



EXPLANATORY STATEMENT

Program participants of the Amputee Peer Support Program

Project ID: 14839

Title: The impact of the Limbs 4 Life Amputee Peer Support Program from the perspective of program participants, peer support volunteers and referring health professionals.

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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?

The Amputee Peer Support Program is an early intervention model and provides a vital link for individuals pre or post amputation (and their families) and / or those who undergo reconstructive surgery for the purpose of prosthetic limb fittings. The program works to provide a holistic “whole of family” approach including support for primary care givers and extended support networks.

The aim of this study is to determine the value of the Amputee Peer Support Program on program participants from the view of peer support program participants, peer support volunteers and referring health professionals.

Participating in the study will involve completing a 20 minute survey prior to participating in the amputee peer support program and / or 6 weeks after participating in the amputee peer support program. The survey prior to participating in the amputee peer support program involves completing two quality of life measures. The survey 6 weeks after participating in the amputee peer support program involves completing the same two quality of life measures as well as some questions about your views on the program.

At the end of the survey 6 weeks after participating in the amputee peer support program, participants from Victoria and South Australia will be asked if they would like to also attend a focus group for a deeper discussion on their experiences and views. The 60 minute focus group will be held in a hospital in South Australia or at the Limbs 4 Life offices in Mt Waverley, Melbourne. This is optional.

Why were you chosen for this research?

You were invited to participate in this study because at the time of completing your baseline Limbs 4 Life data an Evaluation of the Amputee Peer Support Program was in process.

"The completion of the Introductory questions provides baseline data for Limbs 4 Life. The collection of this data is considered standard practice for entry into the Amputee Peer Support Program. Completing these questions enables Limbs 4 Life to ensure ongoing quality improvement activities. In addition to Limbs 4 Life quality improvement activities Limbs 4 Life would like to make your responses available to the Limbs 4 Life researchers for the purpose of evaluating the Amputee Peer Support Program. You would remain anonymous throughout and no identifiable data (your name, date of birth, address or contact details) would be provided to the researchers. Your participation would be optional and your decision to approve or decline consent to the research team would not impact your experience or services provided by the Amputee Peer Support Program.

Source of funding

This research project been funded by Limbs 4 Life to cover the salary of two of the investigators.

Consenting to participate in the project and withdrawing from the research

- (i) The consent process involves ticking a box at the start of the survey
- (ii) You (the participant) have the right to withdraw from further participation at any stage. For example, if you complete the survey prior to participating in the amputee peer support program you do not have to then participate in the second survey 6 weeks after participating in the amputee peer support program. This is unless you choose and consent to doing so.
- (iii) At any time during the survey you are able to withdraw by exiting the survey without pressing the submit button. However, it is not possible to withdraw data after pressing the submit button as the project involves the submission of an anonymous survey. As the survey is anonymous, it will not be possible to withdraw data once you have submitted the responses
- (iv) The alternatives available to those who have chosen not to participate include either not completing the survey, or completing the survey but ticking the NO box for the statement " Do you consent to making your de-identified survey results available to Limb 4 Life researchers? YES / NO" and in this case you survey results will only be used for internal Limbs 4 Life quality improvement activities (not research).

Possible benefits and risks to participants

There is no benefit to the participants, however there are possible benefits for future program participants as the program will be modified and / or expanded based on the feedback you provide. There is a potential level of inconvenience to you (the participant) as the survey will take 20 minutes to complete. There are no reasonably foreseeable risks of harm or side-effects to the potential participants.

Payment

There is no payment or reward offered to participants.

Confidentiality

Anonymity of the data will be maintained as no identifiable data will be provided to the researchers. The results of this research will be published in a peer review journal and presented at a conference. In addition, a summary of the results will be published in the "Amplified" newsletter. This is the Limbs 4 Life newsletter that is sent to all current and past program participants. The focus groups will include the use of a third party transcription service to assist with transcribing the data from the focus groups. The third party transcription service will not be provided with identifiable data and they will be required to sign a confidentiality agreement to maintain confidentiality.

Storage of data

Data will be stored on a password protected database at Limbs 4 Life and only the research team and administrators employed by Limbs 4 Life will have access. As the data is being collected as a part of usual care the data will be required on an ongoing basis.

Results

Participants will be able to access a copy of the results via the "Amplified" newsletter. This is the Limbs 4 Life newsletter that is sent to all current and past program participants.

Complaints

Should you have any concerns or complaints about the conduct of the project, you are welcome to contact the Executive Officer, Monash University Human Research Ethics Committee (MUHREC):

Executive Officer

Monash University Human Research Ethics Committee (MUHREC)

Room 111, Chancellery Building D,

26 Sports Walk, Clayton Campus

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Thank you,



Chief Investigator's name

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