation <i>Bourke-Taylor et al, 2009</i>¹⁶³ Higher scores on the APS¹⁶³ indicate that the child requires greater assistance to enable their participation in play and leisure activities in the home and community</p>
Availability and Participation scale (AvailabilityPS) ^{164, 165}			<p>interpretation <i>Simeonsson et al, 2001</i>¹⁶⁴ (US) English version: teachers' survey Standardized AvailabilityPS^{164, 165} score can be used to rank & compare degree of participation of students with disabilities in a variety of school activities</p> <p>cross cultural use Sweden, Swedish version including student & teacher report</p>
Children's Assessment of Participation and Enjoyment (CAPE) ¹⁶⁶ and accompanying Preference for Activities of Children (PAC) ¹⁶⁶	<p><i>King et al, 2006</i>¹⁶⁶ (Canada)</p> <ul style="list-style-type: none"> • literature review • expert review • pilot testing with children with & without disabilities • based on conceptual model 		<p>administration time <i>Imms, 2008</i>^{188, 189} CAPE¹⁶⁶ 30-45 minutes PAC¹⁶⁶ 15-20 minutes</p> <p>scoring time CAPE¹⁶⁶ & PAC¹⁶⁶ 30 minutes¹⁸⁹</p>

Tool	Content/Face Validity	Responsiveness	Applicability
			<p><i>interpretation</i> <i>Imms, 2008</i>^{188, 189} Higher diversity & intensity scores represent more diverse & intense activity participation Intensity scores represent the average frequency of the total number of activities possible Important not to interpret intensity as average frequency score that child does Intensity score allows comparison across individuals Low 'whom' scores indicate child's participation tends to be solitary or with immediate family, while high scores indicate more social with many types of people Low 'where' scores indicate activities done at home. Higher scores indicate activities done outside the home Higher enjoyment scores reflect greater enjoyment Higher preference scores reflect stronger preference</p> <p><i>cross cultural use</i> Australia, UK & US Hebrew version Dutch version Spain Spanish version Swedish version Puerto Rico Spanish version</p>

Tool	Content/Face Validity	Responsiveness	Applicability
Community Activities Questionnaire (CAQ) ¹⁶⁷	<p><i>Ehrmann, 1995</i>¹⁶⁷ (US)</p> <ul style="list-style-type: none"> • structured after tool • consultation with parents, teachers & health professionals • 25 mothers pilot tested 		
Child and Adolescent Scale of Participation (CASP) ^{168, 169}	<p><i>Bedell, 2004</i>¹⁶⁸ (US)</p> <ul style="list-style-type: none"> • based on conceptual model • targeted rehab outcomes • literature review • existing tools • expert review by service providers, administrators & parents • 21 parents pilot tested 		<p>administration time <i>Ziviani et al, 2010</i>³⁸ 10-15 minutes</p> <p>interpretation <i>Bedell, 2009</i>¹⁹⁰ Higher scores on CASP represent higher levels of children's participation in home, school & community life situations and activities compared with same age peers</p> <p>cross cultural use <i>Bedell, 2009</i>¹⁹⁰ participants from US Canada Australia and Israel Stated Spanish, Hebrew and Arabic versions in development Canada Australia</p>
Child Engagement in Daily Life Measure ¹⁷⁰ Part I Family and recreational activities dimension	<p><i>Chiarello et al, 2014</i>¹⁷⁰ <i>Palisano et al, 2014</i>²⁰⁶ (US & Canada)</p> <p>based on Pediatric Physical Therapy (PT) Outcome Management System³⁵³ for reporting functional outcomes</p> <ul style="list-style-type: none"> • reviewed by 10 paediatric PTs • 6 parents of children with CP pilot tested 	<p><i>Palisano et al, 2014</i>²⁰⁶ (387 parents & children with CP, 110 parents & children typically developing) (US & Canada)</p> <ul style="list-style-type: none"> • small effect magnitude of change from baseline to 1 year re-evaluation reported for children in GMFCS²²⁹ level I (ES = 0.22) & GMFCS²²⁹ levels II–III (ES = 0.34) (For those in GMFCS²²⁹ IV–V (ES = 0.13) did not meet criteria for small effect) <p><i>Palisano et al, 2014</i>²⁰⁶ (33 parents & children with CP) 23 days apart on average MDC Part I = 13.2</p>	<p>administration time <i>Palisano et al, 2014</i>²⁰⁶ 10-15 minutes</p> <p>interpretation <i>Chiarello et al, 2014</i>¹⁷⁰ a higher scaled score represents greater participation in family and recreational activities</p>

Tool	Content/Face Validity	Responsiveness	Applicability
Children Helping Out: Responsibilities Expectations and Supports (CHORES) ¹⁷¹	<p><i>Dunn, 2004</i>¹⁷¹</p> <ul style="list-style-type: none"> • literature review • based on theoretical constructs • 3 parent focus groups of children with & without disabilities participated in item generation & validation • review by OTs • 11 parents (5 of child with disabilities, 6 of child without disabilities) pilot tested 		<p>interpretation <i>Dunn, 2004</i>¹⁷¹ (32 parents of children, 6-11 yrs 13 with & 19 without disabilities)(US)</p> <ul style="list-style-type: none"> • Flesch reading ease score of 62, grade 7 reading level • 11/11 parents reported rating scales easy to understand, items were readable, and tasks relevant to home routines • higher scores for assistance show greater independence in household tasks <p>cross cultural use Brazilian Portuguese version</p>
Canadian Occupational Performance Measure (COPM) ^{96, 172}	<p><i>Law et al, 1990</i>⁹⁶ (Canada)</p> <ul style="list-style-type: none"> • literature review • review of existing measures • based on the Canadian Model of Occupational Performance³⁵⁴ • input from OT's • pilot tested with 20 clients <p><i>Cusick et al, 2007</i>¹⁷²</p> <ul style="list-style-type: none"> • adaptation for paediatric use included: (i) sections dealing with 'paid/unpaid work' and 'household management' deleted (ii) parent instead of child described performance issues & importance ratings of problems (iii) parents rated their child's performance and their own satisfaction • parents provided feedback 	<p><i>Carswell et al, 2004</i>¹⁹⁶ systematic review</p> <ul style="list-style-type: none"> • identified 5 responsiveness studies (none paediatric) • COPM⁹⁶ change score > 2 points is a clinically meaningful change (MCID) <p><i>Cusick et al, 2007</i>¹⁷² (42 parents of children with CP, 2-7 yrs)(Australia) modified COPM^{96, 172} for pediatric use (proxy) detects changes > 2 points MCID</p> <p><i>Cusick et al, 2006</i>²¹¹ (41 parents of children with CP, 2-7 yrs)(Australia) modified COPM^{96, 172} for pediatric use (proxy) change in COPM^{96, 172} scores over 3 months of treatment in with usual medical & OT care (usual care) vs usual medical & OT care + botox (proven treatment)(Australia) <i>Within group change:</i></p>	<p><i>Carswell et al, 2004</i>¹⁹⁶ numerous studies referenced evaluating clinical utility <i>Cusick et al, 2007</i>¹⁷² parents reported comfortable with process, found it useful, instructions clear & easy to understand</p> <p>administration time <i>Law et al, 1990</i>⁹⁶ 20-40 minutes <i>Cusick et al, 2007</i>¹⁷² modified COPM^{96, 172} for paediatric use (proxy) 10-15 minutes baseline 7-12 minutes follow-up</p>

Tool	Content/Face Validity	Responsiveness	Applicability
	<p>on COPM^{96,172} activities, categories, examples at baseline & re-evaluation</p>	<p>Usual care group COPM- P^{96,172} effect size 0.83 ($p < 0.007$) COPM- S^{96,172} effect size 0.63 ($p < 0.04$) Proven treatment group COPM- P^{96,172} effect size 1.61 ($p < 0.0001$) COPM- S^{96,172} effect size 1.44 ($p < 0.0001$) <i>Between group change:</i> COPM- P^{96,172} effect size 0.78 ($p = 0.01$) COPM- S^{96,172} effect size 0.69 ($p = 0.02$)</p> <p><i>Novak et al, 2012²¹² (36 parents of children with CP 4-12yrs, RCT with 3 groups) modified COPM^{96,172} for pediatric use (proxy)</i> Compared with those in the no OT home program group to those in the OT home program groups demonstrated change ($p < 0.01$): COPM^{96,172} Performance scores 4-week group - effect size: 2.4 (CI₉₅: 0.7– 4.2) 8-week group - effect size: 1.4 (CI₉₅: 0.6 –2.2) COPM^{96,172} Satisfaction scores 4-week group - effect size: 2.5 (CI₉₅: 0.8– 4.3) 8-week group - effect size: 1.5 (CI₉₅: CI: 0.3–2.6)</p>	
<p>Child Occupational Self Assessment (COSA)¹⁷³</p>	<p><i>Keller et al, 2005a¹⁷³ (US)</i></p> <ul style="list-style-type: none"> based on Model of Human Occupation³⁵⁵ repeated (pilot) testing & modification in development process 	<p><i>Keller & Kielhofner, 2005b¹⁹⁷ (43 children 8-17yrs, receiving OT)(US)</i> Response scale expanded from 3 to 4 choices to increase sensitivity to change, Rasch analyses showed increased sensitivity to detect change</p>	<p>administration time <i>Kramer et al, 2010¹⁹⁸</i> 27 minutes average cross cultural use <i>Kramer et al, 2009²³¹</i> stated German, Italian & Icelandic & British sign language versions; process of translation & testing detailed in on-line</p>

Tool	Content/Face Validity	Responsiveness	Applicability
	<p><i>Keller et al, 2005b</i>¹⁹⁷ (US)</p> <ul style="list-style-type: none"> • rating responses changed from 3 to 4 point scale • responses rephrased to minimize social desirability • administration guidelines clarified • open-ended questions added <p><i>Kramer, 2011</i>²¹⁴ qualitative data 5 children interviews, taking photos, & cognitive interviewing while completing COSA¹⁷³</p>		<p>supplemental material (unable to access source of supplemental info)</p>
<p>Frequency of Participation Questionnaire (FPQ)^{45, 174}</p>	<p><i>McManus et al, 2008</i>⁴⁵ <i>Michelsen et al, 2009</i>¹⁷⁴</p> <ul style="list-style-type: none"> • developed by SPARCLE research group based on Assessment of Life Habits (Life-H)⁹³ questionnaire • authors stated FPQ^{45, 174} has face validity because items from Life-H⁹³ • excluded LIFE-H⁹³ items sleeping, toileting, moving about home, gardening & using telephone 		<p><i>cross cultural use</i> <i>Michelsen et al, 2009</i>¹⁷⁴ translated into French, Italian, Danish, Swedish & German according to international guidelines, some items modified for cultural differences</p>
<p>Assessment of Life Habits (LIFE-H)⁹³</p>	<p><i>Fougeyrollas et al, 1998</i>⁹³ (Canada)</p> <ul style="list-style-type: none"> • based on Disability Creation Process model⁹³ • review by 12 experts (researchers, clinicians, consumers) • consensus meeting with developers & experts 		

Tool	Content/Face Validity	Responsiveness	Applicability
	<p><i>Noreau et al, 2007²⁰⁷ (Canada)</i></p> <ul style="list-style-type: none"> • adult LIFE-H⁹³ version adapted for children • reviewed by expert panel of 29 including 11 parents, 15 clinicians & 3 researchers • meeting with panel & researchers to reach consensus on further modifications 		
<p>MayoPortland Adaptability Index (MPAI) ^{175, 176}</p> <p>Participation Index</p>	<p><i>Oddson et al, 2006¹⁷⁶ (Canada)</i></p> <p>Modifications of 30 question MPAI 2nd edition (MPAI-2)¹⁷⁵ developed for adults</p> <ul style="list-style-type: none"> • 4 questions restricted to particular ages (e.g. driving a car to 16 yrs) • Some questions interpreted according to developmental norms 		<p>administration time <i>Oddson et al, 2006¹⁷⁶</i> 20-25 minutes</p> <p>interpretation <i>Oddson et al, 2006¹⁷⁶</i> Clinician administering MPAI¹⁷⁶ must have clear understanding of normal paediatric development & function</p>
<p>Pediatric Community Participation Questionnaire (PCPQ)¹⁷⁷</p>	<p><i>Washington et al, 2007¹⁷⁷ (US)</i></p> <ul style="list-style-type: none"> • items generated from parents & health professionals 		<p>administration time <i>Washington et al, 2007¹⁷⁷</i> 5 minutes Flesch–Kincaid Grade 2 reading level</p>
<p>Participation and Environment Measure for Children and Youth (PEM-CY)¹⁷⁸</p>	<p><i>Coster et al, 2011¹⁷⁸ (Canada & US)</i></p> <ul style="list-style-type: none"> • based on theoretical constructs • literature review • development informed by focus groups & in-depth interviews with 42 parents of children & young people with(out) disabilities • reviewed by expert advisory panel of parents researchers, & practitioners • after revision, cognitive 		<p>administration time <i>Coster et al, 2011¹⁷⁸</i> 20-25 minutes</p>

Tool	Content/Face Validity	Responsiveness	Applicability
	interviewing with 13 parents • field-test version created		
Paediatric Interest Profiles (PIP)- Adolescent Leisure Interest Profile (ALIP) ¹⁷⁹	<i>Henry, 1998</i> ¹⁷⁹ (US) • open-ended interviews with 10 11-15yr olds • testing by 856 youth without disabilities • addition of 6 items after testing • reliability testing by 28 youth without disabilities • review by OTs • reliability testing by 88 youth with disabilities		administration time <i>Henry, 1998</i> ¹⁷⁹ 30 minutes cross cultural use <i>Henry, 1998</i> ¹⁷⁹ Spanish version developed but no similar studies of validity & reliability
Preschool Activity Card Sort (Preschool ACS) ^{180,67}	<i>Berg & LaVesser, 2006</i> ¹⁸⁰ <i>Version 1 (79 items)</i> • 68 time log diaries from parents of pre-schoolers informed item development • literature review • based on theoretical concepts • adult PAC tool used as reference • review by 10 expert paediatric OTs & 10 parents of typically developing pre-schoolers		administration time <i>Gronski et al, 2013</i> ¹⁸¹ Version 2 15-20 minutes
Quality of Social Functioning Scale and Index (QOSF) ¹⁸²	<i>Hayes et al, 1999</i> ¹⁸² (US) • review of other tools • interviews with 14 adolescents with physical disabilities, 72% use a wheelchair • review by health professionals & young adults with disabilities		

Tool	Content/Face Validity	Responsiveness	Applicability
Questionnaire of Young People's Participation (QYPP) ¹⁸³	<i>Tuffrey et al, 2013</i> ¹⁸³ (UK) <ul style="list-style-type: none"> • review of other tools • literature review • semi-structured interviews with 17 14-21 yr olds with & without CP • 3 focus groups of young people with & without CP • expert review by 17 professionals • content validity index used to determine proportion of items experts identified as relevant (range 86-98%) • 2 rounds of cognitive testing by 12 young people & 12 caregivers with first round answering questions independently, then second round probing for rationale in completing questionnaire 		<i>administration time</i> <i>Tuffrey et al, 2013</i> ¹⁸³ 20-30 minutes
School Function Assessment (SFA) ¹⁸⁴ Part I Participation Part II Physical Task & Cognitive/Behavioral Task Supports Part III Physical Task & Cognitive/Behavioral Performance	<i>Coster & Mancini, 1999</i> ¹⁸⁴ <i>referencing SFA manual</i> <ul style="list-style-type: none"> • review by 30 content experts (educators & therapists) • review by 40 therapists & educators who work daily with students >80% of reviewers agreed (ratings 4 or 5/5) that SFA¹⁸⁴ • is useful, comprehensive & relevant for elementary school students with disabilities 	<i>Wright et al, 2005</i> ²²⁵ (6 students with CP evaluated baseline & after one year school intervention) Part I (criterion score 1-100) change in mean criterion score 0.2 SD 3.6 SRM = 0.04 (stated no change demonstrated)	<i>administration time</i> <i>Ziviani et al, 2010</i> ³⁸ Part I 10 minutes <i>Davies et al, 2004</i> ²⁰⁴ (referencing <i>Coster et al, 1998</i>) ²⁰³ Administered by persons who know student's performance at school & during school activities <i>cross cultural use</i> <i>Chinese version (Taiwan)</i> <i>Hebrew version</i> <i>Icelandic version</i> <i>Swedish version</i>

Legend: ABI = acquired brain injury; ANOVA = Analysis of variance; ANCOVA = analysis of co-variance; CP = cerebral palsy; CI₍₉₅₎ = (95 percent) confidence interval; et al, = and colleagues; GMFCS = Gross Motor Function Classification System; ²²⁹ MCID = minimal

clinically important difference; MDC_{95} = minimal detectable change (based on 95 percent confidence interval); n = sample size; p = level of significance; r = Pearson's correlation coefficient r_s = Spearman's correlation coefficient ρ ; RSM = Rasch Rating Scale Model; SCI = spinal cord injury; OT = occupational therapy; SD = standard deviation; SDC = smallest detectable change; SEM = standard error of measurement' SRM = standard response mean; UK = United Kingdom; US = United States; vs = versa; yrs = years; & = and; = = equal to; + = plus; ~ = approximately; / = out of; % = percentage; - = to; \geq = greater or equal to; \leq = less than or equal to.

Appendix E Quality Ratings ff Reliability Evidence

Measurement Tool	COSMIN Rating ¹²⁴ Lowest rating as specified in COSMIN guidelines ¹²⁴ (text) provides range of ratings			OMRF Individual Study Reliability Rating ¹²⁵ Rating as specified in OMRF guidelines ¹²⁴ Reliability co-efficient values $P < 0.60$; $0.60 \geq A \leq 0.79$; $E \geq 0.80$			
	Internal consistency	Reliability	Measurement error	Internal consistency	Test-retest	Inter-rater	Intra-rater
Assessment of Preschool Children's Participation (APCP) ¹⁶²	Law 2012 ¹⁶² P (E) Chiarello 2012 ¹⁸⁵ P (F-G) Kelly 2013 ¹⁸⁶ P (F-G)			Law 2012 ¹⁶² A-E Diversity P-A Intensity Chiarello 2012 ¹⁸⁵ E all items Kelly 2013 ¹⁸⁶ P-A Diversity			
Assistance to Participate Scale (APS) ¹⁶³	Bourke Taylor 2009 & 2013 ^{163, 187} F (E)			Bourke Taylor 2009 & 2013 ^{163, 187} E total & 2 subscales			
Availability and Participation Scale (AvailabilityPS) ^{164, 165}	Simeonsson 2001 ¹⁶⁴ P (F-E)			Simeonsson 2001 ¹⁶⁴ E			
Children's Assessment of Participation and Enjoyment (CAPE) ¹⁶⁶ and accompanying Preference for Activities of Children (PAC) ¹⁶⁶	King 2006 ¹⁶⁶ & R Imms 2008 ^{188, 189} CAPE P (G-E) PAC E Kelly 2013 ¹⁸⁶ CAPE P (P-E)	<i>test-retest & inter-rater</i> R Imms 2008 ^{188, 189} CAPE F (F-E)		King 2006 ¹⁶⁶ & R Imms 2008 ^{188, 189} CAPE P-A Frequency PAC A-E Kelly 2013 ¹⁸⁶ CAPE A-E Diversity except P Formal domain 16-18 year olds	R Imms 2008 ^{188, 189} CAPE A-E overall score 2 domains 4/5 activity types P-A activity type enjoyment	R Imms 2008 ^{188, 189} CAPE interviewer vs self-administer E intensity P-A enjoyment	

Measurement Tool	COSMIN Rating ¹²⁴ Lowest rating as specified in COSMIN guidelines ¹²⁴ (text) provides range of ratings			OMRF Individual Study Reliability Rating ¹²⁵ Rating as specified in OMRF guidelines ¹²⁴ Reliability co-efficient values P < 0.60; 0.60 ≥ A < 0.79; E ≥ 0.80			
	Internal consistency	Reliability	Measurement error	Internal consistency	Test-retest	Inter-rater	Intra-rater
Community Activities Questionnaire (CAQ) ¹⁶⁷	Ehrmann 1995 ¹⁶⁷ P (F-E)			Ehrmann 1995 ¹⁶⁷ A			
Child and Adolescent Scale of Participation (CASP) ^{168, 169}	Bedell 2004 & 2009 ^{168, 190} P (P-E) Parent version McDougall 2013 ¹⁶⁹ E Youth version	<i>test-retest</i> Bedell 2004 ¹⁶⁸ F (F-E) Parent version		Bedell 2004 & 2009 ^{168, 190} E Parent version McDougall 2013 ¹⁶⁹ A-E overall Parent & Youth versions	Bedell 2004 ¹⁶⁸ E Parent (time interval not stated)		
Child Engagement in Daily Life Measure ¹⁷⁰	Chiarello 2014 ¹⁷⁰ F (E)	<i>test-retest</i> Chiarello 2014 ¹⁷⁰ P (F-E)	Palisano 2014 ²⁰⁶ P (F-E)	Chiarello 2014 ¹⁷⁰ E Frequency & Enjoyment	Chiarello 2014 ¹⁷⁰ A		
Children Helping Out: Responsibilities Expectations and Supports (CHORES) ¹⁷¹	Dunn 2004 & 2013 ^{171, 191} P (F-E) Dunn 2014 ¹⁹² F (E)	<i>test-retest</i> Dunn 2004 ¹⁷¹ P (G-E)	Dunn 2014 ¹⁹² P (F-E)	Dunn 2004, 2013 & 2014 ^{171, 191, 192} E	Dunn 2004 ¹⁷¹ E		
Canadian Occupational Performance Measure (COPM) ^{96, 172}	Cusick 2007 ¹⁷² Parent proxy F (F-E)	<i>test-retest</i> McColl 2000 ¹⁹³ R P		Cusick 2007 ¹⁷² E Parent proxy with children	McColl 2000 ¹⁹³ R A		
Child Occupational Self Assessment (COSA) ¹⁷³	Keller 2005 a & b ^{173, 197} F (F-E)			Keller 2005 a & b ^{173, 197} a A-E b E			

Measurement Tool	COSMIN Rating ¹²⁴ Lowest rating as specified in COSMIN guidelines ¹²⁴ (text) provides range of ratings			OMRF Individual Study Reliability Rating ¹²⁵ Rating as specified in OMRF guidelines ¹²⁴ Reliability co-efficient values P < 0.60; 0.60 ≥ A < 0.79; E ≥ 0.80			
	Internal consistency	Reliability	Measurement error	Internal consistency	Test-retest	Inter-rater	Intra-rater
	Kramer 2010 ¹⁹⁸ G (E)			Kramer 2010 ¹⁹⁸ E			
Frequency of Participation Questionnaire (FPQ) ^{45, 174}	McManus 2008 ⁴⁵ P (G-E)			McManus 2008 ⁴⁵ A			
Assessment of Life Habits (LIFE-H) ⁹³	Morris 2005 ¹⁰⁹ & Bedell 2008 ¹⁴⁸ R P	<i>test-retest</i> Fougeyrollas 1998 ⁹³ P (F-E) Morris 2005 ¹⁰⁹ R P <i>inter-rater & intra-rater</i> Noreau 2007 ²⁰⁷ F (G-E)		Morris 2005 ¹⁰⁹ & Bedell 2008 ¹⁴⁸ R A-E except Morris 2005 ¹⁰⁹ R P interpersonal relationships	Fougeyrollas 1998 ⁹³ A total score P-A categories	Noreau 2007 ²⁰⁷ A-E	Noreau 2007 ²⁰⁷ A-E except P inter-personal relationships
MayoPortland Adaptability Index (MPAI) ^{175, 176}		<i>test-retest</i> Oddson 2006 ¹⁷⁶ F (F-E) <i>inter-rater</i> Oddson 2006 ¹⁷⁶ P (F-E)			Oddson 2006 ¹⁷⁶ P-E	Oddson 2006 ¹⁷⁶ E	
Pediatric Community Participation Questionnaire (PCPQ) ¹⁷⁷	Washington 2007 ¹⁷⁷ P (F-E)			Washington 2007 ¹⁷⁷ E			
Participation and Environment Measure for Children and Youth (PEM-CY) ¹⁷⁸	Coster 2011 ¹⁷⁸ G (G-E)	<i>test-retest</i> Coster 2011 ¹⁷⁸ F (G-E)		Coster 2011 ¹⁷⁸ P-E Frequency	Coster 2011 ¹⁷⁸ A-E except P school total		

Measurement Tool	COSMIN Rating ¹²⁴ Lowest rating as specified in COSMIN guidelines ¹²⁴ (text) provides range of ratings			OMRF Individual Study Reliability Rating ¹²⁵ Rating as specified in OMRF guidelines ¹²⁴ Reliability co-efficient values P < 0.60; 0.60 ≥ A < 0.79; E ≥ 0.80			
	Internal consistency	Reliability	Measurement error	Internal consistency	Test-retest	Inter-rater	Intra-rater
		Coster 2013 ²⁰¹ P (P-G)		A-E Involvement Environment	Coster 2013 ²⁰¹ A		
Paediatric Interest Profile - Adolescent Leisure Interest Profile (ALIP) ¹⁷⁹	Henry 1998 ¹⁷⁹ P (F-E) Trottier 2002 ²⁰² P (F-E)	<i>test-retest</i> Henry 1998 ¹⁷⁹ (PD) G (G-E) Henry 1998 ¹⁷⁹ (TD) P (G-E) Trottier 2002 ²⁰² (TD) F (F-E)		Henry 1998 ¹⁷⁹ (PD) E total scores P-E subscales Henry 1998 ¹⁷⁹ (TD) E total scores P-E subscales Trottier 2002 ²⁰² E total scores P-E subscales	Henry 1998 ¹⁷⁹ (PD) A total scores P-E subscales Henry 1998 ¹⁷⁹ (TD) P-E totalscore P-E subscales Trottier 2002 ²⁰² E total scores P-E subscales		
Preschool Activity Card Sort (Preschool ACS) ^{180, 181}	Gronski 2013 ¹⁸¹ P (P-E) Version 2	<i>test-retest & inter-rater</i> Gronski 2013 ¹⁸¹ P (F-E)		Gronski 2013 ¹⁸¹ E Version 2	Gronski 2013 ¹⁸¹ E	Gronski 2013 ¹⁸¹ E	
Quality of Social Functioning Scale and Index (QOSF) ¹⁸²	1999 Hayes ¹⁸² P (F-E)			1999 Hayes ¹⁸² A-E			
Questionnaire of Young People's Participation (QYPP) ¹⁸³	Tuffrey 2013 ¹⁸³ E	<i>test-retest</i> Tuffrey 2013 ¹⁸³ F (G-E)		Tuffrey 2013 ¹⁸³ A-E except for P educational life	2013 Tuffrey ¹⁸³ E		

Measurement Tool	COSMIN Rating ¹²⁴ Lowest rating as specified in COSMIN guidelines ¹²⁴ (text) provides range of ratings			OMRF Individual Study Reliability Rating ¹²⁵ Rating as specified in OMRF guidelines ¹²⁴ Reliability co-efficient values P < 0.60; 0.60 ≥ A ≤ 0.79; E ≥ 0.80			
	Internal consistency	Reliability	Measurement error	Internal consistency	Test-retest	Inter-rater	Intra-rater
School Function Assessment (SFA) ¹⁸⁴ Part I Participation Part II Physical Task & Cognitive/Behavioral Task Supports Part III Physical Task & Cognitive/Behavioral Performance	Coster 1999 ¹⁸⁴ Part III only Tryout edition & Standardized edition R P (F-E) Davies 2004 ²⁰⁴ R (F-E) Bedell 2008 ³² Ziviani 2010 ³⁸ R P Mancini 2004 ²⁰⁵ Part I & III F (F-E)	<i>test-retest</i> Coster 1999 ¹⁸⁴ Part III only R F (F-E) Tryout edition & Standardized edition Davies 2004 ²⁰⁴ R P (F-E) Mancini 2004 ²⁰⁵ Part I & III P (P-E) <i>inter-rater</i> Davies 2004 ²⁰⁴ P (F-E)		Coster 1999 ¹⁸⁴ Part III only Tryout edition & Standardized edition R E Davies 2004 ²⁰⁴ R E Mancini 2004 ²⁰⁵ Part I & III E	Coster 1999 ¹⁸⁴ Part III R E Tryout edition & Standardized edition Davies 2004 ²⁰⁴ R E Mancini 2004 ²⁰⁵ Part I A-E Part III P-E	Davies 2004 ²⁰⁴ A	

Legend: A = adequate; COSMIN = Consensus-based Standards for the Selection of health Measurement Instruments;¹²⁴ E = excellent; F = fair; G = good; OMRF = McMaster Outcome Measure Rating Form;¹²⁵ P = poor; R = referenced from other source; unable to locate original, or not peer-reviewed source; PD = those with physical disabilities; TD = those who are typically developing; & = and.

Appendix F Quality Ratings of Validity Evidence

Measurement Tool	COSMIN Rating ¹²⁴ Lowest rating specified in COSMIN guidelines ³⁹ E = excellent, G = good, F= fair, P = poor (text) provides range of ratings				OMRF Individual Study Rating ¹²⁵ Lowest rating as specified in OMRF guidelines ¹²⁵ E = excellent, A = adequate, P = poor		
	Content validity	Structural validity	Hypotheses testing	Responsiveness	Content validity	Construct validity	Responsiveness
Assessment of Preschool Children's Participation (APCP) ¹⁶²	Law 2012 ¹⁶² E		Law 2012 ¹⁶² G (G-E)		Law 2012 ¹⁶² E	Law 2012 ¹⁶²	
Assistance to Participate Scale (APS) ¹⁶³	Bourke 2009 & 2010 ^{163, 208} E	Bourke 2009 & 2013 ^{163, 187} F (F-E)	Bourke 2009 & 2013 ^{163, 187} F (F-E)		Bourke 2009 & 2010 ^{163, 208} E	Bourke 2009 & 2013 ^{163, 187}	
Availability and Participation Scale (AvailabilityPS) ^{164, 165}	Simeonsson 2001 ¹⁶⁴ E	Simeonsson 2001 ¹⁶⁴ F (to E)	Simeonsson 2001 ¹⁶⁴ F (F-E)		Simeonsson 2001 ¹⁶⁴ E		
Children's Assessment of Participation and Enjoyment (CAPE) ¹⁶⁶ and Preference for Activities of Children (PAC) ¹⁶⁶	King 2006 ¹⁶⁶ CAPE & PAC E	King 2006 ¹⁶⁶ CAPE not provided PAC G (G-E)	King 2006 ¹⁶⁶ CAPE & PAC G (G-E) Shikako-Thomas 2013 ²⁰⁹ CAPE F (F-E)		King 2006 ¹⁶⁶ CAPE & PAC E	#	
Community Activities Questionnaire (CAQ) ¹⁶⁷	Ehrmann 1995 ¹⁶⁷ E	Ehrmann 1995 ¹⁶⁷ F (F-E)	Ehrmann 1995 ¹⁶⁷ F (F-E)		Ehrmann 1995 ¹⁶⁷ E	Ehrmann 1995 ¹⁶⁷	
Child and Adolescent Scale of Participation (CASP) ^{168, 169}	Bedell 2004 ¹⁶⁸ E	Bedell 2004 ¹⁶⁸ P (F-E) Bedell 2009 ¹⁹⁰ F (E) McDougall 2013 ¹⁶⁹ E	Bedell 2004 & 2009 ^{168, 190} F (F-E) McDougall 2013 ¹⁶⁹ F (F-E)		Bedell 2004 ¹⁶⁸ E	Bedell 2004 & 2009 ^{168, 190} McDougall 2013 ¹⁶⁹	
Child Engagement in Daily Life Measure (CEDL) ¹⁷⁰	Chiarello 2014 ¹⁷⁰ E	Chiarello 2014 ¹⁷⁰ F (F-E)	Chiarello 2014 ¹⁷⁰ F (F-E)	Palisano 2014 ²⁰⁶ F (F-E)	Chiarello 2014 ¹⁷⁰ E	Chiarello 2014 ¹⁷⁰	Palisano 2014 ²⁰⁶ MDC & ES

Measurement Tool	COSMIN Rating ¹²⁴ Lowest rating specified in COSMIN guidelines ³⁹ E = excellent, G = good, F= fair, P = poor (text) provides range of ratings				OMRF Individual Study Rating ¹²⁵ Lowest rating as specified in OMRF guidelines ¹²⁵ E = excellent, A = adequate, P = poor		
	Content validity	Structural validity	Hypotheses testing	Responsiveness	Content validity	Construct validity	Responsiveness
Children Helping Out: Responsibilities Expectations and Supports (CHORES) ¹⁷¹	Dunn 2004 ¹⁷¹ E	Dunn 2014 ¹⁹² P (P-E)	Dunn 2004, 2013 & 2014 ^{171, 191, 192} F (F-E)		Dunn 2004 ¹⁷¹ E	Dunn 2004, 2013 & 2014 ^{171, 191, 192}	
Canadian Occupational Performance Measure (COPM) ^{96, 172}	Law 1990 ⁹⁶ E Cusick 2007 ¹⁷² Parent proxy E	client specified items; not appropriate analysis	Cusick 2006 & 2007 ^{172, 211} Parent proxy F (F-E)	Cusick 2006 ²¹¹ Parent proxy F (F-E) Novak 2012 ²¹² Parent proxy F (F-E)	Law 1990 ⁹⁶ E Cusick 2007 ¹⁷² Parent proxy E	#	Cusick 2006 ²¹¹ Parent proxy ES Novak 2012 ²¹² Parent proxy ES
Child Occupational Self Assessment (COSA) ^{173, 197}	Keller 2005 a & b ^{173, 197} E Kramer 2011 ²¹⁴ E	Keller 2005 a & b ^{173, 197} P (F-E) Kramer 2009 ²³¹ E	Keller 2005 a & b ^{173, 197} F (F-E) Kramer 2009, 2010 & 2011 ^{198, 214, 231} F (F-E)		Keller 2005a ^{173, 197} E	Keller 2005 a & b ^{173, 197} Kramer 2009, 2010 & 2011 ^{198, 214, 231}	
Frequency of Participation Questionnaire (FPQ) ^{45, 174}	McManus 2008 ⁴⁵ F Michelsen 2009 ¹⁷⁴ F		McManus 2008 ⁴⁵ F (G-E) Michelsen 2009 ¹⁷⁴ F (G-E) Parkes 2010 ¹⁰⁷ F (G-E)		McManus 2008 ⁴⁵ A Michelsen 2009 ¹⁷⁴ A	McManus 2008 ⁴⁵ Michelsen 2009 ¹⁷⁴ Parkes 2010 ²¹⁵	
Assessment of Life Habits (LIFE-H) ⁹³	Fougeyrollas 1998 ⁹³ E Noreau 2007 ²⁰⁷ E		Fougeyrollas 1998 ⁹³ P (F-E) Lepage 1998 a & b ^{216,1} F (G-E) Noreau 2007 ²⁰⁷ G (G-E) Calley 2012 ²²⁷ F (F-E)		Fougeyrollas 1998 ⁹³ E Noreau 2007 ²⁰⁷ E	Fougeyrollas 1998 ⁹³ Lepage 1998 a & b ^{216,1} Noreau 2007 ²⁰⁷ Calley 2012 ²²⁷	

Measurement Tool	COSMIN Rating ¹²⁴ Lowest rating specified in COSMIN guidelines ³⁹ E = excellent, G = good, F= fair, P = poor (text) provides range of ratings				OMRF Individual Study Rating ¹²⁵ Lowest rating as specified in OMRF guidelines ¹²⁵ E = excellent, A = adequate, P = poor		
	Content validity	Structural validity	Hypotheses testing	Responsiveness	Content validity	Construct validity	Responsiveness
MayoPortland Adaptability Index (MPAI) ^{175, 176}	Oddson 2006 ¹⁷⁶ F		Oddson 2006 ¹⁷⁶ P (F-G)		Oddson 2006 ¹⁷⁶ A	Oddson 2006 ¹⁷⁶	
Pediatric Community Participation Questionnaire (PCPQ) ¹⁷⁷	Washington 2007 ¹⁷⁷ E		Washington 2007 ¹⁷⁷ F (G-E)		Washington 2007 ¹⁷⁷ E	Washington 2007 ¹⁷⁷	
Participation and Environment Measure for Children and Youth (PEM-CY) ¹⁷⁸	Coster 2011 & 2012 ¹⁷⁸ E		Coster 2013 ²⁰¹ F (F-E) Bedell 2013 ²¹⁷ F (F-E) Law 2013 ²¹⁸ F (F-E) Khetani 2014 ²¹⁹ F (F-E)		Coster 2011 & 2012 ¹⁷⁸ E	Coster 2013 ²⁰¹ Bedell 2013 ²¹⁷ Law 2013 ²¹⁸ Khetani 2014 ²¹⁹	
Pediatric Interest Profile - Adolescent Leisure Interest Profile (ALIP) ¹⁷⁹	Henry 1998 ¹⁷⁹ F		Henry 1998 ¹⁷⁹ F (F-G) Trottier 2002 ²⁰² F (F-E)		Henry 1998 ¹⁷⁹ E	Henry 1998 ¹⁷⁹ Trottier 2002 ²⁰²	
Preschool Activity Card Sort (Preschool ACS) ^{180, 181}	Berg 2006 ¹⁸⁰ E Stoffel 2008 ²²⁰ E Gronski 2013 ¹⁸¹ E	Gronski 2013 ¹⁸¹ P (F-E)	Berg 2006 ¹⁸⁰ F (F-G) Gronski 2013 ¹⁸¹ F (F-E) Stoffel 2008 ²²⁰ F (F-E) LaVesser 2011 ²²¹ F (F-E)		Berg 2006 ¹⁸⁰ E Gronski 2013 ¹⁸¹ E Stoffel 2008 ²²⁰ E	Berg 2006 ¹⁸⁰ Stoffel 2008 ²²⁰ LaVesser 2011 ²²¹ Gronski 2013 ¹⁸¹	
Quality of Social Functioning Scale and Index (QOSF) ¹⁸²	Hayes 1999 ¹⁸² E		Hayes 1999 ¹⁸² P (P-E)		Hayes 1999 ¹⁸² E	Hayes 1999 ¹⁸²	
Questionnaire of Young People's Participation (QYPP) ¹⁸³	Tuffrey 2013 ¹⁸³ E	Tuffrey 2013 ¹⁸³ P (E)	Tuffrey 2013 ¹⁸³ F (G-E)		Tuffrey 2013 ¹⁸³ E	Tuffrey 2013 ¹⁸³	

Measurement Tool	COSMIN Rating ¹²⁴ Lowest rating specified in COSMIN guidelines ³⁹ E = excellent, G = good, F= fair, P = poor (text) provides range of ratings				OMRF Individual Study Rating ¹²⁵ Lowest rating as specified in OMRF guidelines ¹²⁵ E = excellent, A = adequate, P = poor		
	Content validity	Structural validity	Hypotheses testing	Responsiveness	Content validity	Construct validity	Responsiveness
	Michelsen 2014 ²²² E	Michelsen 2014 ²²² F (F-E)	Michelsen 2014 ²²² F (F-E)		Michelsen 2014 ²²² E	Michelsen 2014 ²²²	
School Function Assessment (SFA) ¹⁸⁴ Part I Participation Part II Physical Task & Cognitive/Behavioral Task Supports Part III Physical Task & Cognitive/Behavioral Performance	Coster 1999 ¹⁸⁴ G part III only Mancini 2000 ²²⁶ E	Coster 1999 ¹⁸⁴ P (F-E) part III only Mancini 2000 ²²⁶ P (F-E) part I & III only	Coster 1999 ¹⁸⁴ F (F-E) part III only Davies 2004 ²⁰⁴ F (G-E) Mancini 2004 ²⁰⁵ F (F-E) Hwang 2002 ²²³ F (G-E) West 2013 ²²⁴ F (F-G)		Coster 1999 ¹⁸⁴ A part III only Mancini 2004 ²⁰⁵ E	Coster 1999 ¹⁸⁴ part III only Davies 2004 ²⁰⁴ Mancini 2000 ²²⁶ Hwang 2002 ²²³ West 2013 ²²⁴	

Legend: A = adequate; COSMIN = Consensus-based Standards for the Selection of health Measurement Instruments; ¹²⁴ E = excellent; ES = effect size; F = fair; G = good; MDC = minimal detectable change; OMRF = McMaster Outcome Measure Rating Form; ¹²⁵ P = poor; & = and; # = numerous studies outside context of review.

Appendix G Round One Questions and Statements Regarding Participation Elements

Questions Regarding Participation Elements	Statements Relating to Participation Elements
1. Who's point of view should be sought when evaluating participation?	A parent's report of their child's participation is most essential
	The child's self report of participation is most essential
	A therapist's report of the child's participation is most essential
	A combination of a parent's report of the child's participation and the child's self report of participation is most essential
2. In what setting should participation be evaluated in?	Participation in home life is most critical to evaluate
	Participation in school life is most critical to evaluate
	Participation in community life is most critical to evaluate
	Participation in a combination of settings (e.g. home, school & community) is most critical to evaluate
3. Whose participation should we evaluate?	Child-only participation is most critical to evaluate
	Family participation is most critical to evaluate
	A combination of family participation & child participation is most critical to evaluate
4. What kinds of participation should we evaluate?	A standard list of scenarios is most valuable to evaluate
	A set of user defined scenarios is most valuable to evaluate
	A combination of a standard list of scenarios along with user defined scenarios is most valuable to evaluate
5. What kind of objective information related to participation should we evaluate?	Documenting the number of activities the child is involved in is most essential
	Documenting the frequency of participation is most essential
	Specifying the location where participating is most essential
	Specifying who the child is participating with is most essential
6. What kind of subjective information related to participation should we evaluate?	The child's satisfaction with his/her participation is most essential
	The child's importance of his/her participation is most essential
	The child's preference of participation is most essential
	The child's enjoyment of participation is most essential
	The parent's satisfaction with the child's participation is most essential
	The parent's importance with the child's participation is most essential
	The child's engagement in participation is critical to evaluate (added in second round)
	The child's autonomy in participation is critical to evaluate (added in second round)
7. What dimensions of participation are most relevant?	Objective information that documents observed behavior is most critical to evaluate
	Subjective information that reflects the individual's personal view is most critical to evaluate
	A combination of objective and subjective information is most critical to evaluate
8. What aspect of participation should we	Measuring capacity is most essential (what child is able to do given their best effort, and set-up)

Questions Regarding Participation Elements	Statements Relating to Participation Elements
evaluate?	Measuring capability is most essential (what child could do in everyday life, if he/she desires) Measuring performance is most essential (i.e. what the child actually does in everyday life) Measuring a combination of capacity, capability & performance is most essential
9. Should barriers and facilitators to participation be evaluated?	Barriers and facilitators of participation should be included in an assessment of participation Barriers & facilitators of participation should be evaluated, but done as a separate assessment from participation Barriers & facilitators of participation should not be evaluated when assessing participation
10. What does participation mean?	Participation should only involve activities where there are interactions with others Participation should include activities that are done alone Personal care activities should be considered as participation
11. With whom should the individual be compared to?	Comparison with peers is critical information Comparison with self over time is critical information Evaluations with peers and with self are equally important
12. How important is it to record the strategies & amount of assistance required for participation?	Documenting the strategy needed to participate is critical Documenting the amount of assistance needed is critical
13. How long should the assessment take to administer? Select the maximum number of minutes acceptable, if administering i) a therapist report questionnaire ii) a parent report questionnaire iii) a child report questionnaire	Taking less than 15 minutes to administer the assessment is acceptable Taking 15-30 minutes to administer the assessment is acceptable Taking more than 30 minutes to administer the assessment is acceptable
14. How long should the assessment take to score? Select the maximum number of minutes acceptable for scoring an assessment:	Taking less than 15 minutes to score the assessment is acceptable Taking 15-30 minutes to score the assessment is acceptable Taking more than 30 minutes to score the assessment is acceptable

Appendix H Round One Summary of Results



DELPHI SURVEY Round One Summary

Consensus reached for total group and all 3 subgroups (parents, clinicians & researchers)

School Age: children aged 6 to 12 years (14 items reached consensus)

Statements
The child's self report of participation is most essential
A combination of a parent's report of the child's participation and the child's self report of participation is most essential
Participation in a combination of settings is most critical to evaluate
A combination of family and child participation is most critical to evaluate
A combination of a standard list of scenarios along with user defined scenarios is most valuable to evaluate
Specifying the location where participating is most essential
The child's satisfaction with his/her participation is most essential
The child's enjoyment of participation is most essential
The child's importance of his/her participation is most essential
The child's preference of participation is most essential
A combination of objective & subjective information is most critical to evaluate
Barriers & facilitators of participation should be included in an assessment of participation
Participation should include activities that are done alone
Comparison with self over time is critical information

Early Childhood: children aged 18 months to 5 years (0 items reached consensus)

No statements reached consensus



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Colour Coding: **Consensus Reached**

Very Close to Consensus

Not Close to Consensus

Consensus Almost Reached for Total Group & 3 Subgroups (parents, clinicians, researchers)

School Age: children aged 6 to 12 years (3 items reached consensus)

Statements	Total Group Response	Parent Group Response	Clinician Group Response	Researcher Group Response
Participation in community life is most critical to evaluate	Very Close to Consensus	Not Close to Consensus	Consensus Reached	Not Close to Consensus
Specifying who the child is participating with is most essential	Very Close to Consensus	Very Close to Consensus	Consensus Reached	Very Close to Consensus
Subjective information that reflects the individual's personal view is most critical to evaluate	Very Close to Consensus	Very Close to Consensus	Consensus Reached	Not Close to Consensus

Early Childhood: children aged 18 months to 5 years (6 items reached consensus)

Statements	Total Group Response	Parent Group Response	Clinician Group Response	Researcher Group Response
Participation in home life is most critical to evaluate	Very Close to Consensus	Very Close to Consensus	Consensus Reached	Not Close to Consensus
The parent's satisfaction with the child's participation is most essential	Very Close to Consensus	Very Close to Consensus	Consensus Reached	Not Close to Consensus
The parent's importance of the child's participation is most essential	Very Close to Consensus	Not Close to Consensus	Consensus Reached	Very Close to Consensus
The child's importance of his/her participation is most essential	Very Close to Consensus	Not Close to Consensus	Consensus Reached	Very Close to Consensus
The child's preference of participation is most essential	Very Close to Consensus	Not Close to Consensus	Consensus Reached	Very Close to Consensus
Participation should include activities that are done alone	Very Close to Consensus	Not Close to Consensus	Consensus Reached	Consensus Reached

Consensus Reached for Total group but not all 3 subgroups (parents, clinicians, researchers)

School Age: children aged 6 to 12 years (6 items reached consensus for total group)

Questions	Total Group Response	Parent Group Response	Clinician Group Response	Researcher Group Response
Participation in school life is most critical to evaluate	Consensus Reached	Consensus Reached	Consensus Reached	Not Close to Consensus
Documenting the frequency of participation is most essential	Consensus Reached	Very Close to Consensus	Consensus Reached	Not Close to Consensus
Documenting the strategy needed to participate is critical	Consensus Reached	Consensus Reached	Consensus Reached	Not Close to Consensus
Documenting the amount of assistance needed is critical	Consensus Reached	Consensus Reached	Consensus Reached	Not Close to Consensus
Measuring performance is most essential (what child actually does in everyday life)	Consensus Reached	Consensus Reached	Consensus Reached	Not Close to Consensus
Measuring a combination of capacity, capability & performance is most essential	Consensus Reached	Consensus Reached	Consensus Reached	Not Close to Consensus

Colour Coding: **Consensus Reached**

Very Close to Consensus

Not Close to Consensus

Consensus Reached for Total group but not all 3 subgroups (parents, clinicians, researchers)

Early Childhood: children aged 18 months to 5 years (13 items reached consensus for total group)

Statements	Total Group Response	Parent Group Response	Clinician Group Response	Researcher Group Response
A parent's report of their child's participation is most essential	Consensus Reached	Very Close to Consensus	Consensus Reached	Very Close to Consensus
A combination of a parent's report of the child's participation and the child's self report of participation is most essential	Consensus Reached	Very Close to Consensus	Consensus Reached	Consensus Reached
Participation in a combination of settings is most critical to evaluate	Consensus Reached	Very Close to Consensus	Consensus Reached	Consensus Reached
A combination of family and child participation is most critical to evaluate	Consensus Reached	Very Close to Consensus	Consensus Reached	Very Close to Consensus
A combination of a standard list of scenarios along with user defined scenarios is most valuable to evaluate	Consensus Reached	Not Close to Consensus	Consensus Reached	Consensus Reached
The child's satisfaction with his/her participation is most essential	Consensus Reached	Not Close to Consensus	Consensus Reached	Consensus Reached
The child's enjoyment of participation is most essential	Consensus Reached	Very Close to Consensus	Consensus Reached	Consensus Reached
Documenting the strategy needed to participate is critical	Consensus Reached	Very Close to Consensus	Consensus Reached	Not Close to Consensus
Documenting the amount of assistance needed is critical	Consensus Reached	Not Close to Consensus	Consensus Reached	Not Close to Consensus
A combination of objective & subjective information is most critical to evaluate	Consensus Reached	Not Close to Consensus	Consensus Reached	Consensus Reached
Measuring a combination of capacity, capability & performance is most essential	Consensus Reached	Very Close to Consensus	Consensus Reached	Not Close to Consensus
Barriers & facilitators of participation should be included in an assessment of participation	Consensus Reached	Not Close to Consensus	Consensus Reached	Consensus Reached
Comparison with self over time is critical information	Consensus Reached	Not Close to Consensus	Consensus Reached	Consensus Reached

Appendix I Round Two Summary of Results

Colour Coding: **Consensus Reached**

Very Close to Consensus

Not Close to Consensus

Section A *very close to achieving consensus for total group, some but not reaching consensus for subgroups*

School Age: children aged 6 to 12 years (1 item reached consensus across all groups)

Statement	Total Group Response	Parent Group Response	Clinician Group Response	Researcher Group Response
Participation in community life is most critical to evaluate	Consensus Reached	Consensus Reached	Consensus Reached	Consensus Reached
Specifying who the child is participating with is most essential	Very Close to Consensus	Not Close to Consensus	Consensus Reached	Not Close to Consensus
Subjective information that reflects the individual's personal view is most critical to evaluate	Very Close to Consensus	Consensus Reached	Not Close to Consensus	Consensus Reached

Early Childhood: children aged 18 months to 5 years (2 items reached consensus across all groups)

Statement	Total Group Response	Parent Group Response	Clinician Group Response	Researcher Group Response
Participation in home life is most critical to evaluate	Consensus Reached	Consensus Reached	Consensus Reached	Consensus Reached
The parent's satisfaction with the child's participation is most essential	Consensus Reached	Consensus Reached	Consensus Reached	Consensus Reached
The parent's importance of the child's participation is most essential	Consensus Reached	Very Close to Consensus	Consensus Reached	Consensus Reached
The child's importance of his/her participation is most essential	Very Close to Consensus	Consensus Reached	Very Close to Consensus	Very Close to Consensus
The child's preference of participation is most essential	Consensus Reached	Not Close to Consensus	Consensus Reached	Consensus Reached
Participation should include activities that are done alone	Not Close to Consensus	Very Close to Consensus	Not Close to Consensus	Very Close to Consensus

Section B *consensus achieved for the total group but not for all subgroups*

School Age: children aged 6 to 12 years (2 items reached consensus across all groups)

Statement	Total Group Response	Parent Group Response	Clinician Group Response	Researcher Group Response
Participation in school life is most critical to evaluate	Consensus Reached	Consensus Reached	Consensus Reached	Consensus Reached
Documenting the frequency of participation is most essential	Very Close to Consensus	Not Close to Consensus	Consensus Reached	Not Close to Consensus
Documenting the strategy needed to participate is critical	Consensus Reached	Very Close to Consensus	Consensus Reached	Consensus Reached
Documenting the amount of assistance needed is critical	Consensus Reached	Consensus Reached	Consensus Reached	Very Close to Consensus
Measuring performance is most essential (what child actually does in everyday life)	Consensus Reached	Consensus Reached	Consensus Reached	Consensus Reached
Measuring a combination of capacity, capability & performance is most essential	Consensus Reached	Consensus Reached	Consensus Reached	Not Close to Consensus

Section B *consensus achieved for the total group but not for all subgroups*

Early Childhood: children aged 18 months to 5 years (5 items reached consensus across all groups)

Statement	Total Group Response	Parent Group Response	Clinician Group Response	Researcher Group Response
A parent's report of their child's participation is most essential	Green	Green	Green	Green
A combination of a parent's report of the child's participation and the child's self report of participation is most essential	Green	Green	Green	Red
Participation in a combination of settings is most critical to evaluate	Green	Green	Green	Green
A combination of family and child participation is most critical to evaluate	Green	Green	Green	Green
A combination of a standard list of scenarios along with user defined scenarios is most valuable to evaluate	Red	Green	Red	Red
The child's satisfaction with his/her participation is most essential	Green	Green	Green	Red
The child's enjoyment of participation is most essential	Green	Green	Green	Green
Documenting the strategy needed to participate is critical	Green	Green	Green	Yellow
Documenting the amount of assistance needed is critical	Green	Green	Green	Red
A combination of objective & subjective information is most critical to evaluate	Green	Yellow	Green	Green
Measuring a combination of capacity, capability & performance is most essential	Yellow	Green	Green	Red
Barriers & facilitators of participation should be included in an assessment of participation	Green	Green	Green	Green
Comparison with self over time is critical information	Yellow	Green	Green	Red

Section C *statements came from comments provided in Round 1*

School Age: children aged 6 to 12 years (1 item reached consensus across all groups)

Statements	Total Group Response	Parent Group Response	Clinician Group Response	Researcher Group Response
The child's engagement in participation is critical to evaluate	Green	Green	Green	Green
The child's autonomy in participation is critical to evaluate	Green	Yellow	Green	Green

Early Childhood: children aged 18 months to 5 years (1 item reached consensus across all groups)

Statements	Total Group Response	Parent Group Response	Clinician Group Response	Researcher Group Response
The child's engagement in participation is critical to evaluate	Green	Green	Green	Green
The child's autonomy in participation is critical to evaluate	Red	Yellow	Red	Red

Statements that reached consensus of total group and all subgroups (in Round One)

School Age: Children Aged 6 to 12 years (14 Items Reached Consensus Across All Groups)

Statements	Total Group Response	Parent Group Response	Clinician Group Response	Researcher Group Response
The child's self report of participation is most essential				
A combination of a parent's report of the child's participation and the child's self report of participation is most essential				
Participation in a combination of settings is most critical to evaluate				
A combination of family and child participation is most critical to evaluate				
A combination of a standard list of scenarios along with user defined scenarios is most valuable to evaluate				
Specifying the location where participating is most essential				
The child's satisfaction with his/her participation is most essential				
The child's enjoyment of participation is most essential				
The child's importance of his/her participation is most essential				
The child's preference of participation is most essential				
A combination of objective & subjective information is most critical to evaluate				
Barriers & facilitators of participation should be included in an assessment of participation				
Participation should include activities that are done alone				
Comparison with self over time is critical information				



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Appendix J Round Three Summary of Results



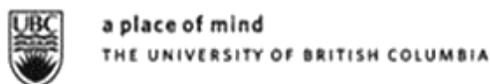
DELPHI SURVEY Round Three Summary

It's important to understand the results of our last survey, as it sets out the criteria from which we identified suitable participation tools. If you remember, there were fewer statements in the younger age group that reached consensus (8 compared to 18 for the older age group). We took the top 5 statements for the younger group, and took the top 7 statements for the older group. The results were analyzed using several different strategies. These top ranked statements were consistent in their position across all strategies. The top ranked statements for each of the two age groups were:

<i>For children 18 months to 5 years of age</i>	Group ranking of importance
Participation in a combination of settings (e.g. home & community) is most critical to evaluate	1
A combination of <u>family participation</u> and <u>child participation</u> is most critical to evaluate	2
The child's <u>engagement</u> in participation is most critical to evaluate	3
<u>Barriers</u> and <u>facilitators</u> of participation are critical to evaluate	4
The child's <u>enjoyment</u> of participation is most essential	5

<i>For children 6 years to 12 years of age</i>	Group ranking of importance
Participation in a combination of settings (e.g. home, school & community) is most critical to evaluate	1
A combination of a parent's report of the child's participation and the <u>child's self report</u> of participation is most essential	2
The child's <u>engagement</u> in participation is critical to evaluate	3
<u>Barriers</u> and <u>facilitators</u> of participation are critical to evaluate	4
A combination of family participation and <u>child participation</u> is critical to evaluate	5
A combination of <u>objective</u> and <u>subjective</u> information is critical to evaluate	6
The child's <u>satisfaction</u> with his/her participation is most essential	7

[Shaded cells identify those statements that reached consensus in both age groups]



Statements That Reached Consensus In Both Age Groups
Participation in a combination of settings is most critical to evaluate
A combination of family and child participation is most critical to evaluate
The child's engagement in participation is critical to evaluate
Barriers and facilitators should be included in an assessment of participation
A child's enjoyment of participation is most essential

Statements That Reached Consensus For Children 18 Months To 5 Years Of Age not ranked in Top 5/8 statements (<i>in no particular order</i>)
A parent's report of their child's participation is most critical
The parent's satisfaction is most essential
Participation in home life is most critical to evaluate

Statements That Reached Consensus For Children 6 To 12 Years Of Age not ranked in Top 7/18 statements (<i>in no particular order</i>)
A child's enjoyment of participation is most essential
Child's preference is most essential
Child's importance is most essential
Child's self report is most essential
Comparison with self over time is critical
Combination of standard list & user defined scenarios are critical
Specifying the location where participating is critical
Measuring performance is most essential (i.e. what the child actually does in everyday life)
Participation including activities that are done alone is critical to evaluate
Participation in school life is most critical
Participation in community life is most critical

Appendix K Other Documentation Provided with Round Four Survey

Appendix K(i) Comparison of Paediatric Participation Measures for Early Childhood

Most Promising Assessments for Early Childhood (18 Months to 5 Years) For Inclusion in the POWER Mobility Toolkit						
Tool Description Appropriate Ages Areas Explored Reported Completion Time	Evaluates Combination of Settings	Evaluates Family & Child Participation	Measures Child's Engagement	Measures Barriers & Facilitators	Measures Child's Enjoyment	Measurement Properties <i>McMaster OMRF* Ratings</i> E = excellent A = adequate P = poor [na] = no evidence found
Participation and Environment Measure for Children and Youth (PEM-CY)						
5-17 yrs* 25 items home participation school participation community participation 20-25 min*	home school community	some items may involve family	yes involvement defined as level of engagement rated on 5 pt* scale from <i>very involved</i> to <i>minimally involved</i> using whatever supports typically used	yes perceived supports & barriers evaluated using a 3 or 4 pt* scale along with open-ended questions	no	Reliability Ratings: Internal consistency A-E Inter rater reliability [na] Test retest reliability P-E Validity Ratings: Content validity: A Construct validity:A Responsiveness: [na]
Preschool Activity Card Sort (PACS)						
3-6 yrs* 85 items self care community mobility leisure social interaction domestic chores education completion time not reported	home (pre)school community	some items may involve family	yes involvement rated from <i>fully participating</i> to <i>currently not participating at all</i>	yes barriers identified as child, parent or environmental reasons	no	Reliability Ratings: Internal consistency [na] Inter rater reliability [na] Test retest reliability [na] Validity Ratings: Content validity: E Construct validity:A Responsiveness: [na]

Most Promising Assessments for Early Childhood (18 Months to 5 Years) For Inclusion in the POWER Mobility Toolkit						
Tool Description Appropriate Ages Areas Explored Reported Completion Time	Evaluates Combination of Settings	Evaluates Family & Child Participation	Measures Child's Engagement	Measures Barriers & Facilitators	Measures Child's Enjoyment	Measurement Properties <i>McMaster OMRF* Ratings</i> E = excellent A = adequate P = poor [na] = no evidence found
Children Participation Questionnaire (CPQ)						
4-6 yrs* 44 items activities of daily living instrumental activities of daily living play leisure social participation education completion time not reported	home preschool community	some items may involve family e.g. playing games with rules, going to family events	not specifically diversity total number of items child reported to participate in intensity rated on 6 pt* scale ranging from <i>everyday</i> to <i>never</i> independence rated on 6 pt* scale ranging from <i>independent</i> to <i>needs much assistance</i>	no	yes rated on 6 pt* scale ranging from takes much pleasure to does not take pleasure	Reliability Ratings: Internal consistency A-E Inter rater reliability [na] Test retest reliability E Validity Ratings: Content validity: A Construct validity: A Responsiveness: [na]
Assessment of Preschool Children's Participation (APCP)						
2 - 5 yrs 11 mos* 45 preselected items play activities skill development active physical recreation social activities + 3 self-selected items	home community	some items may involve family e.g. exploring or going for walks, going on a full day or half day outing	no participation in item within the last 4 months rated yes/ no frequency of participation rated on 7 pt* scale from <i>one time in past 4 months</i> to <i>one time a day or more</i>	no	no	Reliability Ratings: Internal Consistency P-E Inter rater reliability [na] Test retest reliability [na] Validity Ratings: Content validity: E Construct validity: A Responsiveness: [na]

Most Promising Assessments for Early Childhood (18 Months to 5 Years) For Inclusion in the POWER Mobility Toolkit						
Tool Description Appropriate Ages Areas Explored Reported Completion Time	Evaluates Combination of Settings	Evaluates Family & Child Participation	Measures Child's Engagement	Measures Barriers & Facilitators	Measures Child's Enjoyment	Measurement Properties <i>McMaster OMRF* Ratings</i> E = excellent A = adequate P = poor [na] = no evidence found
Canadian Occupational Performance Measure (COPM)						
<p>all ages parent (if child < 8yrs) or child (if ≥8 yrs)</p> <p>identifies & rates up to 5 individualized goals (self-care, productivity, or leisure)</p> <p>modification for use with children items 'paid/unpaid work' and 'household management' deleted</p> <p>10-15 minutes baseline 7-12 minutes follow-up</p>	not specifically, but could identify goals across settings	not specifically, but could identify goals involving child and family	<p>no</p> <p>individualized goals identified and rated</p> <p>importance rated on a 10 pt* scale</p> <p>if child 8 yrs or older: rates performance on 5 highest priorities, uses 10 pt* scale</p> <p>if parent: rates parent perception of child's performance on 10 pt* scale</p>	not specifically, but could identify goals that address barriers or facilitators	no	<p>Reliability Ratings: Internal Consistency E Inter rater reliability >80% agreement with parent goals Test retest reliability numerous studies cited</p> <p>Validity Ratings: Content validity: E Construct validity: E Responsiveness: E</p>

Legend: OMRF = Outcome Measure Rating Form; pt = point; min = minutes; yr = years of age; mos = months of age.

*Law M. Outcome Measures Rating Form and Guidelines. 2004 Available at: <http://www.canchild.ca/en/canchildresources/resources/>
Accessed July 9, 2010

Appendix K(ii) Comparison of Paediatric Participation Measures for School-aged Children Part I And II
Part I

Most Promising Assessments for School-aged Children (6 to 12 Years) for Inclusion in the POWER Mobility Toolkit				
Tool Description Appropriate Ages Areas Explored Reported Completion Time	Evaluates Combination of Settings	Seeks Combination of Parent & Child Report of Information	Measures Child's Engagement	Measures Barriers & Facilitators
Participation and Environment Measure for Children and Youth (PEM-CY)				
5-17 yrs* 25 items home participation school participation community participation 20-25 min*	home school community	parent report	yes involvement defined as level of engagement rated on 5 pt* scale from <i>very involved</i> to <i>minimally involved</i> using whatever supports typically used	yes perceived supports & barriers evaluated using a 3 or 4 pt* scale along with open-ended questions
Preschool Activity Card Sort (PACS)				
3-6 yrs* 85 items self care community mobility leisure social interaction domestic chores education completion time not reported	home school community	parent interview	yes involvement rated on 11 pt* scale from <i>fully participating</i> to <i>currently not participating at all</i>	yes barriers identified as child, parent or environmental reasons; adult assistance and environmental considerations documented
Children's Assessment of Participation and Enjoyment (CAPE)				
6-21 yrs* 55 items formal activities 15 informal activities 40 across 5 activity types: recreational	home community	report by child or parent can be completed by interview	not specifically	no

Most Promising Assessments for School-aged Children (6 to 12 Years) for Inclusion in the POWER Mobility Toolkit				
Tool Description Appropriate Ages Areas Explored Reported Completion Time	Evaluates Combination of Settings	Seeks Combination of Parent & Child Report of Information	Measures Child's Engagement	Measures Barriers & Facilitators
social active-physical skill-based self-improvement 30-45 min*				
Child Occupational Self Assessment (COSA)				
6-17 yrs* 25 items 27 min* average	home school community	child report	not specifically	no
Canadian Occupational Performance Measure (COPM)				
all ages identifies & rates up to 5 individualized goals (self-care, productivity, or leisure) modification for use with children items 'paid/unpaid work' and 'household management' deleted 10-15 minutes baseline 7-12 minutes follow-up	not specified could include home, school and/or community	parent or child (if ≥ 8 yrs) semi-structured interview	not specifically	not specifically, but could identify goals that address barriers or facilitators

Legend: OMRF = Outcome Measure Rating Form; pt = point; min = minutes; yr = years of age; mos = months of age. *Law M. Outcome Measures Rating Form and Guidelines. 2004 Available at: <http://www.canchild.ca/en/canchildresources/resources/> Accessed July 9, 2010.

Part II

Most Promising Assessments for School-aged Children (6 to 12 years) for Inclusion in the POWER Mobility Toolkit			
Evaluates Family & Child Participation	Combination of Objective & Subjective Information	Measures Child's Satisfaction with Participation	Measurement Properties <i>McMaster OMRF* Ratings</i> E = excellent A = adequate P = poor [na] = no evidence found
Participation and Environment Measure for Children and Youth (PEM-CY)			
some items may involve family	parent's perception of frequency of participation in item over the last 4 months rated on 7 pt* scale parent's desire for change	no	Reliability Ratings: Internal consistency A-E Inter rater reliability [na] Test retest reliability P-E Validity Ratings: Content validity: A Construct validity:A Responsiveness: [na]
Preschool Activity Card Sort (PACS)			
some items may involve family	parent's perception of importance parent's perception of frequency	no parent's satisfaction	Reliability Ratings: Internal consistency [na] Inter rater reliability [na] Test retest reliability [na] Validity Ratings: Content validity: E Construct validity:A Responsiveness: [na]
Children's Assessment of Participation and Enjoyment (CAPE)			
with whom rated alone, with family, other relatives, friends, or others	diversity item participated within last 4 months rated yes/no intensity rates how often over last 4 months using 7 pt* scale with whom rated on 5 pt* scale location rated on 6 pt* scale enjoyment rated on 5 pt* scale from <i>love it</i> to <i>not at all</i>	no	Reliability Ratings: Internal consistency P-A Inter rater reliability na Test retest reliability A-E Principal Component Analysis to determine domains

Most Promising Assessments for School-aged Children (6 to 12 years) for Inclusion in the POWER Mobility Toolkit			
Evaluates Family & Child Participation	Combination of Objective & Subjective Information	Measures Child's Satisfaction with Participation	Measurement Properties <i>McMaster OMRF* Ratings</i> E = excellent A = adequate P = poor [na] = no evidence found
			Validity Ratings: Content validity: E Construct validity: E Responsiveness: [na]
Child Occupational Self Assessment (COSA)			
some items may involve family e.g. eating meals, doing things with my family, use money to buy things	importance rated on 4 pt* scale from <i>most important of all to me</i> to <i>not really important to me</i> . competence rated on 4 pt* scale from <i>I am really good at doing this</i> to <i>I have a big problem doing this</i> . a 2 pt* scale can be used for younger children or those with intellectual disabilities	not specifically	Reliability Ratings: Internal consistency E Inter rater reliability [na] Test Retest reliability [na] Rasch Analyses confirmed hierarchical structure Validity Ratings: Content validity: A Construct validity: E Responsiveness: [na]
Canadian Occupational Performance Measure (COPM)			
not specifically, but could identify goals involving child and family	individualized goals identified and rated importance rated on a 10 pt* scale if child 8 yrs or older: rates performance on 5 highest priorities, uses 10 pt* scale if parent: rates parent perception of child's performance on 10 pt* scale	if child 8 yrs or older: rates satisfaction on 5 highest priorities, uses 10 pt* scale if parent: rates parent's satisfaction on 10 pt* scale	Reliability Ratings: Internal Consistency E Inter rater reliability >80% agreement with parent goals Test retest reliability numerous studies cited Validity Ratings: Content validity: E Construct validity: E Responsiveness: E

Legend: OMRF = Outcome Measure Rating Form; pt = point; min = minutes; yr = years of age; mos = months of age.

*Law M. Outcome Measures Rating Form and Guidelines. 2004 Available at: <http://www.canchild.ca/en/canchildresources/resources/>

Appendix K(iii) Comparison of Potential Paediatric Participation Measures for Early Childhood

Potential Assessments for Early Childhood (18 Months to 5 Years) for Inclusion in the POWER Mobility Toolkit						
Tool Description Appropriate Ages Areas Explored Reported Completion Time	Evaluates Combination of Settings	Evaluates Family & Child Participation	Measures Child's Engagement	Measures Barriers & Facilitators	Measures Child's Enjoyment	Measurement Properties <i>McMaster OMRF* Ratings</i> E = excellent A = adequate P = poor [na] = no evidence found
School Function Assessment (SFA)						
5-12 yrs* Part I Participation 6 items regular/special ed class playground or recess transportation to/from school bathroom/toileting transitions to/from class mealtime/snack time Part II Task Supports 21 items [Part III Activity Performance over 100 items]	school	child participation at school only	not specifically	yes Part II Task Supports assistance and adaptations rated on a 4 pt* scale ranging from <i>none</i> to <i>extensive</i>	no	Reliability Ratings: Internal consistency E Inter rater reliability [na] Test retest reliability E Validity Ratings: Content validity: E Construct validity: A Responsiveness: A

Potential Assessments for Early Childhood (18 Months to 5 Years) for Inclusion in the POWER Mobility Toolkit						
Tool Description Appropriate Ages Areas Explored Reported Completion Time	Evaluates Combination of Settings	Evaluates Family & Child Participation	Measures Child's Engagement	Measures Barriers & Facilitators	Measures Child's Enjoyment	Measurement Properties <i>McMaster OMRF* Ratings</i> E = excellent A = adequate P = poor [na] = no evidence found
Assessment of Life Habits (LIFE-H)						
5-13 yrs* short form 58 items <u>Social Roles</u> responsibility interpersonal relations community education employment recreation <u>[daily activities-</u> communication personal care housing mobility nutrition fitness]	home school community	some items involve family activities	no	yes amount of human assistance required by child beyond that needed by same aged peer rated on 4 pt* scale ranging from <i>minimal assistance</i> to <i>maximum assistance</i>	no	Reliability Ratings: Internal consistency [na] Inter rater reliability A-E Test retest reliability na Validity Ratings: Content validity: A Construct validity: A Responsiveness: [na]

Legend: OMRF = Outcome Measure Rating Form; pt = point; min = minutes; yr = years of age; mos = months of age.

*Law M. Outcome Measures Rating Form and Guidelines. 2004 Available at: <http://www.canchild.ca/en/canchildresources/resources/>

Appendix K(iv) Comparison of Potential Paediatric Participation Measures for School-aged Children Part I and II
Part I

Potential Assessments for School-aged Children (6 to 12 Years) for Inclusion in the POWER Mobility Toolkit				
Tool Description Appropriate Ages Areas Explored Reported Completion Time	Evaluates a Combination of Settings	Seeks Combination of Parent & Child Report of Information	Measures Child's Engagement	Measures Barriers & Facilitators
Children Helping Out: Responsibilities Expectations and Supports (CHORES)				
6-11 yrs* 34 items self-care family-care	home	parent report	no	no
Pediatric Community Participation Questionnaire (PCPQ)				
8-20 yrs 19 items activities of daily living play or leisure 5 min*	home community	child report in person or by phone interview	not specifically	no
School Function Assessment (SFA)				
5-12 yrs* Part I Participation 6 items regular/special ed class playground or recess transportation to/from school, bathroom/toileting transitions to/from class mealtime/snack time Part II Task Supports 21 items Part III Activity Performance over 100 items	school	teacher or therapist report or interview	not specifically	yes Part II Task Supports assistance and adaptations rated on a 4 pt* scale ranging from <i>none</i> to <i>extensive</i>

Potential Assessments for School-aged Children (6 to 12 Years) for Inclusion in the POWER Mobility Toolkit				
Tool Description Appropriate Ages Areas Explored Reported Completion Time	Evaluates a Combination of Settings	Seeks Combination of Parent & Child Report of Information	Measures Child's Engagement	Measures Barriers & Facilitators
Assessment of Life Habits (LIFE-H)				
5-13 yrs* short form 58 items <u>daily activities-</u> communication personal care housing mobility nutrition fitness social roles responsibility interpersonal relations community education employment recreation	home school community	interview with parent	no	yes amount of human assistance required by child beyond that needed by same aged peer rated on 4 pt* scale ranging from <i>minimal</i> <i>assistance</i> to <i>maximum assistance</i>
Frequency of Participation Questionnaire (FPQ)				
7-13 yrs* 14 items housework eating out relaxing pursuits school pursuits tourist pursuits	home school community	parent report	no	no

Potential Assessments for School-aged Children (6 to 12 Years) for Inclusion in the POWER Mobility Toolkit				
Tool Description Appropriate Ages Areas Explored Reported Completion Time	Evaluates a Combination of Settings	Seeks Combination of Parent & Child Report of Information	Measures Child's Engagement	Measures Barriers & Facilitators
Paediatric Interest Profiles (PIP) includes Kid Play Profile (KPP), Preteen Play Profile (PTP), and Adolescent Leisure Interest Profile (ALIP)				
Kid Play Profile (KPP) 6-9 yrs* 55 items Preteen Play Profile (PTP) 9-12 yrs* 64 items Both versions include: creative activities sport activities outside activities indoor activities lessons / classes socializing activities other activities (up to 5 self identified)	home community	child report	not specifically	no

Legend: OMRF = Outcome Measure Rating Form; pt = point; min = minutes; yr = years of age; mos = months of age.

*Law M. Outcome Measures Rating Form and Guidelines. 2004 Available at: <http://www.canchild.ca/en/canchildresources/resources/>

Part II

Potential Assessments for School-aged Children (6 to 12 Years) for Inclusion in the POWER Mobility Toolkit			
Evaluates Family & Child Participation	Combination of Objective (O) & Subjective (S) Information	Measures Child's Satisfaction with Participation	Measurement Properties <i>McMaster OMRF* Ratings</i> E = excellent A = adequate P = poor na = no evidence found
Children Helping Out: Responsibilities Expectations and Supports (CHORES)			
some items may involve family	<p>parent perception of participation rated as yes/no</p> <p>parent perception of level of assistance rated on 7 pt* scale ranging from <i>does on own initiative</i> to <i>cannot do task + not expected</i></p>	<p>no</p> <p>parent satisfaction rated using 6 pt* scale ranging from very satisfied to very dissatisfied</p>	<p>Reliability Ratings: Internal consistency E Inter rater reliability [na] Test retest reliability A-E</p> <p>Validity Ratings: Content validity: E Construct validity: A Responsiveness: [na]</p>
Pediatric Community Participation Questionnaire (PCPQ)			
some items may involve family e.g. go to places like the movies or library, buy something at the store, go out to eat	perceived degree of difficulty in participating in item rated on a 6 pt* scale ranging from <i>no problem</i> to <i>can't do + not applicable</i>	no	<p>Reliability Ratings: Internal consistency E Inter rater reliability [na] Test retest reliability [na]</p> <p>Validity Ratings: Content validity: A Construct validity: A Responsiveness: [na]</p>
School Function Assessment (SFA)			
child participation at school only	Part I Participation participation in six settings rated on 6 pt* scale ranging from <i>full participation</i> to <i>extremely limited</i>	no	<p>Reliability Ratings: Internal consistency E Inter rater reliability [na] Test retest reliability E</p> <p>Validity Ratings: Content validity: E Construct validity: A Responsiveness: A</p>

Potential Assessments for School-aged Children (6 to 12 Years) for Inclusion in the POWER Mobility Toolkit			
Evaluates Family & Child Participation	Combination of Objective (O) & Subjective (S) Information	Measures Child's Satisfaction with Participation	Measurement Properties <i>McMaster OMRF* Ratings</i> E = excellent A = adequate P = poor na = no evidence found
Assessment of Life Habits (LIFE-H)			
some items may involve family	reported accomplishment of a life habit (i.e. daily activity or social role) rated on a 10 pt* scale ranging from <i>optimal social participation</i> (performed without difficulty and without assistance) to <i>total impairment</i> (not accomplished or achieved) + <i>not applicable</i>	no parent satisfaction rated using 5 pt* scale ranging from very satisfied to very unsatisfied	Reliability Ratings: Internal consistency [na] Inter rater reliability A-E Test retest reliability [na] Validity Ratings: Content validity: A Construct validity: A Responsiveness: [na]
Frequency of Participation Questionnaire (FPQ)			
some items may involve family	frequency of participation rated on 6 pt* scale ranging from <i>a few times a week</i> to <i>never</i>	no	Reliability Ratings: Internal consistency [na] Inter rater reliability [na] Test retest reliability [na] Validity Ratings: Content validity: P Construct validity: P Responsiveness: [na]
Paediatric Interest Profiles (PIP) includes Kid Play Profile (KPP), Preteen Play Profile (PTP)			
with whom rated on 3 pt* scale including by myself, with friends, with a grown up	KPP reported participation rated as <i>yes/no with whom</i> child asked how much he/she likes item rated on 3 pt* scale ranging from <i>a lot</i> to <i>not at all</i>	not specifically	KPP Reliability Ratings: Internal consistency E Inter rater reliability [na] Test retest reliability P-E Validity Ratings: Content validity: A Construct validity: [na] Responsiveness: [na]

Potential Assessments for School-aged Children (6 to 12 Years) for Inclusion in the POWER Mobility Toolkit			
Evaluates Family & Child Participation	Combination of Objective (O) & Subjective (S) Information	Measures Child's Satisfaction with Participation	Measurement Properties <i>McMaster OMRF* Ratings</i> E = excellent A = adequate P = poor na = no evidence found
	PTP reported participation rated as <i>yes/no</i> reported frequency of participation in item rated on a 3 pt* scale with whom interest rated on 3 pt* scale ranging from <i>very</i> to <i>not at all</i> competence rated on 3 pt scale ranging from <i>very good</i> to <i>not so good</i>		PTP Reliability Ratings: Internal consistency A Inter rater reliability [na] Test retest reliability P-E Validity Ratings: Content validity: A Construct validity: [na] Responsiveness: [na]

Legend: OMRF = Outcome Measure Rating Form; pt = point; min = minutes; yr = years of age; mos = months of age.

*Law M. Outcome Measures Rating Form and Guidelines. 2004 Available at: <http://www.canchild.ca/en/canchildresources/resources/>

Appendix K(v) Tools Not Selected for Inclusion in the POWER Mobility Toolkit

Tools Not Selected for Inclusion in the POWER Mobility Toolkit
<p>Activities Scale for Kids (ASK)</p> <p>The ASK is a 30 item self report of a child's capability (what he/she could do) or performance (what he/she usually does do) for those aged 5-15 years. (Parent report is also acceptable). Items include personal care, dressing, other skills, play, locomotion, standing skills and transfers. Activities could be performed in home, school, or community settings. Some items may involve other family members. There are two versions: the ASKp (measuring performance) captures the frequency of an item over the last week rated using a 5 point scale ranging from <i>all of the time</i> to <i>none of the time</i>, + <i>not applicable</i>, while the ASKc (measuring capability) captures the degree of difficulty with item in last week rated using 5 point scale ranging from <i>with no problem</i> to <i>I could not</i>.</p> <p>This tool was not selected as <85% of items were related to participation.</p>
<p>Child and Adolescent Scale of Participation (CASP)</p> <p>The CASP is a 20 item parent report of a child's participation in home, school and community settings for children and youth aged 3-22 years. Some items ask about participation with others including family or friends, and there are open-ended questions to illicit information about barriers and facilitators to participation.</p> <p>This tool was not selected because the response scale compares the child or youth's participation to same-aged peers only (ranging from <i>age expected</i>, <i>somewhat limited</i>, <i>very limited</i>, <i>unable</i>, or <i>not applicable</i>); an element that was not selected as being important in the Round 1 survey. We also thought that the tool would be less likely to demonstrate change over a (shorter) period of time (e.g. before and after receiving a new power wheelchair).</p>
<p>Functional Independent Measure for Children (Wee FIM)</p> <p>The WeeFIM is an 18 item therapist rating of observed behaviour or caregiver (e.g. parent or teacher) interview about the functional independence of children and youth. It was initially developed for those ages 6 months to 7 years however it has been revised and extended from 7 to 18 years. Items include self-care, sphincter control, transfers, locomotion, communication, social cognition. Independence is rated on 7 point scale ranging from <i>complete independence</i> to <i>total assistance needed</i>.</p> <p>This tool was not selected as <85% of items were related to participation.</p>
<p>Goal Attainment Scaling (GAS)</p> <p>GAS is an individualized method of rating accomplishment of goals. It is useful for all ages. Through a semi-structured interview with parent and/or child an individualized number of goals are established and measurement criteria set. Goals could include home, school or community settings and could address barriers or facilitators. Accomplishment of goals rated using 5 point scale from -2 to +2, with 0 being the desired outcome.</p> <p>This tool was not selected because it was not specifically related to participation, and it was reported to take a longer period of time to administer compared to others.</p>

Tools Not Selected for Inclusion in the POWER Mobility Toolkit
<p>Lifestyle Assessment Questionnaire (LAQ)</p> <p>There are two different versions of the LAQ. The LAQ-CP is a 46 item parent report of impact of disability developed for children aged 3-10 years who have cerebral palsy. The LAQ-CP was developed first and includes items of physical independence, mobility, clinical burden, economic burden, schooling and social integration. The LAQ-G is a 53 item tool developed for children 5-7 years who have a variety of diagnoses. The LAQ-G has slightly different items: communication, mobility, self care, domestic life, interpersonal interactions & relationships, community & social life. This tool was not selected as <85% of items were related to participation.</p>
<p>Pediatric Evaluation of Disability Inventory (PEDI)</p> <p>The PEDI is a 3 part tool developed for children aged 6 months to 7½ years, although it can be used with older children if they have not reached a maximum functioning level. Part I evaluates 197 functional skills on 2 point scale with 1 being <i>capable of performing item in most situations</i> and 0 <i>being unable or limited in capability to perform in most situations</i>. Part II evaluates the amount of caregiver assistance on 20 items, rated on a 6 point scale ranging from <i>independent to total assistance</i>. Part III rates 20 items related to modifications required for performance using a 4 point scale ranging from <i>no modifications</i> to <i>extensive modifications</i>. Each part of the tool addresses 3 domains: self-care, mobility and social function. This tool was not selected as <85% of items were related to participation.</p>
<p>Preferences for Activities of Children (PAC)</p> <p>The PAC is a 55 item self report of a child’s preference for activities, designed for use with children and youth aged 6-21 years. It is a companion to the CAPE and represents the same categories of activities: formal and informal activity domains, as well as 5 different types of activities - recreational, social, active-physical, skill-based and self-improvement in home or community settings. The child/youth is asked to rate his/her preference for an activity based on a 3 point scale from <i>I would really like to do</i> to <i>I would not like to do at all</i>. If the child is unable to indicate their preferences a parent proxy is acceptable.</p> <p>Although child preference was one of the statements that reached consensus for the 6-12 age group in Round 2, it was not a highly ranked statement in Round 3. In addition, because the rating was on a 3 point scale of what the child would like to do, (instead of what his/she actually did) we thought the tool would be less likely to demonstrate change over (a shorter) period of time (e.g. before and after receiving a new power wheelchair).</p>
<p>School Outcome Measure (SOM)</p> <p>The SOM is a 28 item therapist rating of children and youth aged 3-18 years who attend school. Assistance required is rated on 6 point scale for self care and mobility items and 4 point scale for all other items. Items include self care, mobility, assuming student role, expressing learning behaviour. This tool was not selected as <85% of items were related to participation.</p>
<p>Short Child Occupational Profile (SCOPE)</p> <p>The SCOPE is a 25 item therapist rating of areas of childhood occupation that impact participation for children and youth aged 2-21 years. The therapist uses a 4 point scale to rate volition, habituation, communication & interaction skills, process skills, motor skills, and environment. This tool was not selected as <85% of items were related to participation.</p>

Appendix K(vi) Reference List for Measurement Tools in Round Four

MOST PROMISING TOOLS for Inclusion in the POWER Mobility Toolkit
Participation and Environment Measure for Children and Youth (PEM-CY)
<p>Coster W, Bedell G, Law M, Khetani MA, Teplicky R, Liljenquist K, et al. Psychometric evaluation of the Participation and Environment Measure for Children and Youth. <i>Dev Med Child Neurol</i> 2011;53(11):1030-1037.</p> <p>Coster W, Law M, Bedell G, Khetani M, Cousins M, Teplicky R. Development of the Participation and Environment Measure for Children and Youth: conceptual basis. <i>Disabil Rehabil</i> 2012;34(3):238-246.</p>
Preschool Activity Card Sort (PACS)
<p>Berg C, LaVesser P. The Preschool Activity Card Sort. <i>OTJR Occup Participation Health</i> 2006;26(4):143-151.</p> <p>LaVesser P, Berg C. Participation patterns in preschool children with an autism spectrum disorder. <i>OTJR Occup Participation Health</i> 2011;31(1):33-39.</p> <p>Stoffel A, Berg C. Spanish translation and validation of the Preschool Activity Card Sort. <i>Phys Occup Ther Pediatr</i> 2008;28(2):171-189.</p>
Children Participation Questionnaire (CPQ)
<p>Rosenberg L, Jarus T, Bart O. Development and initial validation of the Children Participation Questionnaire (CPQ). <i>Disabil Rehabil</i> 2010(00):1-12.</p>
Assessment of Preschool Children's Participation (APCP)
<p>Law M, King G, Petrenchik T, Kertoy M, Anaby D. The Assessment of Preschool Children's Participation: Internal consistency and construct validity. <i>Phys Occup Ther Pediatr</i> 2012;32(3):272-287.</p>
Canadian Occupational Performance Measure (COPM)
<p>Carswell A, McColl MA, Baptiste S, Law M, Polatajko H, Pollock N. The Canadian Occupational Performance Measure: a research and clinical literature review. <i>Can J Occup Ther</i> 2004;71(4):210-222.</p> <p>Cusick A, Lannin NA, Lowe K. Adapting the Canadian Occupational Performance Measure for use in a paediatric clinical trial. <i>Disabil Rehabil</i> 2007;29(10):761-766.</p> <p>Cusick A, McIntyre S, Novak I, Lannin N, Lowe K. A comparison of Goal Attainment Scaling and the Canadian Occupational Performance Measure for paediatric rehabilitation research. <i>Dev Neurorehabil</i> 2006;9(2):149-157.</p> <p>Law M, Baptiste S, McColl M, Opzoomer A, Polatajko H, Pollock N. The Canadian Occupational Performance Measure: an outcome measure for occupational therapy. <i>Can J Occup Ther</i> 1990;57(2):82-87.</p>

Children's Assessment of Participation and Enjoyment (CAPE)
<p>King GA, Law M, King S, Hurley P, Hanna S, Kertoy M, et al. Measuring children's participation in recreation and leisure activities: construct validation of the CAPE and PAC. <i>Child Care Health Dev</i> 2006;33(1):28-39.</p> <p>King G, Law M, King S, Hurley P, Rosenbaum P, Hanna S, et al. <i>Children's Assessment of Participation and Enjoyment & Preferences for Activities of Children Manual</i>. San Antonio, TX: PsychCorp, a brand of Harcourt Assessment Inc.;2004.</p> <p>Imms C. Review of the Children's Assessment of Participation and Enjoyment and the Preferences for Activity of Children. <i>Phys Occup Ther Pediatr</i> 2008 10;28(4):386-401.</p>
Child Occupational Self Assessment (COSA)
<p>Keller J, Kielhofner G. Psychometric characteristics of the Child Occupational Self-Assessment (COSA), part two: Refining the psychometric properties. <i>Scand J Occup Ther</i> 2005;12(4):147-158.</p> <p>Kramer JM, Kielhofner G, Smith EV. Validity evidence for the Child Occupational Self Assessment. <i>Am J Occup Ther</i> 2010;64(4):621-32.</p> <p>Kramer JM, Smith Jr EV, Kielhofner G. Rating scale use by children with disabilities on a self-report of everyday activities. <i>Arch Phys Med Rehabil</i> 2009;90(12):2047-2053.</p>
POTENTIAL TOOLS For Inclusion In The POWER Mobility Toolkit
School Function Assessment (SFA)
<p>Coster W. Occupation-centered assessment of children. <i>Am J Occup Ther</i> 1998 May;52(5):337-344.</p> <p>Coster W, Sargent College of Health and Rehabilitation Sciences. <i>School Function Assessment: SFA: User's Manual: Psychological Corp.</i>;1998.</p> <p>Coster WJ, Mancini MC, Ludlow LH. Factor structure of the School Function Assessment. <i>Educ Psychol Measure</i> 1999;59(4):665.</p> <p>Davies PL, Soon PL, Young M, Clausen-Yamaki A. Validity and reliability of the School Function Assessment in elementary school students with disabilities. <i>Phys Occup Ther Pediatr</i> 2004;24(3):23-43.</p>
Assessment of Life Habits (LIFE-H)
<p>Fougeyrollas P, Noreau L, St-Michel G. <i>Life Habits measure—shortened version (LIFE-H 3)</i>. Lac St-Charles, Quebec, Canada: CQCIDIH 2001.</p> <p>Lepage CÉ, Noreau L, Bernard PM, Fougeyrollas P. Profile of handicap situations in children with cerebral palsy. <i>J Rehabil Med</i> 1998;30(4):263-272.</p> <p>Noreau L, Lepage C, Boissiere L, Picard R, Fougeyrollas P, Mathieu J, et al. Measuring participation in children with disabilities using the Assessment of Life Habits. <i>Dev Med Child Neurol</i> 2007;49(9):666-671.</p>

Children Helping Out: Responsibilities Expectations and Supports (CHORES)
Dunn L. Validation of the CHORES: A measure of school-aged children's participation in household tasks. <i>Scand J Occup Ther</i> 2004;11(4):179-190.
Dunn L, Coster WJ, Cohn ES, Orsmond GI. Factors associated with participation of children with and without ADHD in Household Tasks. <i>Phys Occup Ther Pediatr</i> 2009;29(3):274-294.
Dunn L, Coster WJ, Orsmond GI, Cohn ES. Household task participation of children with and without attentional problems. <i>Phys Occup Ther Pediatr</i> 2009;29(3):258-273.
Pediatric Community Participation Questionnaire (PCPQ)
Washington LA, Wilson S, Engel JM, Jensen MP. Development and preliminary evaluation of a pediatric measure of community integration: the Pediatric Community Participation Questionnaire (PCPQ). <i>Rehabil Psychol</i> 2007;52(2):241-245.
Frequency of Participation Questionnaire (FPQ)
Michelsen SI, Flachs EM, Uldall P, Eriksen EL, McManus V, Parkes J, et al. Frequency of participation of 8-12-year-old children with cerebral palsy: a multi-centre cross-sectional European study. <i>Europ J Paediatr Neurol</i> 2009;13(2):165-177.
Paediatric Interest Profiles (PIP) includes Kid Play Profile (KPP), Preteen Play Profile (PTP), and Adolescent Leisure Interest Profile (ALIP)
Henry AD. Pediatric Interest Profiles: Surveys of Play for Children and Adolescents, Kid Play Profile, Preteen Play Profile, Adolescent Leisure Interest Profile: Therapy Skill Builders;2000.
Henry AD. Development of a measure of adolescent leisure interests. <i>Am J Occup Ther</i> 1998;52(7):531-539.

Appendix K(vii) Reference List for Measurement Tools Not Selected for Inclusion in the POWER Mobility Toolkit

Tools Not Selected for Inclusion in the POWER Mobility Toolkit
Preferences for Activities of Children (PAC)
<p>King GA, Law M, King S, Hurley P, Hanna S, Kertoy M, et al. Measuring children's participation in recreation and leisure activities: construct validation of the CAPE and PAC. <i>Child Care Health Dev</i> 2006;33(1):28-39.</p> <p>King G, Law M, King S, Hurley P, Rosenbaum P, Hanna S, et al. <i>Children's Assessment of Participation and Enjoyment & Preferences for Activities of Children Manual</i>. San Antonio, TX: PsychCorp, a brand of Harcourt Assessment Inc.;2004.</p> <p>Imms C. Review of the Children's Assessment of Participation and Enjoyment and the Preferences for Activity of Children. <i>Phys Occup Ther Pediatr</i> 2008;28(4):386-401.</p>
Child and Adolescent Scale of Participation (CASP)
<p>Bedell G. Further validation of the Child and Adolescent Scale of Participation (CASP). <i>Dev Neurorehabil</i> 2009;12(5):342-351.</p> <p>Bedell GM. Developing a follow-up survey focused on participation of children and youth with acquired brain injuries after discharge from inpatient rehabilitation. <i>NeuroRehabil</i> 2004;19(3):191-205.</p> <p>Bedell GM, Dumas HM. Social participation of children and youth with acquired brain injuries discharged from inpatient rehabilitation: A follow-up study. <i>Brain Injury</i> 2004;18(1):65-82.</p>
Activities Scale for Kids (ASK)
<p>Plint AC, Gaboury I, Owen J, Young NL. Activities Scale for Kids: an analysis of normals. <i>J Pediatr Orthopaedics</i> 2003;23(6):788.</p> <p>Young N. <i>The Activities Scale for Kids (ASK)</i>. Toronto, ON: Hospital for Sick Children 1997.</p> <p>Young NL, Williams JI, Yoshida KK, Wright JG. Measurement properties of the Activities Scale for Kids. <i>J Clin Epidemiol</i> 2000;53(2):125-137.</p> <p>Young NL, Yoshida KK, Williams JI, Bombardier C, Wright JG. The role of children in reporting their physical disability. <i>Arch Phys Med Rehabil</i> 1995;76(10):913-918.</p>
Functional Independent Measure for Children (Wee FIM)
<p>Ottenbacher KJ, Taylor ET, Msall ME et al. The stability and equivalence reliability of the Functional Independence Measure for Children (WeeFIM). <i>Dev Med Child Neurol</i> 1996;38:907-915.</p> <p>Sperle PA, Ottenbacher KJ, Braun SL, Lane SJ, Nochajski S. Equivalence reliability of the Functional Independence Measure for Children (WeeFIM)-Administration methods. <i>Am J Occup Ther</i> 1997;51:35-41.</p>

Tools Not Selected for Inclusion in the POWER Mobility Toolkit
Lifestyle Assessment Questionnaire (LAQ)
Mackie P, Jessen E, Jarvis S. Creating a measure of impact of childhood disability: statistical methodology. <i>Public Health</i> 2002;116(2):95-101. Jessen E, Colver A, Mackie P, Jarvis S. Development and validation of a tool to measure the impact of childhood disabilities on the lives of children and their families. <i>Child Care Health Dev</i> 2003;29(1):21-34.
Goal Attainment Scaling (GAS)
Cusick A, McIntyre S, Novak I, Lannin N, Lowe K. A comparison of Goal Attainment Scaling and the Canadian Occupational Performance Measure for paediatric rehabilitation research. <i>Dev Neurorehabil</i> 2006;9(2):149-157. McDougall J, Wright V. The ICF-CY and Goal Attainment Scaling: benefits of their combined use for pediatric practice. <i>Disabil Rehabil</i> 2009;31(16):1362-1372. Steenbeek D, Ketelaar M, Galama K, Gorter JW. Goal attainment scaling in paediatric rehabilitation: a critical review of the literature. <i>Dev Med Child Neurol</i> 2007;49(7):550-556.
School Outcome Measure (SOM)
McEwen IR, Arnold SH, Hansen LH, Johnson D. Interrater reliability and content validity of a minimal data set to measure outcomes of students receiving school-based occupational therapy and physical therapy. <i>Phys Occup Ther Pediatr</i> 2003;23(2):77-95.
Pediatric Evaluation of Disability Inventory (PEDI)
Feldman AB, Haley SM, Coryell J. Concurrent and construct validity of the Pediatric Evaluation of Disability Inventory. <i>Phys Ther</i> 1990;70(10):602-610. Haley S, Coster W, Ludlow L, Haltiwanger J, Andrellos P. <i>Pediatric Evaluation of Disability Inventory: Development, standardization, and administration manual</i> . Boston, MA: Trustees of Boston University 1992. Haley SM, Coster WI, Kao YC, Dumas HM, Fragala-Pinkham MA, Kramer JM, et al. Lessons from use of the Pediatric Evaluation of Disability Inventory: where do we go from here? <i>Pediatr Phys Ther</i> 2010;22(1):69-75. Haley SM, Coster WJ, Faas RM. A content validity study of the Pediatric Evaluation of Disability Inventory. <i>Pediatr Phys Ther</i> 1991;3(4):177-184.
Short Child Occupational Profile (SCOPE)
Bowyer PL, Kramer J, Kielhofner G, Maziero-Barbosa V, Girolami G. Measurement properties of the Short Child Occupational Profile (SCOPE). <i>Phys Occup Ther Pediatr</i> 2007;27(4):67-85. Kramer J, Bowyer P, Kielhofner G, O'Brien J, Maziero-Barbosa V. Examining rater behavior on a revised version of the Short Child Occupational Profile (SCOPE). <i>OTJR Occupation Participation Health</i> 2009;29(2):88-96.

Appendix L Wheelchair Outcome Measure for Young People (WhOM-YP)

The Wheelchair Outcome Measure (WhOM) for Young People

It's important for young people to have their opinions heard about how and why they use their wheelchairs, and how well their wheelchairs work for them in doing the things they want or need to do. The WhOM helps young people make judgements about what participation outcomes are important to them when using their wheelchair and then rate how satisfied they are with their performance.

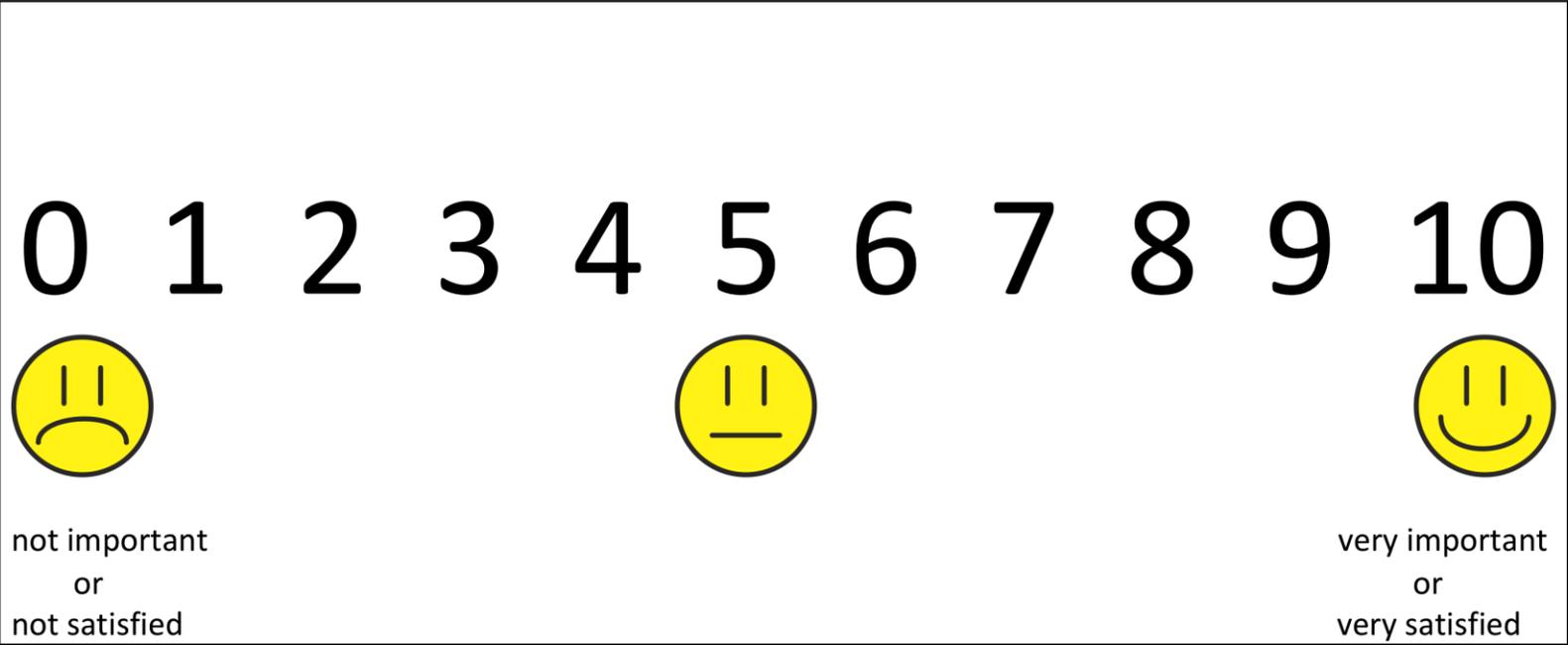
Some young people find it difficult to communicate their ideas clearly and may wish to have a parent or other person of significance help them. This fine, but it is important to document how much assistance is provided. Parents should be encouraged to relay the young person's opinions where possible; if they have opinions of their own these should be recognized as such. We recommend color-coding the responses of the young person separately from the parent (i.e. use a blue coloured pen for young person's answers and a black coloured pen for the parent's). We also recommend **Identifying what wheelchair is used** (i.e. manual, power or both). A number line is provided as a visual cue. It can be cut out and laminated for ease of use and durability.

General Instructions for Administration:

The WhOM has three sections. The first section addresses participation **in the home**. The second section addresses participation **outside the home, either at school or in the community** (e.g., classes, events, clubs or teams). The third section relates to posture and comfort when sitting in the wheelchair that may affect how easily they participate in the things they want or need to do. The first two sections have a similar format: Have the young person (along with a parent if desired) *identify activities they participate in* that are important to them. For each, rate the importance using a scale from 0 (not important at all) to 10 (very important). Then ask them to rate their satisfaction with their performance at the present time using a scale from 0 (not satisfied at all) to 10 (very satisfied). If satisfaction scores are ≤ 7 , this may be worth addressing. It is important to work together to determine why they are not satisfied with their performance, and to identify what specifically can be done to improve on the outcome.



Please use the following number line when answering the questions:



Part I. PARTICIPATION IN HOME

Instructions for Administration: Some people use their wheelchairs because they want to participate in activities in or around their home, such as playing a computer game, making a snack, doing arts and crafts, or playing in the yard. *What important activities do you do in your home that you use your wheelchair for?* For each activity rate how important this is to you using the scale 0-10. Then please rate how satisfied you are with doing these activities now using the same number scale.

E.g. Making a snack, listening to music, drawing, playing a game, doing chores, completing homework, or being with friends.

Initial assessment Date:				Reassessment Date:	
Participation goals:	Importance	Satisfaction 1		Satisfaction 2	
	How important is this activity to you? (0 - 10) 0 = NOT important 😞 10 = VERY important 😊	How satisfied are you with doing this activity? (0 - 10) 0 = NOT satisfied 😞 10 = VERY satisfied 😊	Importance x Satisfaction 1	How satisfied are you with your ability to do this activity? (0 - 10) 0 = NOT satisfied 😞 10 = VERY satisfied 😊	Importance x Satisfaction 2
1.					
2.					
3.					
4.					
5.					
			Score 1		
			Total of Importance x Satisfaction 1 scores =	Score 2	
			Total of Importance x Satisfaction 1 scores =	Total of Importance x Satisfaction 2 scores =	
			Change in Satisfaction = Score 2	-	Score 1 =

Part II. PARTICIPATION OUTSIDE OF HOME

Instructions for Administration: Some people use their wheelchairs because they want to participate in activities outside of their home including at school (e.g. attending classes or clubs, playing in the playground) or in the community (e.g. visiting the park, shopping at the mall, going to music lessons or playing on a sports team). *What important activities do you do outside your home (at school or in the community) that you use your wheelchair for?* For each activity rate how important this is to you using the scale 0-10. Then please rate how satisfied you are with doing these activities now using the same number scale.

Eg. Hanging out at the beach, visiting a friend or relative, getting from class to class in school, being part of an extracurricular activity like a band or library monitors, or joining a club in school.

Initial assessment Date:				Reassessment Date:	
Participation goals:	Importance	Satisfaction 1		Satisfaction 2	
<div style="display: flex; align-items: center;"> <div style="border: 1px solid black; width: 100px; height: 100px; margin-right: 10px;"></div>  </div>	How important is this activity to you? (0 - 10) 0 = NOT important 😞 10 = VERY important 😊	How satisfied are you with your ability to do this activity? (0-10) 0 = NOT satisfied 😞 10 = VERY satisfied 😊	Importance x Satisfaction 1	How satisfied are you with your ability to do this activity? (0 - 10) 0 = NOT satisfied 😞 10 = VERY satisfied 😊	Importance x Satisfaction 2
1.					
2.					
3.					
4.					
5.					
			Total of Importance x Satisfaction 1 scores = <input type="text"/>	Total of Importance x Satisfaction 2 scores = <input type="text"/>	
			Change in Satisfaction = Score 2 <input type="text"/> - Score 1 <input type="text"/> = <input style="border: 2px solid black;" type="text"/>		

Part III. SITTING POSTURE & COMFORT IN YOUR WHEELCHAIR

Instructions for Administration: **Some people experience problems when sitting in their wheelchair that makes it difficult to do the things they want to do. These next questions help to identify if this is a problem for you. Answer questions #1 & #2 using the same 0-10 scale. For question #3 please circle Y for yes, or N for no.**

Initial assessment Date: Questions	Time 1	Reassessment Date: Time 2
1. How comfortable are you sitting in your wheelchair? (0 – 10) 0 =Not comfortable at all 😞 10 = Very comfortable 😊		
2. How satisfied are you with how you are sitting in your wheelchair? (0 – 10) 0 = Not satisfied at all 😞 10 = Very satisfied 😊		
3. Over the past month have you had any skin problems on your bottom or other parts of your body because of sitting in your wheelchair? (Please circle)	Y N	Y N
3a. If yes, in your opinion, how bad has your skin problem been? (0 - 10) 0 = Very bad 😞 10 = Not bad at all 😊		
	Score 1	Score 2
	Total =	Total =
	Change = Score 2	– Score 1 =

Is there anything else you think is important to know to help you make the most of using your wheelchair to do the things you want or need to do?

Did someone assist in completing the WhOM? Y N

How much assistance they did provide to the young person?

- i) the young person identified all the answers but the assistant helped clarify responses
- ii) the young person identified most of the answers (>75%) but the assistant helped identify some answers (<25%)
- iii) the young person identified about half of the answers (~50%), but the assistant helped with the other half
- iv) the young person identified some of the answers (<25%) but the assistant answered most (>75%)
- v) the assistant answered all questions

Appendix M Socio-Demographic Information Form

Socio-Demographic Information

The following questions are designed to help us learn about *you* and your family, to help us understand your specific situation *and create a description of the participants in the study.*

Your individual personal information will not be shared with anyone outside of the research team and will not be individually identified in publications, presentation, or other knowledge exchange activities.

Please select the appropriate response(s), you may indicate more than one response if appropriate.

1- What is your **primary** language spoken? _____

2- What **other** languages do you **speak**? _____

3- What **primary** language do you use for **written communication**? _____

4- What **other** languages do you use for **written communication**? _____

5- What is your **highest** level of education?

- Attended Elementary School Attended Secondary/High School
 Secondary/High School Graduate Post-Secondary College Diploma/Certificate/Trade
 University Undergraduate Diploma/Certificate/Degree Graduate Degree
 Other: please specify _____

6- What is your age (**in years**)?

- 19-29 30-39 40-49 50-59 60-65 65+

7- What is your sex?: Male Female

8- How many people live with you in your household?(excluding yourself):

- 1 2 3 4 5 6 7 8+

9- For the people that live with you, what is their relationship(s) to you?

9.1) partner 9.2) children 9.2b) #___ 9.3) parent(s) 9.3b) #___

9.4) extended family 9.4b) #___ 9.5) other(s) 9.5b) #___

10- What is your relationship to the child (who will be obtaining a new power mobility device)? Mother

Father Legal Guardian

Grandmother Grandfather Other (specify) 10b) : _____

Socio-Demographic Information

Information Related to the Child

The following questions are designed to help us learn about the child who will be receiving the new power mobility device. **Please select the appropriate response(s), you may indicate more than one response if appropriate.**

- 11- What is the sex of the child? Male Female
- 12- What is the child's age? _____ 13. What is the child's birthdate (mm/yy)? _____
- 14- What is the child's **primary** language **spoken**? _____
- 15- What **other** languages does the child **speak**? _____
- 16- What **primary** language does the child use for **written communication**? _____
- 17- What **other** languages does the child use for **written communication**? _____
- 18- Where does the child spend most of the day?
- Home Daycare Preschool School Other

19- For School-Aged children only:

- What is your child's grade? kindergarten 1 2 3 4 5 6 7
 8 9 10 11 12 Other: Please specify _____

20- How many **days per week** does the child spend at (pre) school / daycare?

- 5 4 3 2 1 none

Comments: _____

21- How much time (**in hours**) does the child spend at (pre) school / daycare **each day**?

- none 0<2 2-4 5-7 7+

Comments: _____

22- How long (**in years**) has the child had mobility limitation? _____ year(s)

if less than 1 year please indicate how many months: _____

23- What is the primary diagnosis of your child that affects mobility? Please specify

Appendix N Historical Power Mobility Information Form

Historical Information About Your Child's Power Mobility Use

The following questions are designed to help us learn about your child's wheeled mobility experience. **Please select the appropriate response(s), you may indicate more than one response if appropriate.**

1- What age was your child (in years) when they first obtained their own wheeled mobility device (e.g. walker, tricycle, manual or power wheelchair, specialized stroller, wheeled activity chair, wheeled base for sitting or lying)?

_____year(s) old

if less than 2 please indicate how many months old _____months

2- Please specify type of wheeled mobility device(s) used:

- | | | | |
|---|---|---|--|
| <input type="checkbox"/> walker | <input type="checkbox"/> tricycle | <input type="checkbox"/> manual wheelchair | <input type="checkbox"/> power wheelchair |
| <input type="checkbox"/> specialized stroller | <input type="checkbox"/> wheeled activity chair | <input type="checkbox"/> wheeled base for sitting | <input type="checkbox"/> wheeled base for lying down |

3- What age was your child (in years) when they first tried a power mobility device (e.g. power wheelchair, GoBOT, scooter, power toy vehicle), during therapy sessions, or at (pre) school?

_____year(s) old

if less than 2 please indicate how many months old _____months

4- What age was your child (in years) when they first received their own power mobility device?

_____year(s) old

if less than 2 please indicate how many months old _____months

5- Please estimate how many power mobility devices has your child used in total (including during therapy sessions, on loan, or purchased for child)?

0 1 2 3 4 5+

6- How many power mobility devices has the child obtained for his/her own use (purchased/loaned)?

0 1 2 3 4 5+

7- If more than one, why was the power mobility equipment changed?

- not applicable outgrew size broken, needed replacement child's abilities changed
situation changed other (please explain briefly) 7b): _____

8- What is the primary reason that your child uses a power mobility device?

9- How many days per week does your child use a power mobility device?

less than once/week 1-2 days/week 3-4 days/week 5-6 days/week every day

10- How many hours per day does your child use a power mobility device?

< 1hr between 1-3hrs between 4-7hrs between 8-12hrs > 12 hrs

Appendix O Functional Mobility Scale

The Functional Mobility Scale (FMS)

Please rate the child's usual walking ability for each of the distances listed below.

Please write, in the space provided, the number that best describes the child's ability or

Walking Distance	Rating (1–6)
Walking 5 Meters (eg, in bedroom or other room)	
Walking 50 Meters (eg, at school, in the classroom & playground)	
Walking 500 Meters (eg, in shopping mall or street)	

need for assistance, at each of the distances listed.

1. Uses wheelchair, stroller or buggy: May stand for transfers and may do some stepping supported by another person or using a walker/frame
2. Uses K-Walker or other walking frame: without help from another person
3. Uses two crutches: without help from another person
4. Uses one crutch or two sticks: without help from another person
5. Independent on level surfaces: does not use walking aids or need help from another person. If uses furniture, walls, fences, shop fronts for support please use 4 as the appropriate description
6. Independent on all surfaces: does not use any walking aids or need any help from another person when walking, running, climbing and climbing stairs.

Appendix P Level of Sitting Scale

LEVEL OF SITTING SCALE (LSS) Scoring Form	
(LSS developed by Sunny Hill Health Centre for Children, 1989)	
<p>The Level of Sitting Scale (LSS) was adapted from the Chailey Level of Sitting Ability Scale (LSAS). For information on the LSAS, refer to Mulcahy C, Pountney T, Nelman R, Green E, Gillington G. Adaptive seating for the motorically handicapped – problems, a solution, assessment and prescription. <i>Physiotherapy</i> 1988, 74:531-536.</p>	
Level (circle highest level achieved)	Descriptor
1	One Person <u>Unable To Support</u> Individual In Sitting
2	Individual Supported in Sitting <u>from Head Downward</u> by One Person
3	Individual Supported in Sitting <u>from Shoulders or Trunk Downward</u> by One Person
4	Individual Supported in Sitting <u>from Pelvis Downward</u> by One Person
5	Individual <u>Maintains Sitting Position Independently</u> DOES NOT MOVE OUT OF BASE OF SUPPORT
6	Individual <u>Shifts Trunk FORWARD</u> Out of BASE of SUPPORT, RE-ERECTS WITHOUT ASSISTANCE
7	Individual <u>Shifts Trunk LATERALLY</u> , Out of BASE of SUPPORT, RE-ERECTS WITHOUT ASSISTANCE
8	Individual <u>Shifts Trunk BACKWARD</u> , Out of BASE of SUPPORT, RE-ERECTS WITHOUT ASSISTANCE

Modified Mini-Mental Scale
Functions Tests

2.	One point each, total score of 3
Minimum of 2 and Maximum of 4 digits backwards Digits: 4 3 2 1	
Total: _____/3	

3. Registration & Sensory Perception	One point each, total score of 3
Identify 3 objects by name 1. 2. 3.	/1
	/1
	/1
Total: _____/3	

4. Recall	One point each, total score of 3
Tell 3 objects presented previously 1. 2. 3.	/1
	/1
	/1
Total: _____/3	

5. Language	One point each, total score of 5
Name 5 Body Parts 1. 2. 3. 4. 5.	/1
	/1
	/1
	/1
	/1
Total: _____/5	

Modified Mini-Mental Scale
Functions Tests

5. Command	One point for each, total score 3
Unwrap the toffee	/1
Give the wrapper to the doctor	/1
Then eat it	/1

Total: _____/3

5. Repeat sentence	Total score of 1
“The cat drinks the milk”	/1

Total: _____/1

5. Reading	Total score of 1
Reads his/ her name	/1

Total: _____/1

5. Writing	Total score of 1
Writes own name	/1

Total: _____/1

5. Copy a design	Total score of 1
	
<hr style="border: 1px solid black;"/>	

Total: _____/1

Total score = _____/37

Adapted from: Jain M, & Passi GR. (2005). Assessment of a Modified Mini-Mental Scale for Cognitive Functions in Children. *Indian Pediatrics*, 42, 907-912. September 17, 2005

Appendix R Assessment of Learning Power Mobility Use

	Activity & Movement	Understanding of Tool Use	Expressions & Emotions	Interaction & Communication
8 Expert Attention well established and sustained Relaxed, active not tense	Occupation, composed of two or more activities Fluid, smooth and precise movements. Driving is automatic. A means for doing other activities in multiple settings. Intuitively organizes and understands the task they are encountering. Knows what to do based on mature and practiced understanding.	Integrated Tool Use Consciousness is focused on the other parts of the occupation. Driving more or less subconscious. Consistent precision control of powered wheelchair. Consciously deliberates a situation and performs their own judgement of how to resolve the situation. Takes care of others while driving powered wheelchair.	Dependent on the doing of “other” activities	Multi-level Integrated interaction Is able to interact with the machine, interact with the environment and interact with social partners.
7 Proficient Multi-channeled attention Generally focused	Occupation for its own sake Refinement of graded, timed movements. Driving for the sheer pleasure of driving. Navigating within the physical space.	Fluent Precise Use of Tool. Aware of consequences and conscious of how to control the steering with the joystick. Refining manoeuvring skills to fluent use. Takes care of themselves within the powered wheelchair.	Happiness Satisfaction	Concurrent Interactions Openness to multi-level interactions - displays readiness to interact at more than one level. No longer easily interrupted by occurrences. Interacting with the machine in a playful way. Contrives interactions within the social space.
6 Competent Multi-channeled attention but easily disrupted Focused on the goal	Activity Controlled but unrefined movements. Able to coarsely steer in a desired direction. Concentrating on getting from A to B often ignores the environment and people around them.	Competent Use of Tool Conscious of the need for sequencing of the acts in a certain order to reach a desired point or place. Controlled but coarse use of the tool. Regression to use body movements instead of tool use – using arm or foot to push away from obstacle.	Serious Content Laugh Excited	Consecutive Interactions One level interactions occur one after the other: interaction with the machine has to stop due to disruptive occurrences

<p>5</p> <p>Sophisticated Beginner Two-channeled attention</p> <p>Active, concentrated</p>	<p>Sequences of chains of acts</p> <p>Intentional more eager or violent movements. Exploring the machine. Experimenting with steering by composing effects in different patterns. Experimenting to find the pattern of the tool.</p>	<p>Idea of Competent Use is Born</p> <p>Conscious of the ability to cause many different effects, motion in different directions. Searching the steering pattern. Understands the use of electronic mobility guidance systems.</p>	<p>Eager Smile Serious</p> <p>Frustration Periods of frustration. Knowing possibilities but not achieving desired tool use goals. Periods of blocking intertwined with short peaks of success.</p>	<p>Reciprocated interaction</p> <p>Directs attention by pointing to convey a message that requires the playmate to respond</p> <p>Triadic Interaction</p>
<p>4</p> <p>Advanced Beginner Single channeled attention but able to shift spontaneously</p> <p>Attentive</p>	<p>Chain of acts Intentional but cautious, careful movements. Exploring the joystick. Exploration of different effects – drive, stop. Testing out different grips. Able to press a single switch, hold and release</p>	<p>Exploration of Extended Use</p> <p>Conscious of more than one effect. Motion in different directions depending on how acts are combined. Exploring the consequences of activating the tool. Understands 2 switches have different functions.</p>	<p>Serious Smile Sometimes Laugh</p> <p>Exhibits a desire to explore beyond the world of their tray</p> <p>Shift focus in between near and far</p>	<p>Mutual interaction</p> <p>Requests the attention of the playmate by pointing at objects or events in their close vicinity</p>
<p>3</p> <p>Beginner Single channeled attention but able to shift attention</p> <p>Alert</p>	<p>Act</p> <p>Distinct targeted movements. Activates joystick to get the effect of motion. Applying force. Able to press a single switch.</p>	<p>Basic Use</p> <p>Conscious of how one act can cause one effect. Act starts motion. Change position within the room e.g.circling. Regression to using body movements to try and move the machine.</p>	<p>Serious Contented Smile</p>	<p>Initiates interaction Keeps or responds to eye- contact Facial signalling</p>

<p>2</p> <p>Curious Novice</p> <p>Single channeled</p> <p>At times more alert</p> <p>Passive</p>	<p>Pre-act Diffuse vague multi-directed movements. Touches or hits different parts of the chair. In between sitting still. Touches or hits a switch – experimenting with exerting a force.</p>	<p>Idea of Basic Use is Born Pre-conscious of how a self-initiated act can cause the effect of setting the chair in motion.</p>	<p>Contented Curious Anxious Angry</p>	<p>Responds to interaction Gets in eye-contact Physical contact Behavioural mirroring Joint focussing on activity</p>
<p>1</p> <p>Novice</p> <p>Extreme distractibility No response to interaction (focus on the novel tool or novel situation)</p> <p>Passive or anxious</p>	<p>Excited Interested in looking at and touching the tool</p> <p>Non-Act No specific intentional movements. May accidentally activate the joystick. Is still for long periods Protective withdrawal body language</p> <p>Rejection Displays stereotyped or rejecting behaviours, wanting to get out of the powered wheelchair.</p>	<p>No or Vague Idea of Use Unconscious of how own activity can cause an effect.</p>	<p>Open Shows joy in experiencing guided motion</p> <p>Neutral Displays minimal facial expressions Whole body displays motionlessness</p> <p>Anxiety Worry, fear, annoyance, crying</p>	<p>No response May be aware of others attention. Perceptive Physical proximity – close in, draw back</p> <p>Avoidance Avoidance of touch from social partner. No wish for interaction Wants to get rid of the social partner</p>

Appendix S PEM-CY¹⁷⁸ Item Means for Total Group

PEM-CY ¹⁷⁸ Items	Frequency % Possible (1-100%)	Average Involvement (1-5)	% Desired Change (1-100%)
Home Participation (10 items) n=31 except % Desired Change n=30			
Watching TV, videos & DVD	96.8	4.5	40.0
Getting together with others	96.7	4.1	64.3
Computer & video games	93.5	4.6	37.9
Arts, crafts music & hobbies	90.0	4.4	30.4
Socializing using technology	89.7	4.0	46.2
Indoor play & games	86.7	4.3	41.7
Homework	86.7	4.2	46.4
Personal care management	86.7	3.4	50.0
School preparation	66.7	3.0	56.5
Household chores	63.3	2.8	72.7
School Participation (5 items) n=30 except % Desired Change n=29			
Classroom activities	100	4.2	37.5
Getting together with peers outside of class time	93.3	4.0	56.0
Fieldtrips & school events	89.7	3.9	52.4
Special roles at school	31.0	3.6	33.3
Teams, clubs & organizations	17.2	3.0	75.0
Community Participation (10 items) n=31 except % Desired Change n=29			
Neighborhood outings	100	3.8	36.7
Community events	87.1	3.8	48.1
Getting together with other kids	83.3	4.0	54.2
Organized physical activities	80.6	4.1	63.0
Unstructured physical activities	77.4	3.9	46.2
Overnight visits or trips	50.0	4.5	59.1
Religious or spiritual gatherings	46.7	3.2	31.8
Classes or lessons	35.5	3.4	68.4
Groups, clubs, volunteering	16.7	3.8	68.4
Work for pay	16.7	2.8	53.3

Appendix T CAPE¹⁶⁶ Subscale Mean Scores for Total Group

Subscale Score (# items)	Diversity (# items)	Intensity (1-7)	Whom (1-5)	Where (1-6)	Enjoy (1-5)
Formal (15)	5.1	1.5	3.8	3.9	4.0
Informal (40)	24.6	2.9	2.5	2.6	4.0
Recreation (12)	8.5	3.7	2.2	1.9	4.2
Social (10)	7.7	3.2	2.6	2.9	4.2
Self-improvement (10)	5.3	2.6	2.5	2.8	3.6
Skill-based (10)	4.1	1.9	3.5	3.5	3.9
Active Physical (13)	4.1	1.4	3.0	3.2	3.7

Appendix U WhOM-YP Identified Participation Outcomes by ICF^{33,34} Domains and Categories

Appendix U(i) WhOM-YP Identified Inside Participation Outcomes

Chapter 6 Domestic Life	Chapter 6 Domestic Life	Chapter 7 Interpersonal Interactions & Relationships	Chapter 9 Community, Social & Civic Life
d630 Preparing Meals (10)	d640 Doing Housework (9)	d710 Basic Interpersonal Interactions(1)	d920 Recreation & Leisure (25)
Helping cook	Doing chores-folding washcloths	Interacting with family & friends	Watching TV (2)
Helping mom in kitchen	Independently putting away things & helping with chores	d760 Family Relationships &/or d920 Recreation & Leisure (7)	Being able to watch TV independently
Helping dad cook	Clean up around the house	Hanging out with my family	Watching TV while standing up
Making dinner	Doing chores-dusting	Playing with sister	Playing video games (2)
Seeing what's in the pantry	Helping conserve energy around the house by turning off lights	Playing with family	Listening to music & dancing
Having a meal (2)	Doing different things around home independently	Playing with younger brothers and sister	Listening to music independently (2)
Getting snacks	Helping bring things in the house (from vehicle) (3)	Playing drums with family	Creating art
Setting up/cleaning after meals		Watching hockey at home with family	Making cards
Getting ready for meals by washing hands independently		Playing video games with family	Standing whenever I want (perceived as d920 play)
d629 Acquisition of Necessities (8)		d720 Complex Interpersonal interactions &/or d750 Informal social relationships (4)	Playing in yard (3) & with brother & sister (1)
Getting things around my house by myself	Getting to washroom & back to what I was doing quickly	Playing games with friends	Playing in driveway
Getting ready for school (4)	Being in charge of where I go	Playing hockey with neighborhood kids	Play snakes & ladders on driveway
Getting ready for school (getting in & out of bedroom by myself)		Hanging out on street with friends	Playing with brothers outside (2)
d650 Caring for Household Objects (2)		Playing games with friends	Playing on street with sister & friends
Walking dog		Chapter 8 Major Life Areas d820 School Education (1)	Playing games outside with family and friends
Looking after our garden		Doing my homework independently	Going outside to play (3)

Legend: (number) = number of children identifying this as an outcome; & = and.

Appendix U(ii) WhOM-YP Identified Outside Participation Outcomes

Chapter 6 Domestic Life	Chapter 8 Major Life Areas	Chapter 9 Community, Social & Civic Life	Chapter 9 Community, Social & Civic Life
d620 Acquisition of Goods & Services (13)	d820 School education (46)	d910 Community life (21)	d920 Recreation and leisure (18)
Going shopping (2)	Using computer for schoolwork (2)	Gardening at community garden	Playing power soccer (4)
See what I want to see in stores	Using computer at lunch	Playing in the park (5)	Controlling RC vehicles, & being part of RC club
Clothes shopping	Picking out library books (4)	Doing what I want at playground	Going swimming (2)
Shopping at the store & market	Attending school (5)	Visiting the airpark	Participating in MD walk
Shopping at the mall (4)	Getting around school by self (5)	Riding at the skatepark	Visiting the aquarium
Shopping with sister or friend	Attending classes (4) + using elevator by myself (1)	Seeing an event while in a crowd	Seeing a movie (with friends) (2)
Shopping with family (2)	Seeing chinchillas on 2 nd floor	Choosing where to go when out	Geocaching
Doing errands with family	Delivering messages (school) (2)	Going out evenings & weekends	Eating out with family
Chapter 7 Interpersonal Interactions & Relationships	Getting things in library, class, for schoolwork Working in school kitchen	Going for walks (3) around home (2) with family (1) with friends (2) in neighbourhood (1)	Traveling out of neighborhood (overnight trips) Camping with family
d720 Complex Interpersonal interactions &/or d750 Informal social relationships (17)	Doing art (at school) Dancing (at school)		Spending time at grandma and grandpa's cottage
Keeping up with friends (3)	Doing school wide runs (2)		Getting food when out
Hanging out with friends (5)	Picking out & playing with toys (school)		Having fun, driving obstacle course
Having fun with my friends giving rides on back of my wheelchair	Playing soccer at school (2) Playing games, soccer, races, hockey		d930 Religion and spirituality (1)
Talking with friends (at eye level) (2)	MD Walk, Terry Fox Run at school		Going to church
Visiting friend(s) (5)	Play at recess / lunch with friends (6)		
Play games with friends at school (manhunt, hide & seek, tag)	Going on fieldtrips (3)		
	Graduating-'walking' across stage		

Legend: (number) = number of children identifying this as an outcome; & = and.

FEASIBILITY INDICATORS Data Collection Form

1. **Total Driving Time:** _____
Driving to Appointment: _____ start finish
Driving from Appointment: _____ start finish

2. **Total Driving Mileage:** _____
To Appointment: _____ start finish
From Appointment: _____ start finish

3. **Arrival Time:** _____

4. **Time to review Consent & Assent:** _____

5. **Time of Commencement of parent assessments:** _____

6. **Time of Completion of parent assessments:** _____

7. **Time of Commencement of student assessments:** _____

8. **Time of Completion of student assessments:** _____

9. **Total time spent scheduling session:** _____
Parent: _____ Teacher: _____
Therapist: _____ Other: _____

10. **Total time spent preparing for session:** _____
Documentation: _____
Equipment (video camera, backpack): _____
Other: _____

11. **Time spent summarizing session:** _____
WhOM: _____ PMP: _____
WST: _____ ALP: _____
Context form: _____ Other: _____

Appendix W Contextual Observation Form

Contextual Observation Form

Physical Environment (community/neighbourhood/housing/room layout).
Include comments about the weather conditions(rain, snow, cold etc).

Interview Administration (who did you interview (mother, father, primary caregiver), family members present during the interview, interview flow (including distractions, parent attentiveness))

Family Information of Note

Other Observations

Appendix X Feasibility Study Semi-Structured Interview Guide

1. Intervention Evaluation

What does participation mean to you?

How does your PMD affect your ability to do the things you want or need to do?

What are the benefits of using power mobility to do what you want or need to do?

What things help you to succeed when using your PMD?

What things stop you from doing what you want when you are using your PMD?

Does your PMD meet your expectations?

Is there anything you would like to do differently when using your PMD?

Is there anything you would like to change about your PMD?

Are there any problems with your PMD?

Is there anything you can think of that would help you use your PMD better?

2. Study Evaluation

What did you think about *the way* this study was conducted?

How satisfied were you with the experience?

How did you find out about the study? Any suggestions for making it more appealing?

What did you think about *how* the sessions were carried out?

What did you think about the method and the frequency of communication?

What did you think about how many sessions were involved?

What did you think about how long each session was? And how many tests were involved?

What would have made it easier for you to participate in this study?

Is there anything you can think of that would help make the experience more enjoyable

Appendix Y Summary of Completion Times and Number of Days Between Sessions

Appendix Y(i) Session Completion Times

	Mean completion time for child evaluations in minutes (SD)	Mean completion time for parent evaluations in minutes (SD)	Completion time for overall session in minutes (SD)
New PM Group			
T1	70.0 (24.3)	72.5 (18.9)	91.4 (17.9)
T2	57.3 (22.5)	60.9 (16.1)	67.3 (19.8)
T3	67.5 (22.3)	55.4 (25.7)	79.6 (26.4)
T4	55.8 (19.6)	51.0 (14.9)	66.3 (17.5)
T5	94.6 (20.1)	87.5 (20.6)	101.7 (13.7)
Average T1-T5 [CI ₉₅]	69.0 (25.2) [62.7, 75.4]	65.5 (23.2) [59.4, 71.5]	81.3 (23.4) [75.4, 87.1]
Stable PM Group			
T1	75.6 (23.3)	63.8 (21.6)	84.2 (25.2)
T2	64.6 (22.8)	71.1 (23.6)	87.1 (21.8)
Average T1+T2 [CI ₉₅]	70.0 (23.4) [61.9, 78.0]	67.4 (22.5) [59.2, 75.7]	85.6 (23.3) [77.6, 93.6]

Legend: CI₉₅ = 95% Confidence Interval; SD = standard deviation; T = session number

Appendix Y(ii) Number of Days Between Sessions for New PM Group

Participant	Initial contact to enrollment	T1-T2	T2-T3	T3-T4	T4-T5	T1-T3	T1-T4	T1-T5	T3-T5
P35-1	26	--	--	21	70	12	33	103	91
P35-2	70	12	17	29	68	29	58	126	97
P35-3	13	18	50	29	61	68	97	158	90
P35-4	41	31	39	28	57	70	98	155	85
P35-5	13	11	56	--	--	67	--	159	92
P35-6	8	9	60	35	63	69	104	167	98
P35-7	10	6	11	35	62	17	52	114	97
P35-8	13	12	8	36	55	20	56	111	91
P35-9	8	11	23	14	69	34	48	117	83
P35-10	16	27	36	20	84	63	83	167	104
P35-11	21	12	10	47	--	22	69	--	--
P35-12	40	9	150	55	45	159	214	259	100
P35-13	13	--	--	30	70	10	40	110	100
P35-14	42	--	--	--	--	--	--	--	--
Mean	23.9	14.4	41.8	31.6	64.0	49.2	79.3	153.3	94.0
(SD)	(18.1)	(7.9)	(40.5)	(11.3)	(10.1)	(40.8)	(48.6)	(43.4)	(6.4)
CI ₉₅	13.4,34.3	9.1,19.6	14.6,69.0	24.4,38.8	57.2,70.8	24.6,73.9	48.5,110.2	125.7, 180.9	90.0,98.0

Legend: CI₉₅ = 95% Confidence Interval; SD = standard deviation; T = session number

Appendix Y(iii) Number of Days Between Sessions for Stable PM Group

Participant	Initial Contact To Enrollment	T1-T2
P32-1	3	18
P32-2	31	14
P32-3	58	14
P32-4	43	13
P32-5	32	14
P32-6	7	21
P32-7	15	18
P32-8	13	14
P32-9	21	14
P32-10	21	14
P32-11	21	14
P32-12	21	14
P32-13	1	28
P32-14	11	14
P32-15	3	13
P32-16	13	14
P32-17	17	20
P32-18	11	--
Mean	19.0	15.9
(SD)	(14.6)	(4.0)
CI ₉₅	7.3, 26.3	13.1, 18.0

Legend: CI₉₅ = 95% Confidence Interval; SD = standard deviation; T = session number

Appendix Z Comparison of Summary Change Scores for New PM Group

	T2 - T1 T2 n=11; T1 n =13	T3 - T1 T3 n= 13	T4 - T1 T4 n=12	T5 - T1 T5 n=12	◆Friedman's Test □ Wilcoxon's Test <i>p</i> = 0.05
PEM-CY Home participation Frequency % possible mean change & SD [95% CI of mean] median change min / max	2.0 (12.3) [-6.8, 10.8] 0 -20 / 20	1.7 (8.4) [-3.6, 7.0] 0 -10 / 20	1.8 (8.7) [-4.1, 7.7] 0 -10 / 20	4.5 (8.2) [-1.0, 10.0] 0 0 / 20	◆0.63
PEM-CY School participation Frequency % possible mean change & SD [95% CI of mean] median change min / max	0.0 (15.1) [-12.6, 12.6] 0 - 20 / 20	5.4 (15.7) [-5.1, 16.0] 0 -20 / 40	6.00(21.19) [-9.16,21.16] 0 -20/40	6.0 (21.2) [-9.2, 21.2] 0 -20 / 40	◆0.15
PEM-CY Community participation Frequency % possible Mean change & SD [95% CI of mean] median change min / max	3.0 (17.7) [-9.6, 15.6] 0 -20 / 40	0.8 (10.8) [-6.1, 7.7] 0 -20 / 20	-0.9 (11.4) [-8.5, 6.7] 0 -20 / 10	-0.9 (14.5) [-10.6, 8.8] 0 -20 / 30	◆0.82
PEM-CY Home participation % change desired mean change & SD [95% CI of mean] median change min / max	-4.4 (19.5) [-18.3, 9.5] -3.0 -37.5 / 30	-9.4 (19.0) [-21.5, 2.7] -9.5 -40 / 30	-11.2 (14.7) [-21.1, -1.5] -14.3 -37.5 / 20	-13.5 (17.7) [-25.4, -1.6] -10 -50 / 2.5	◆0.59
PEM-CY School participation % change desired mean change & SD [95% CI of mean] median change min / max	4.5 (27.3) [-20.7, 29.7] 0 -26.7 / 60	-0.5 (22.6) [-16.7,15.7] 0 -33.3 / 40	-9.6 (32.8) [-37.0, 17.8] -8.3 -66.7 / 40	-1.1 (38.5) [-30.7, 28.5] 0 -66.7 / 50	◆0.15

	T2 - T1 T2 n=11; T1 n =13	T3 - T1 T3 n= 13	T4 - T1 T4 n=12	T5 - T1 T5 n=12	◆Friedman's Test □ Wilcoxon's Test <i>p</i> = 0.05
PEM-CY Community participation % change desired mean change & SD [95% CI of mean] median change min / max	2.5 (17.4) [-10.9, 15.9] 0 -16.7 / 44.4	-5.3 (25.3) [-22.4, 11.7] 0 -53.3 / 44.4	-2.4 (24.7) [-20.1, 15.2] -5 -43.3 / 50	-1.2 (14.6) [-11.7, 9.2] 0 -20 / 30	◆0.31
CAPE Overall diversity mean change & SD [95% CI of mean] median change min / max				0.3 (9.2) [-5.5, 6.2] -1 -15 / 17	
CAPE Overall intensity mean change & SD [95% CI of mean] median change min / max				-0.0 (0.9) [-0.6, 0.6] 0.0 -1.7 / 1.2	
CAPE Overall enjoy mean change & SD [95% CI of mean] median change min / max				0.2 (0.5) [-0.7, 1.0] 0.1 -0.7 / 1.0	
WhOM-YP Child Inside Mean Satisfaction mean change & SD [95% CI of mean] median change min / max	-1.5 (3.2) [-3.8, 0.8] -0.2 -9 / 1	-0.2 (4.2) [-2.9, 2.4] -0.5 -6.3 / 7.7	-0.2 (5.4) [-3.8, 3.4] 1.0 -10 / 7.7	1.8 (5.2) [-1.4, 5.1] 2.7 -9 / 7.7	◆0.14
WhOM-YP Child Outside Mean Satisfaction mean change & SD [95% CI of mean] median change min / max	-0.0 (1.6) [-1.1, 1.1] 0.20 -3.0 / 2.6	0.3 (4.0) [-2.0, 2.7] -0.4 -4.6 / 10.0	1.4 (3.9) [-1.1, 3.9] 1.4 -4.0 / 10.0	4.6 (2.8) [2.8, 6.3] 5.0 0.1 / 10.0	◆0.02^ □0.79 T3.T1-T2.T1 □0.21 T4.T1-T2.T1 □0.01^ T5.T1-T2.T1 □0.14 T4.T1-T3.T1 □0.003^ T5.T1-T3.T1 □0.007^ T5.T1-T4.T1

	T2 - T1 T2 n=11; T1 n =13	T3 - T1 T3 n= 13	T4 - T1 T4 n=12	T5 - T1 T5 n=12	◆Friedman's Test □ Wilcoxon's Test <i>p</i> = 0.05
WhOM-YP Parent Inside					
Mean Satisfaction					
mean change & SD	-0.5 (1.2)	0.8 (3.2)	-0.5 (6.0)	1.4 (3.2)	
[95% CI of mean]	[-1.9, 1.0]	[-2.6, 4.2]	[-10.0, 9.0]	[-1.9, 4.7]	◆0.52
median change	-1.0	0.5	-1.0	1.8	
min / max	-1.7 / 1.3	-3.0 / 6.0	-7.0 / 7.0	-3.0 / 6.0	
WhOM-YP Parent Outside					
Mean Satisfaction					
mean change & SD	-0.2 (0.8)	-2.0 (2.2)	0.1 (2.6)	2.1 (2.3)	
[95% CI of mean]	[-1.0, 0.6]	[-4.3, 0.4]	[-3.1, 3.3]	[-0.3, 4.5]	◆0.11
median change	0.0	-2.3	-0.8	2.4	
min / max	-1.5 / 0.5	-4.2 / 0.8	-2.8 / 4.0	-1.0 / 4.5	

Legend: CI = confidence interval; ◆Friedman's Test = Friedman's Related Samples ANOVA by Ranks test; max = maximum value; min = minimum value; SD = standard deviation; T() = session number; □ Wilcoxon's Test = Wilcoxon's Related Sample Signed Rank Test; *pairwise deletion; ^ = statistically significant at *p*=0.05