



Parent/Guardian Participant Information and Consent Form

HREC Project Number:	HREC 2019.135		
Short Name of Project:	Management of Paediatric Upper Limb Difference		
Principal Researcher:	Lisa Robin, Occupational Therapist, Royal Children's Hospital Melbourne (RCH) & Monash University		
Version Number:	1.1	Version Date:	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:

- You and your child's experience and satisfaction with services provided for upper limb difference
 - You and your child's 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 have a child aged 0-20 years old with an upper limb difference.
 - You will need to answer survey questions about
 - The products your child has used for their upper limb difference e.g. prostheses, 3D printed devices
 - The services and support they 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) or Beyond Blue 24/7 phone counselling service (1300 224 636).
 - To protect your child's 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.
- Please answer from your child's point of view. If you can ask them for their opinions about upper limb difference. Please skip any questions you feel you cannot answer for your child.

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.

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.