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Subject: *Invitation to participate in a "Pain Measurement in Cerebral Palsy" survey*

Dear clinician, parent, or young person,

Young people with cerebral palsy (CP) frequently experience pain which can affect day to day activity levels and quality of life. However in children with CP, pain is hard to pick up and measure due to different causes of pain, levels of disability, and communication type. We are a group of researchers conducting a series of electronic surveys to work out the best way to measure pain in young people with CP. You are being asked to take part in this survey as you are either a clinician (allied health professional, doctor, nurse, or psychologist) who works with young people with CP, a parent of a young person with CP, or a young person with CP yourself. The aim of this survey is to help clinician's and researcher's measure pain in a meaningful way for young people and their families by using the best available tools.

As pain can be measured from a number of different ways or methods (domains), the first stage of this survey involves working out the most meaningful domains to include when measuring pain in young people with CP. The survey will take approximately 10-15 minutes to complete. By agreeing to take part, you will also be sent follow up surveys which may take a similar time or longer to complete. A number of surveys (up to 3) will be sent until a set of pain domains and measurement tools to use in clinical and research practice with young people with CP has been agreed upon. This first part of this survey will collect details about you and then ask questions about different aspects (domains) important to consider when measuring pain in young people with CP.

This research project is being funded by a Clinical Sciences Grant through the Murdoch Children's Research Institute, Melbourne, Victoria. Any identifiable information we collect from you will be treated as confidential. We will disclose information only with your permission, except as required by law. Your information will be stored on a secure password protected online data base while the survey is being undertaken. This database will store your email address in identified format during the survey series, so the appropriate follow up emails can be sent directly to you. However after the survey series has been completed, this information will be de-identified and held on the same secure password protected online data base for a minimum of 7 years post study closure. When we write or talk about study results, we will report only information about the whole group results rather than individual results. Study results may be presented at conferences or seminars, or published in professional journals.



Electronic survey methods will be used for collecting data. Electronic survey methods have been considered for this research as it provides an environmentally friendly as well as cost and time effective way to carry out research. REDCap™ is the data capture and storage system to be utilised. REDCap™ is made specifically for academic research, and the system is maintained and administered by experienced database specialists.

By taking part in this survey you will be giving **"IMPLIED CONSENT"**, which assumes that by completing this survey you consent to the conditions described in this email. You can withdraw from taking part in this survey at any point. For parents or young people, if you decide not to take part or to withdraw from the survey, this will not affect your/your child's treatment or clinical care.

If you are interested in taking part in the survey, you may open the survey in your web browser by clicking on the link below.

<https://redcap.mcri.edu.au/surveys/?s=XEWRMYN34W>

If you are interested in taking part, we would like you to complete the survey within two weeks. Thank you for considering to be involved in this project. If you have any questions regarding this survey please feel free to contact Adrienne Harvey (03) 9345 5522 ext 57540.

Yours sincerely,

Adrienne Harvey

Senior Research Fellow

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The Research Team includes: Principle Investigator Dr. Adrienne Harvey^{1,4}; Associate Investigators: Ms. Clare McKinnon^{1,4}, Ms. Katarina Ostojic³, Dr. Simon Paget³, Dr. Angie Morrow³, Mrs. Nadine Smith².

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