

Project title: National Survey Regarding Amputation / Limb Loss

EXPLANATORY STATEMENT Project ID: 50230

Survey for people in Australia living with amputation or born with a limb difference

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You are invited to take part in this study. Please read this Explanatory Statement in full before deciding whether or not to participate in this research. If you would like further information regarding any aspect of this project, you are encouraged to contact the researchers via the phone numbers or email addresses listed above.

What does the research involve?

If you are living with amputation, were born with a limb difference, or are a partner or carer of a person living with amputation we are asking you to complete an online survey which will take approximately 20 minutes. The survey focuses on your satisfaction with prosthetic products and services in Australia.

The survey can also be completed in hard copy form mailed in the post with a reply paid envelope. At the end of the survey, you will be invited to participate in future interviews or focus groups that may be face to face, or most likely via Zoom or phone.

Why were you invited for this research?

You are invited to participate in this project because you are part of the Limbs 4 Life organisation. As invitations were sent via Limbs 4 Life, the research team does not have your contact details. Limbs 4 Life has sent invitations to all of their mailing list participants, which includes people with amputation, or people born with limb differences, and their partners and caregivers.

Source of funding

Lifetime Support Authority (South Australia) and Limbs 4 Life have funded this project.

- **Consenting to participate in the project and withdrawing from the research**

Option 1 Online survey: you will be asked to tick and indicate that you have understood that completing and submitting the survey indicates you consent to participate in this research project.

- Option 2: Paper-based survey: if you choose to complete a paper-based survey, you will be asked to tick a 'consent' box which explains that posting the survey back to us indicates your consent. Your

data is anonymous. Once you click submit on the survey, or post the paper-based survey back, we will not be able to identify or withdraw your data.

Possible benefits and risks to participants

This project will aim to assist your responses reach a wide audience of people and organisations (anonymously) to help improve the prosthetic products needed to live everyday life in Australia. Your personal details will not be recorded nor will others know you are involved in this project.

There is a risk of discomfort to you in completing the survey, because the survey will ask about the reason for your amputation / limb difference, and your experience in the early stages of prosthetic use.

- **Services on offer if adversely affected**

Lifeline (Australia) 13 11 14: 24/7 crisis support and suicide prevention www.lifeline.org.au

Confidentiality

The survey is presented in a program called REDCap which de-identifies you to keep all survey responses confidential. (The survey will be anonymous).

No AI models will be used in collecting survey responses.

When the results of the survey are presented in reports, publications and conferences, codes and numbers will be used to continue to keep all information anonymous and confidential.

Storage of data

The data will be stored for at least 5 years on secure Monash University servers accessible only to members of the research team (current and future). The data (both hard copies or electronic) will be destroyed when it is no longer required.

Use of data for other purposes

This data will not be used for other purposes.

Results

A summary of the results will be available on the project webpages:

- <https://www.limbs4life.org.au/>
- <https://www.monash.edu/medicine/spahc/rail/research/current-research-projects>

After project completion, full results will be published in a scientific journal.

Complaints

If you have a complaint concerning how this research (Project Number 50230) is conducted, please contact:

Executive Officer

Monash University Human Research Ethics Committee (MUHREC)

Office of Research Ethics and Integrity

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