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THE UNIVERSITY OF BRITISH COLUMBIA

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Information and Consent Form – Clinician/Researcher

PAEDIATRIC PARTICIPATION OUTCOMES FOR WHEELCHAIR EVALUATION IN REHABILITATION (POWER) MOBILITY
Development of a Toolkit of Measures- Phase 1 Delphi Survey

Principal Investigator: William C. Miller, PhD FCAOT, Professor, Department of Occupational Science and Occupational Therapy, University of British Columbia (UBC) (billm@mail.ubc.ca, 1-604-714-4107).

This study is part of the PhD thesis requirements for Debbie Field M.HSc.OT, PhD Candidate, Graduate Programs in Rehabilitation Sciences UBC, and is funded by Canadian Institutes of Health Research.

Dear Clinician and/or Researcher, April 4, 2012

You are invited to participate in this study because you have demonstrated a strong interest in working with children aged 18 months-12 years, who may use power mobility. As a professional you are knowledgeable about children with mobility limitations' participation in daily routines and social activities***. Your expertise in working with children who may use a power mobility device is valuable to us.***

The information contained in this sheet will provide you with more details about the study so that you can decide if you wish to participate.

Background

Independent mobility is important for taking part in life activities. More children than ever before are using power mobility to move around and to participate in the things they need and want to do. Although we know that providing power mobility makes a difference in children's lives, we have little research evidence supporting the effectiveness of this intervention. One of the reasons for this is the lack of measurement tools designed specifically to capture information about the impact that power mobility has on a child's participation in chosen activities.

What is the Purpose of this Study?

The purpose of this study is to develop an assessment toolkit of participation measures (to be known as the Paediatric Participation Outcomes for Wheelchair Evaluation in Rehabilitation (POWER) Mobility toolkit) that will assist therapists and families in their decision-making for power mobility prescriptions for children, and improve their ability to document the effectiveness of therapeutic strategies that use power mobility.

This study will use a series of computer-based online surveys to identify the important elements of participation for children who use power mobility, and then identify measurement tools that can be used to evaluate their participation in daily and social activities. **Your opinions will help us better understand and meet the needs of children who use power mobility.**

Who is Conducting the Study?

This study is being conducted by researchers from the University of British Columbia and Sunny Hill Health Centre for Children. Sunny Hill Health Centre for Children is part of Children's and Women's Health Centre of British Columbia. The study is funded by Canadian Institutes of Health Research.

Participation is Voluntary

Your participation in this project is entirely voluntary. Before you decide, it is important for you to understand what our research involves. This letter explains the study in detail. If you wish to participate in this study, you will be asked to provide your consent, but you are still free to withdraw at any time without giving any reasons for the decision.

Who Can Participate in the Study?

To participate in this study you are either a clinician or researcher:
As a **Clinician,** you:

1) are a certified occupational and/or physical therapist,
2) have worked *5 years or more* with children 18 months to 12 years of age with chronic mobility limitations,
3) *in the last year*, have prescribed power mobility for *at least 5* of these children, or have assessed or trained *at least 5* of these children in the use of power mobility.

or
As a **Researcher** you have:

1) *at least 3 years'* experience investigating power mobility and/or participation in children between the ages of 18 months to 12 years,
2) *at least 1* peer-reviewed journal publication on paediatric power mobility and/or participation *in the last 5 years*,
3) presented on paediatric power mobility and/or participation at a national or international level conference *at least once in the last 5 years*.

Furthermore, you have a good understanding of what is important to children and their families with regard to participation in daily and social activities, and you are able to comprehend written English at a Grade 12 level. You also have access to a computer with internet availability.

What Does the Study Involve?

The study involves a computer-based online Delphi survey. This is a series of questionnaires over time, used to gather information and build consensus about a topic. ***Your time commitment for the study is less than 1 hour for each session, for a total of 4 sessions, over a period of 8 months*.** Although 4 surveys are planned, the number of rounds may be adjusted (plus or minus 1 round) dependent on survey results. We are expecting 60 individuals to take part in all sessions, including parents, therapists and researchers. A summary of background information will be provided, and will include a summary of responses for each session.

If You Decide to Participate in this Study

Before the First Session

Please contact the research coordinator by email or telephone, to have your questions answered, determine your eligibility, go over this consent form and obtain a schedule of the sessions.

First Session

You will be notified by email of the dates when the first survey is available online. *On the day of commencement for the first survey an email will be sent with the link to the electronic survey, clicking on the link will imply consent*. The survey will be available for completion 24 hours a day for a period of three weeks.

Second and Remaining Sessions

For the remaining rounds of surveys, an email reminder will be sent one week prior to commencement of the survey, and the same protocol as above will be followed.

What Are My Responsibilities?

For each session, you are asked to read the information provided to you in an email message, and then complete the online survey, answering the questions to the best of your ability. If for any reason you are unable to complete the sessions, please notify Debbie Field at 1-604-737-6314, or dfield1@interchange.ubc.ca.

What Are the Possible Harms and Side Effects of Participating?

There are no known risks nor any cause for discomfort from participating in this survey. If a topic is difficult for you to address, you do not have to answer those questions.

What Are the Benefits of Participating in this Study?

There are no direct benefits to you from taking part in this study. The results may be used in the future to assist therapists and families in measuring children's participation, and to determine what interventions are effective.

What Happens if I Decide to Withdraw My Consent to Participate?

Your participation in this study is entirely voluntary. You may decline to enter this study or withdraw from the study at any time without any consequences. You will not have to provide any reasons for

this decision. Data collected up to the point of your withdrawal from the study must be kept for data analysis purposes under strict provisions of confidentiality.

What Happens if Something Goes Wrong?

You do not waive any of your legal rights by providing consent to participate.

After the Study is Finished

If you are interested in the results of the study you may ask the researchers to notify you when the study results are available. The specific information related to your participation in this study will be kept confidential.

What Will the Study Cost Me?

In order to defray costs associated with your time, you will receive an honorarium of $100 (Canadian dollars) for your participation. You will receive half of the honorarium after the second session, and the other half of the honorarium upon completion of the final session. If you withdraw from the study before the final session, your honorarium will be pro-rated.

Will My Taking Part in this Study Be Kept Confidential?

Your confidentiality will be respected. No information that discloses your identity will be released or published without your specific consent to the disclosure. However, research records identifying you may be inspected in the presence of the Investigator or his or her designate by representatives of Health Canada, and the UBC Research Ethics Board for the purpose of monitoring the research. However, no records which identify you by name or initials will be allowed to leave the investigators' offices.

The Canadian-based FluidsSurvey will be used to ensure secure and confidential data storage in Canada. This product has the ability to use Secure Sockets Layer (SSL) for encryption, ensuring security of the collected responses over the internet. *All documents resulting from this study will be identified by only a code* and kept in a secure location, or on a password-protected computer by the study co-coordinator. The only people having access to this information will be the investigators or one of their designated research assistants.

Who Do I Contact If I Have Questions About the Study During My Participation?

If you have any questions or desire further information about this study before or during participation, you can contact the study coordinator **Debbie Field** at email: dfield1@interchange.ubc.ca or telephone: 1-604-737-6314. The Principal Investigator, Dr. Bill Miller, is also available at email: billm@mail.ubc.ca or telephone: 1-604-714-4107.

Who Do I Contact If I Have Questions or Concerns About My Rights as a Subject During the Study?

If you have any concerns about your rights as a research subject or your experience while participating in this study, contact the Research Subject Information Line in the University of British

Columbia Office of Research Services at e-mail: RSIL@ors.ubc.ca, telephone: 1-604-822-8598 or toll-free telephone number: 1-877-822-8598.

Subject Consent to Participate

I am satisfied that the information contained in this consent form was explained to me, that all my questions have been answered, that I fully understand the information, and that I agree to participate in the research.

- ڤ I have read and understood the information and consent form.
- ڤ I have had sufficient time to consider the information provided and to ask for advice if necessary.
- ڤ I have had the opportunity to ask questions and have had satisfactory responses to my questions.
- ڤ I understand that all of the information collected will be kept confidential and that the result will only be used for scientific objectives.
- ڤ I understand that my participation in this study is voluntary and that I am completely free to refuse to participate or to withdraw from this study at any time.
- ڤ I understand that I am not waiving any of my legal rights as a result of providing consent.
- ڤ I understand that there is no direct benefit to me by participating in this study.
- ڤ I have read this form and freely consent to participate in this study.

_____	_____	_____
Printed Name of Participant	Signature of Participant	Date
_____	_____	_____
Printed Name, Principal Investigator	Signature, Principal Investigator	Date