Participant Information Sheet

Lay title	**Chronic Pain Assessment in Cerebral Palsy**
Scientific title	Tailoring Chronic Pain Assessment to Children and Young People with Cerebral Palsy
Principal Investigator	**Ms Meredith Smith (Physiotherapist & PhD student)**
Investigators	Prof Rachel Gibson A/Prof Adrienne Harvey A/Prof Ray Russo

1 Introduction

This research project is finding out information on how we should measure ongoing pain in children and young people with cerebral palsy. We know that chronic pain affects many areas of life such as typical daily activities, exercise, mental health and sleep. We also know that many children and young people with cerebral palsy have ongoing pain, but it is not often treated. We think this might be because appropriate pain assessment tools are not available or widely used. We want to know which chronic pain assessment tools are most meaningful and appropriate. We also want to know how we could modify these tools so they are more relevant for people with cerebral palsy.

We plan to survey people with cerebral palsy, parents of children with cerebral palsy, health professionals and researchers. We will also be running small group and individual interviews. We will use this information to modify existing chronic pain assessment tools so that they are more relevant to children and young people with cerebral palsy.

This Participant Information Sheet tells you about the research project. Please read this information carefully. Ask questions about anything that you don't understand or want to know more about.

Participation in this research is entirely voluntary. If you do not wish to take part, you do not have to. You will receive the best possible care whether you take part or not.

2 Why is this study being conducted?

We want to know how to better measure pain and its impact for people with cerebral palsy, so that health care providers can better manage pain in cerebral palsy. A number of the assessment tools that are currently available are either not relevant for children and young people with cerebral palsy, or don't capture the wide impact pain can have on a person's life. This makes research difficult as health care providers can't be sure that the treatments they are using are having an impact. We want to have pain assessments that tell us about how pain impacts a person's daily life, their ability to participate in the things they most enjoy and how they cope with their pain. We want to make sure that these assessments cover the things that are unique to a child or young person with cerebral palsy.

3 What does participation in the research involve?

Online survey - round 1

Study participants will be asked to participate in an online survey. This survey will be conducted over a maximum of 3 rounds. Each round should take no more than 30 minutes to complete.

The first round will ask you to rate a number of existing chronic pain assessment tools. You will be asked to rate how meaningful the tool is. You will also be asked how appropriate you think the tool is for use. This includes things like how long the tool takes to complete, how much it costs and what materials you need to complete it.

Interview or group discussion (online) (1)

You will then have the option to participate in a smaller group (focus group) or one to one discussion (interview) with the investigators. The focus groups and interviews will be a maximum length of 1 hour and will take place on Zoom. The most popular tools from the online survey in round 1 of the survey will be presented. You will be asked to make suggestions as to how these tools could be changed to be more relevant for people with cerebral palsy. This could include changes to the questions in the tool, how the tool is structured or what the response options are. You do not need to participate in the focus group or the interview to continue participating in the online survey

Online survey- rounds 2-3

The second round will bring together the suggestions from the focus groups and interviews. You will be asked to rate how appropriate you think the suggested changes to the tools are. We will then compare how similar the ratings are across all the participants. You may then be sent a third round, where we show you what other participants have said and ask if you would like to change your answer. We will use this as a 'round table discussion' to come to an agreement on how to change the tools to be most relevant for people with cerebral palsy.

You can choose to participate in the survey and interview/group interviews, or just one.

4 How is the research project being conducted?

This study is looking for ideas and suggestions from people with cerebral palsy, parents of children with cerebral palsy, clinicians and researchers about how to modify chronic pain assessment tools. The version/s of the adapted tool/s from the final round of the survey will be tested in future studies to ensure that they are robust enough to be used in health care and research settings.

5 What are the possible benefits of taking part?

We cannot guarantee that you will receive any benefits from this research. This research will help us to adapt tools to better assess pain in children with cerebral palsy. In future studies, the adapted tools will be further tested to make sure they are robust enough to be used by healthcare providers and researchers. We hope this will lead to better research and treatment options for chronic pain in children and young people with cerebral palsy.

For focus group and interview participants, you will each receive a $50 gift voucher.

6 What are the possible risks and disadvantages of taking part?

For people with cerebral palsy there is a risk that talking about pain may distress you. If you are distressed during the interview or focus group, the moderator speak with you and will contact your parent or caregiver. You may also be referred to a relevant professional service if this is appropriate

7 What if I withdraw myself from this research project?

If you decide to withdraw yourself from the project, please notify an Investigator listed above. If you withdraw during the project, the study staff will not collect additional personal information, although personal information already collected will be retained to ensure that the results of the project can be properly measured. Your access to the health service will not be affected at the present or any future time by deciding to withdraw from this study.

8 What happens when the research project ends?

Following completion of this study, your information will remain confidential except in the case of a legal requirement to pass on personal information to authorised third parties. This requirement is standard and applies to information collected both in research and non-research situations. Such requests to access information are rare; however we have an obligation to inform you of this possibility. No identifiable information will be use in future studies, however the adapted tools developed will be tested in future studies. You will have the opportunity to be contacted about future studies, however this is optional. You will have the opportunity to accept or deny this offer in the final round of the survey.

9 Who is organising and funding the research?

Ms Meredith Smith is a PhD student at the University of Adelaide and she is funded by the Australian Government Domestic Research Training Program. Ms Smith is under the supervision of an experienced research team (Prof Gibson, A/Prof Russo and A/Prof Harvey). All research costs are supported by the research team. There are no other funders or sponsors of this project.

10 Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this research project have been approved by the HREC of the Women's and Children's Health Network. This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007).* This statement has been developed to protect the interests of people who agree to participate in human research studies.

11 Further information and who to contact

We will collect your contact details so that we can communicate with you throughout the study. We will only need your name and email address.

If you would like to contact us, the person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if you have any other concerns, you can contact a member of the study team:

CONTACT DETAILS:	
Name:	Meredith Smith
Position:	Physiotherapist (WCH), Lecturer – Physiotherapy (University of Adelaide) & PhD student
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Email:	Meredith.smith@adelaide.edu.au
Name:	Prof Rachel Gibson
Position:	Director- Allied Health, University of Adelaide
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Name:	A/Prof Ray Russo
Position:	Head of Research – Rehabilitation Department, WCH
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This study has been approved by the Women's & Children's Health Network Human Research Ethics Committee. If you have any complaints about any aspect of this project, the way it is being conducted or any questions about being a research participant in general, then you may contact

Review HREC name:	Women's & Children's Health Network
HREC Executive Officer:	Mr Luke Fraser
Telephone:	8161 6521