

## Supplementary file 2

Example participant information sheet and consent form

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### Participant Information Sheet

**Project Title:** Supporting the Transition of Children and Young People with a Spinal Cord Injury from Paediatric to Adult Healthcare Services

**Project Summary:** You are invited to participate in a research study being conducted by Ms Emily Bray, PhD student at the School of Nursing and Midwifery, Western Sydney University under the supervision of Associate Professor Lucie Ramjan, School of Nursing and Midwifery, Western Sydney University.

The research aims to explore the experience and needs of children and young people with a Spinal Cord Injury (SCI) in their transition from paediatric to adult healthcare services. The PhD project also aims to co-develop a healthcare transition support tool or resource for children and young people with a SCI.

#### How is the study being paid for?

The SpineCare Foundation has funded this study.

#### What will I be asked to do?

You are being invited to participate in an interview (or upon request a paired interview with another young person with a SCI) that aims to explore your experiences, needs, and expectations regarding healthcare transition and the transfer to adult health services. The interview will be conducted via telephone or videoconference or face-to-face at a time most convenient for you. The interview will be audio-recorded.

Following this, you will participate in a co-design workshop to co-develop a healthcare transition support tool or resource. The workshop will be held in person at the Northcott offices/Western Sydney University or via videoconference. The workshop will be video-recorded and transcribed.

After the tool or resource has been developed you will be asked to provide feedback on the developed healthcare transition support tool or resource. To do this we will ask you to take part in an online videoconference focus group, this will be video-recorded.

Lastly following a period of use, we will ask you to evaluate the tool or resource. The evaluation will consist of an interview conducted via telephone or videoconference at a time most convenient for you. The interviews will be audio-recorded.

### **How much of my time will I need to give?**

It is anticipated that after enrolling, the initial interview will take 30-45 minutes and the co-design workshop will run on a separate day for 60-90 minutes. After the development of a transition resource or tool, the feedback focus group will run for 60 minutes and following a period of resource use the evaluative telephone interview will take 15-20 minutes. In total, participation in this study will be expected to take 165-215 minutes over a staggered time-frame, approximately 12 months.

### **What benefits will I, and/or the broader community, receive for participating?**

The findings of this study will help us provide better support to children and young people with SCI and their families in their transition from paediatric to adult healthcare services. The findings will provide insight into the development of an effective healthcare transition support resource or tool that complements current services and assists in providing children and young people with SCI with the necessary skills to better manage the current transition process.

As thanks for their time and effort, participants will receive three \$20 Westfield vouchers (\$60 total), one at the completion each of the three phases of the study; the initial interview, workshop and focus group, and the evaluative interview.

### **Will the study involve any risk or discomfort for me? If so, what will be done to rectify it?**

It is not anticipated that there will be any risk or discomfort to participants choosing to participate in this study. However, if you do experience any discomfort you are able to withdraw consent or choose not to answer particular questions without any consequence. If required, participants will be offered information on how to contact their local counsellor or be provided with information for accessing counselling via free counselling services including: KidsHelpline: 1800 551 800 Beyond blue: 1300 224 636, or Lifeline: on 13 11 14.

### **How do you intend to publish or disseminate the results?**

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that the participant cannot be identified, except with your permission. i.e. pseudonyms will be assigned to participants to ensure anonymity. Data will be stored securely on a password-protected computer and any physical data will be stored in a secure storage space at Western Sydney University.

**Will the data and information that I have provided be disposed of?**

All data files will be stored for a minimum period of 5 years from the date of publication. After this time, all paper files will be destroyed according to the requirements of Western Sydney University (i.e. destroyed using a shredder). All electronic files will be permanently deleted from the cloud drive and PhD student's computer.

Please be assured that only the researchers will have access to the raw data you provide. However, the same research team and/or another research student may use your data in other related projects for an extended period of time.

**Can I withdraw from the study?**

Participation is entirely voluntary and you are not obliged to be involved. If you do participate you can withdraw at any time without giving reason. You can withdraw via phone or email to Ms Emily Bray or Dr Lucie Ramjan.

If you do choose to withdraw, any information that you have supplied *will be destroyed*. Where participant's information cannot be withdrawn, for example the audio recording of a focus group, the information provided by the participant will not be used in this study or disseminated in any circumstance.

**Can I tell other people about the study?**

Yes, you can tell other people about the study by providing them with the PhD student's contact details. They can contact the PhD student to discuss their participation in the research project and obtain a copy of the information sheet.

**What if I require further information?**

Please contact Ms Emily Bray or Dr Lucie Ramjan should you wish to discuss the research further before deciding whether or not to participate.

**PhD student:**

Ms Emily Bray, School of Nursing and Midwifery, Western Sydney University  
Building EB/LG, Parramatta South Campus  
P: 0416 269 500 | E: [16251104@student.westernsydney.edu.au](mailto:16251104@student.westernsydney.edu.au)

**Supervisor:**

Dr Lucie Ramjan, Associate Professor, School of Nursing and Midwifery, Western Sydney University  
Building EB/LG Room 35, Parramatta South Campus  
P: 96859032 | E: [l.ramjan@westernsydney.edu.au](mailto:l.ramjan@westernsydney.edu.au)

**What if I have a complaint?**

If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through Research Engagement, Development and Innovation (REDI) on Tel +61 2 4736 0229 or email [humanethics@westernsydney.edu.au](mailto:humanethics@westernsydney.edu.au).

Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

If you agree to participate in this study, you may be asked to sign the Participant Consent Form. The information sheet is for you to keep and the consent form is retained by the researcher/s.

This study has been approved by the Western Sydney University Human Research Ethics Committee. The Approval number is H14029.

## Consent Form

**Project Title:** Supporting the Transition of Children and Young People with a Spinal Cord Injury from Paediatric to Adult Healthcare Services

This study has been approved by the Human Research Ethics Committee at Western Sydney University. The ethics reference number is: H14029

**I hereby consent to participate in the above named research project.**

**I acknowledge that:**

- I have read the participant information sheet (or where appropriate, have had it read to me) and have been given the opportunity to discuss the information and my involvement in the project with the researcher/s
- The procedures required for the project and the time involved have been explained to me, and any questions I have about the project have been answered to my satisfaction.

**I consent to:**

- Participate in an interview/paired interview*
- Participate in a co-design workshop*
- Participate in a focus group*
- Participate in telephone interview*
- Having their information audio recorded*
- Having their photo/activities taken/video recorded*

**I consent for my data and information provided to be used in this project and other related projects for an extended period of time.**

**I understand that the information gained during the study may be published and stored for other research use but no information about me will be used in any way that reveals my identity.**

**I understand that my participation in this study will have no effect on my relationship with the researcher/s, and any organisations involved, now or in the future. I understand that I will be unable to withdraw my data and information recorded in the focus group and/or workshop from this project but should I decide to withdraw (before data analysis), this information will not be used.**

**Signed:**

**Name:**

**Date:**

**Return address:** *[please insert the land address]*

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