



Dear AACPDMD Colleagues;

We are writing to invite you to participate in an important research regarding the World Health Organization (WHO)'s International Classification of Functioning, Disability and Health (ICF) as it relates to children and youth with motor impairments, specifically cerebral palsy (CP).

The WHO developed the ICF in 2001 and went on to publish the child and youth version (ICF-CY) in 2007. The goal of the ICF-CY is to create a framework to define and classify the health and function of children and youth around the world and to provide a comprehensive classification system of childhood disability that could be used across service systems.

In order to facilitate the use of the very comprehensive ICF, adult research groups working in collaboration with the WHO, have gone on to create "core sets". A core set is a subset of many items of the ICF and is created to make the ICF-CY more user friendly in every day practice. To date, no core sets have been developed for children and youth.

Our research group, based in the Department of Pediatrics at UBC is working in collaboration with the ICF Research Branch of the WHO, located at the Department of Physical Medicine and Rehabilitation at Ludwig-Maximilian-University in Munich, Germany to develop ICF "core sets" for children and youth with CP.

The core set development will have a number of projects and we are inviting you, as an expert in the field of childhood CP, to be part of one of the first projects. We are identifying experts in the assessment and management of children and youth with CP who are willing to participate in an internet-based expert survey. In keeping with the standard protocol for the development of ICF core sets; this worldwide survey of clinical experts will be performed to identify all relevant areas of functioning for children and youth with CP. Over 350 experts from all 6 WHO regions of the globe are being sought.

Therefore we are seeking the help of individuals who fulfill the following criteria:

- Your professional background includes one of the following: *pediatrics, developmental pediatrics, pediatric rehabilitation physician, pediatric neurology, pediatric neurosurgery, orthopedic surgery, occupational therapy, physiotherapy, speech and language pathology, rehabilitation nursing, social worker and special education teachers* **and**,
- For at least 5 years, you have been working in the field of child/adolescent physical disability including CP (including clinical, educational, research and/or administrative roles) **and**,

- Your focus is mainly in pediatric physical disabilities **and**,
- You are fluent in English.

Your participation is completely voluntary. If you agree to participate, your name will be added to a bank of experts and subsequently a random sample will receive an electronic survey to complete. If you are randomly selected, completion of the survey will require approximately 30 minutes of your time. You are free to withdraw at any time. Your identity will be kept strictly confidential. Your completed survey information will be stored with no personal identifiers as participants will be assigned an identification number and responses will be kept anonymous. Only the researchers have access to the data which will be held securely in the Children and Youth with Disability in Society (CYDiS) research unit of the Child and Family Research Institute of the University of British Columbia. Results will be reported only in aggregate form without naming specific individuals, universities or cities.

More information regarding this project is available from the research project team: Dr. Veronica Schiariti, Dr. Maureen O'Donnell, Dr. Robert Armstrong (from the University of British Columbia and Sunny Hill Health Centre for Children/BC Children's Hospital) and Dr. Alarcos Cieza (Ludwig-Maximilian University, Germany).

More information can be also obtained by visiting:

http://www.cfri.ca/our_research/programs_crosscutting_theme/community_child_health/ICF_expert_survey.asp or by contacting the project coordinator, Dr. Veronica Schiariti ICF_CerebralPalsy@cw.bc.ca.

The project has been approved by the Research Ethics Board of the University of British Columbia. If you have any concerns about your rights or treatment as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598 or if long distance e-mail to RSIL@ors.ubc.ca.

As an expert in the field of CP, we thank you for considering your participation in this important survey. If you are willing to participate in the survey please complete the attached spreadsheet and email it back to the contact below.

Finally, if you are aware of other experts in this field who have are not aware of this project, please provide them with this information and invite them to contract Dr. Veronica Schiariti. In addition, it would be very helpful for our research project, if you could name other experts in the field who are known to you.

I would like to thank you in advance for collaborating in this important international project. Please complete the Table of Contact Information by downloading the form found at: http://www.aacpdm.org/UserFiles/file/WHO_Survey_Project_FORM.doc

Looking forward to hearing from you soon,

Yours sincerely,
Veronica Schiariti, MD MHS PhD (C)
(Expert Survey Coordinator)

