

## Participant Information Sheet

(Adult with childhood-onset disability, parent/caregiver, or provider)

**Research Title: Sports Priorities and Objectives for Research & Translation of Youth with childhood-onset disability (the SPORTY project)**

<i>Dr Georgina Clutterbuck</i>	<i>Lecturer</i>	<i>The University of Queensland</i>
<i>Ms Afra Islam</i>	<i>Honours Student</i>	<i>The University of Queensland</i>
<i>Ms Chelsea Mobbs</i>	<i>Director</i>	<i>Little Seeds Allied Health</i>
<i>Mr Joseph Vida</i>	<i>Physiotherapist</i>	<i>Little Seeds Allied Health</i>

Thank you for your interest in participating in this research project. Please read the following information about the project so that you can decide whether you would like to take part in this research. Please feel free to ask any questions you might have about your involvement in the project.

If you decide to participate in this research, please keep in mind that your participation is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to stop at any time, and you would not need to give any explanation for your decision to stop participating. As data will not be identifiable after collection, should you choose to stop participating, any data already collected will continue to be used in the research.

You will be given the Participant Information and Consent Form to sign, and you will be given a copy to keep. Your decision to take part, not take part, or take part and then withdraw, will not affect your relationship with the University of Queensland.

### **What is this research about?**

This research aims to determine the questions that people with childhood onset disability most want researchers to focus on answering. We hope to identify a priority list that will help researchers to choose what research to conduct, and organisations to choose what research to fund. To do this, we are seeking the opinions of people with childhood onset disability, as well as the opinions of their parent/caregivers, and people who provide leisure-time physical activities to people with childhood onset disability. The opinions of parents/caregivers and providers will provide additional context to the information provided by people with childhood onset disability.

### **What will I need to do?**

If you agree to participate in the focus group, you will attend a 60-90 minute group where a researcher will facilitate discussion about leisure-time physical activity research with 4-7 participants. This will occur in a location convenient to participants, or online, using the Zoom platform. The group will be video recorded. No reimbursement for expenses will be provided.

### **What are the possible benefits of taking part?**

By participating in this research, you will have the opportunity to share your thoughts about the type of research that you think should be conducted in the area of leisure-time physical activity for people with childhood-onset disability. There will not be any direct benefit to you for participating in this research.

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

It is not expected that the questions will be distressing, however if you become upset during the focus group, you will be able to take a break at any time. You will be provided with information on who to contact for support if you require this.

**What will happen to the information about me?**

All information collected about you will remain confidential. Data collected for this research will be stored at the University of Queensland. Any hard copy materials will be stored in a locked filing cabinet. All electronic data will be stored on the UQ Research Data management system. Only the research team will have access to the data. Data will be kept for at least 5 years after the research is conducted.

It is anticipated that the results of this research project will be published and/or presented in a variety of forms. In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except with your express permission.

**What will happen if I decide to withdraw?**

Your participation in this research is voluntary and you are free to withdraw from the research at anytime without needing to provide an explanation. You would not receive any penalty or bias as a result of your withdrawal. As data will not be identifiable after collection, should you choose to withdraw, any data already collected will continue to be used in the research.

**Can I hear about the results of this research?**

Infographics presenting the research and translation priorities will be distributed to participants who request this information and provide their contact details, as well as via social media.

Publications will include journal articles aimed at peer-reviewed journals, such as Disability & Rehabilitation and Adapted Physical Activity Quarterly. Conference presentations will include the Asia-Pacific Society for Physical Activity, Australasian Academy of Cerebral Palsy and Developmental Medicine, American Academy of Cerebral Palsy and Developmental Medicine and European Academy of Childhood Disability conferences.

**Who can I contact if I have any concerns about the project?**

This study adheres to the guidelines of the ethical review process of The University of Queensland and the National Statement on Ethical Conduct in Human Research. Whilst you are free to discuss your participation in this study with the researcher contactable on [g.clutterbuck@uq.edu.au](mailto:g.clutterbuck@uq.edu.au), if you would like to speak to an officer of the University not involved in the study, you may contact the Ethics Coordinator on +617 3365 3924 / +617 3443 1656 or email [humanethics@research.uq.edu.au](mailto:humanethics@research.uq.edu.au)

This research Ethics ID number: 2023/HE000091

## Participant Information Sheet (Child)

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Thank you for your interest in this research. Please read the following information so that you can decide if you would like to take part. Please ask any questions you might have about the project.

If you do not want to take part in this research, you do not have to. If you decide to take part and then change your mind, you can stop at any time. You would not need to tell us why you want to stop. If you decide to stop, we will keep the information we have already collected as we would not be able to tell which information was yours.

You will be given this Information Sheet and a Consent Form to sign and you will be given a copy to keep. Your decision to take part, not take part, or take part and then stop, will not affect your relationship with the University of Queensland, or your other activities.

### **What is this research about?**

This research aims to help researchers understand the questions that children with disabilities want them to answer. We hope to make a list of questions that will help researchers to choose what research to do.

### **What will I need to do?**

If you agree to participate in the focus group, you will attend a 60-90 minute group with 4-7 other children where you will talk to a researcher about physical activities like sport. This will occur near where you live or go to school, or online on a video call. We will take a video of this group to help us remember what you say. You will not get paid for this group.

### **What are the possible benefits of taking part?**

By participating in this research, you will help us know what questions that you want researchers to answer about physical activity for children with disabilities. There will not be any direct benefit to you for participating in this research.

### **What are the possible risks and disadvantages of taking part?**

It is not expected that the questions will upset you, however if you become upset, you will be able to take a break at any time. Your parents will be provided with information on who to contact for support after the group if you need this.

### **What will happen to the information about me?**

All information collected about you will only be read by the researchers. We will keep all the information in a locked filing cabinet or on the UQ Research Data management system, which needs a password to access. Only the research team will be able to see your information. Your information will be kept for at least 5 years after the research is conducted.

The results of this research will be presented to other people. Your name will not be included and nobody will know that you participated in the study.

**What will happen if want to stop?**

You can stop at any time without telling us why. As we don't put your name on the information, anything you've already said will still be used in our research.

**Can I hear about the results of this research?**

If your parent/guardian requests the results, we will share the results of this study with you.

**Who can I contact if I have any concerns about the project?**

This study adheres to the Guidelines of the ethical review process of The University of Queensland and the National Statement on Ethical Conduct in Human Research. Whilst you are free to discuss your participation in this study with the researcher contactable on [g.clutterbuck@uq.edu.au](mailto:g.clutterbuck@uq.edu.au) , if you would like to speak to an officer of the University not involved in the study, you may contact the Ethics Coordinator on +617 3365 3924 / +617 3443 1656 or email [humanethics@research.uq.edu.au](mailto:humanethics@research.uq.edu.au)

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