



## Young Person Participant Information and Consent Form

|                               |   |                      |            |
|-------------------------------|---|----------------------|------------|
| <b>HREC Project Number:</b>   | HREC 2019.135   |                      |            |
| <b>Short Name of Project:</b> | Management of Paediatric Upper Limb Difference  |                      |            |
| <b>Principal Researcher:</b>  | Lisa Robin, Occupational Therapist, Royal Children's Hospital Melbourne (RCH) & Monash University |                      |            |
| <b>Version Number:</b>        | 1.1   | <b>Version Date:</b> | 13/08/2021 |

We are inviting you to take part in an Australia wide project about young people with upper limb difference. This project is a survey about:

- Your experience and satisfaction with services provided for upper limb difference
  - Your experience and satisfaction with products such as prostheses and 3D printed devices
- The project is part of a Masters course at Monash University. The protocol was written by Lisa Robin, occupational therapist at RCH. The study team also includes Kate Gledhill and Dr Mong-Lin Yu, the Masters supervisors.
- You are invited to take part if you are aged 12-20 years old with an upper limb difference. Please discuss this with your parent/guardian and ask for help completing it if you would like to.
- You will need to answer survey questions about
  - The products you have used for your upper limb difference e.g. prostheses, 3D printed devices
  - The services and support you have received e.g. occupational therapy
- If there are any questions that you do not feel comfortable answering, please leave these out. If you feel upset, please ask for support from someone that you trust such as a family member or your GP. Further information and support is available through Head to Health ([headtohealth.gov.au](http://headtohealth.gov.au)) or Beyond Blue 24/7 phone counselling service (1300 224 636).
- To protect your privacy the information collected will be anonymous. It will be stored in a password-protected file for a period of 7 years at the Royal Children's Hospital and at Monash University. Members of the project team will be able to access this information. After this time, the data will be destroyed.
- You can stop taking part in the project at any time, by exiting the survey. However, once you have completed the survey, you are unable to withdraw your answers.



- Complete the survey by clicking on the link below. If you are happy to participate please click 'Start survey', this implies consent.

If you have any questions about the project, you can contact Lisa Robin on 9345 9300. You can also email the researchers at [lisa.robin@rch.org.au](mailto:lisa.robin@rch.org.au).

Thanks very much for your time.

Lisa Robin

Occupational Therapist

Royal Children's Hospital

You can contact the Director of Research Ethics & Governance at The Royal Children's Hospital Melbourne if you:

- have any concerns or complaints about the project
- are worried about your rights as a research participant
- would like to speak to someone independent of the project.

The Director can be contacted by telephone on (03) 9345 5044.