Research Project

Impact of the Limbs 4 Life Amputee Peer Support Program

Client Name: Limbs 4 Life
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Prepared By: Alpha Crucis Group

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EXECUTIVE SUMMARY

In Australia, a significant number of people are living with limb loss. Within a 5 year period (commencing 2007), over 35,000 Australians lost lower limbs due to cancer, infection, birth defects, vascular disease and diabetes, with two thirds over the age of 60 (Dillon et al., 2017). While physical rehabilitation is routinely provided post amputation, gaps exist with the provision of psycho-social rehabilitation (Murray and Forshaw, 2013), such as peer support. The provision of peer support from those who have already made positive adjustments to amputation is recommended for all people incurring a major limb amputation (Reichmann and Bartman, 2018), however few receive this service.

Limbs 4 Life is the peak body for people with limb loss and limb deficiency in Australia. The Limbs 4 Life vision is that no amputee goes through the process of limb loss alone and, to support this, access to an organisation that can facilitate their needs. The flagship service for Limbs 4 Life is the Amputee Peer Support Program (the "Program") which commenced in 2005 and this service is the focus of this research project. In early 2016, the Program expanded from a multi-state Program (Victoria, South Australia and Tasmania) into a National Program. The Program is an early intervention model and provides a vital link for individuals' pre or post amputation (and their families), for those who undergo reconstructive surgery for the purpose of prosthetic limb fittings, and for parents and carers of children living with limb deficiency (Limbs 4 Kids program). This research project undertook a program evaluation to investigate the impact of the Program from a referring Health Professionals, Program Volunteers and Program Participant perspective.

Between July 2014 and June 2018, 793 people participated in the Program. This was serviced by 256 Program Volunteers who were trained during this period. The cost of the Program over five years was $631,497 ($AUD 2018/19). This included direct Volunteer training cost, 1:1 program costs and group program costs; indirect costs such as marketing and insurance; as well as in-kind donations of goods and services. Per Program Participant, the cost of the Program was $796; per Program Volunteer, the cost was $2,467.

Thirty-eight Health Professionals, 86 Program Volunteers and 25 Program Participants (13 in the Pre-Program Participant Group and 12 in the Post-Program Participant Group) across Australia participated in the program evaluation by completing a questionnaire about the impact of the Program and their experience with the Program. In addition, there were two Volunteer Focus Groups and one sole interview with a Program Participant. The Program was reported to be of significant benefit and value to all investigated parties. The themes of access to resources and information and the provision of social and emotional wellbeing were identified across all three groups as being significantly important and positively achieved. The sharing of the lived experience between a Program Volunteer and Program Participant provided a sense of belonging and connection and confirmed that the Program Volunteers were in a strong position to understand the challenges faced following an amputation. This assisted the Program Participants in coping with various challenges and possibly eased the adjustment process. The findings highlight benefits in providing peer support and suggest that such support may prove a powerful and inexpensive addition to routine care. The Program Participant quality of life did not change from pre (n=13) to post (n=12) participation in the Program ($p>0.05$), however there was limited data available.

Health Professionals, Program Volunteers and Program Participants were asked to report their willingness to pay for the Program from a number of different perspectives. All three groups presented a similar pattern with a higher willingness to pay for the Health Service (range $113 to $450), NDIS (range $156 to $432) and Private Health Insurance (range $153 to $347), and a lower willingness to pay for the Program Participant (range $23 to $49). It was the Program Participants who most closely approximated the true cost of the Program per Program Participant ($796) with their willingness to pay from the perspective of the Health Service ($450), NDIS ($432) and Private Health Insurance ($347). Limbs 4 Life clearly state that regardless of the actual cost, this will remain a free service to Program Participants.

The Limbs 4 Life Program was evaluated against the Limbs 4 Life Program Framework. Through the questionnaires and the Focus Groups results, the following recommendations are presented for consideration.

1. Consideration could be given to ongoing contact as the Program Volunteers and Program Participants indicated a desire for ongoing 1:1 peer contact with greater support to transition to a group Limbs 4 Life program

Results indicated that Program Participants would like further follow up after their initial contact with a Limbs 4 Life Program Volunteer. Program Volunteer results also indicate that they would like to know how effective their contact was and how the Program Participant is progressing. Consideration could be given to explore if Limbs 4 Life is able to alter its framework and facilitate a Program Participant follow-up phone call to seek out their interest and need in future contact with their original Program Volunteer, another Program Volunteer, or for support to transition to a group program.

2. Consideration could be given to reinforcing current safety standards around Peer Support place of meeting and transference of personal details

According to the Framework, if the meeting is to occur outside the health care facility, the visit must take place in a public venue such as a café or a park. As evidenced within the results, 10% of Program Volunteers reported that they have conducted meetings in private homes. According to the Framework document, a Program Volunteer should hand out generic Limbs 4 Life contact detail cards to Program Participants and any future Program Participant meetings must be organised directly through Limbs 4 Life rather than direct to the Program Volunteer, however 31% of Program Volunteers (n=26/84) have provided Program Participants with their personal details.

3. Consideration could be given towards the recruitment strategy for Program Volunteers to maximise the proportion who are utilised in the 1:1 Program

There was great diversity across the Program Volunteers regarding on how many occasions they had been called upon to provide a service, some experiencing greater than 20 visits and some still awaiting a first visit. It was evident through this program evaluation that variation in Program Volunteer utilisation was influenced by Volunteer availability, Volunteer supply, and that not all Volunteers were appropriate to undertake Peer Support visits post training.

4. A cost recovery strategy could be considered to determine different funding models for the Program based on willingness to pay

The current evaluation explored the cost of the Program to determine the cost per Program Participant ($796). Presently this cost is borne by Limbs 4 Life through fund raising and this is a significant financial liability for such a valid service. Consideration could be given to explore different payment models.

Throughout the program evaluation, there were a number of barriers to the process of implementing this research project. To counter these barriers in future Limbs 4 Life research projects / program evaluations, two methodological recommendations have been made.

i. Across 2018 and 2019, Limbs 4 Life implemented a new administration server to manage data for the organisation. The current research project aligned itself to this new administration server with the intent of dove-tailing the questionnaires from the evaluation into everyday Limbs 4 Life data collection practice. Due to the complexity of the new administration server and delays in the server going live for Limbs 4 Life, the program evaluation was delayed and data transfer from the administration server into a usable research format required additional time from an information technology expert. Due to these barriers, it is unlikely that the questionnaires from the program evaluation will transition into everyday Limbs 4 Life data collection practice.

   Recommendation: Independent research projects / program evaluations using questionnaire methodology could consider using tested administration systems which are purpose built, readily available and allow easy data transfer (such as Survey Monkey).

ii. The questionnaire response rate for the Program Participants of the Program was 10%. While there are many potential reasons for this low response rate, it is hypothesised that a questionnaire around the time of amputation and then again at 6 weeks post amputation may not be appropriate; the questionnaire may have been too long as it contained multiple sections and two quality of life questionnaires (WHO BREF and EuroQOL); and while 85% of the referrals are via the online portal, the email capture rate was low and therefore relied on Health Professionals to administer and return the questionnaire. However, for the 10% who did complete the questionnaire they completed it in full.

   Recommendation: Questionnaires for Program Participants of the Program could be brief, outside of the immediate amputation period and have a robust process for delivery of the questionnaire to and from the Program Participant.

Conclusion: The Program was reported to be of significant benefit and value to Health Professionals, Program Volunteers and Program Participants. The sharing of the lived experience between a Program Volunteer and Program Participant provided a sense of belonging and connection and confirmed that the Program Volunteers were in a strong position to understand the challenges faced following an amputation. The findings highlight benefits in providing peer support and suggest that such support may prove a powerful and inexpensive addition to routine care. Considerations for future iterations of the Program have been presented and these include ongoing 1:1 contact, reinforcing current safety considerations, changes to the recruitment strategy for the Program Volunteers, as well as introducing a cost recovery strategy.

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ACKNOWLEDGEMENTS

Face to face (top) and online (right) Volunteer focus groups discussing the impact of the Amputee Peer Support Program.

Acknowledgement of the valuable contribution from the following people:

- All the Health Professionals, Program Volunteers and Program Participants who were involved in the questionnaires and focus groups
- Ms Melissa Noonan: Limbs 4 Life, CEO
- Ms Leahe Walker: Limbs 4 Life, Administration
- The research team:
    - Ms Sarah Foster: Project Lead (Alpha Crucis Group)
    - Dr Tash Brusco: Project Consultant and Health Economist (Alpha Crucis Group)
    - Dr Narelle Warren: Project Consultant (Monash University; School of Social Sciences)

INTRODUCTION

Title

Impact of the Limbs 4 Life Amputee Peer Support Program from the perspective of the referring Health Professionals, Program Volunteers and Program Participants.

Background

In Australia, a significant number of people are living with limb loss. Within a 5 year period (commencing 2007), over 35,000 Australians lost lower limbs due to cancer, infection, birth defects, vascular disease & diabetes, with two thirds over the age of 60 (Dillon et al., 2017). While physical rehabilitation is routinely provided post amputation, gaps exist with the provision of psycho-social rehabilitation (Murray and Forshaw, 2013). Peer support is a key part of psycho-social rehabilitation. The provision of peer support from those who have already made positive adjustments to amputation is recommended for all people incurring a major limb amputation (Reichmann and Bartman, 2018), however few receive this service.

Limbs 4 Life is the peak body for people with limb loss and limb deficiency in Australia and was founded as an incorporated charity in 2004. The Limbs 4 Life vision is that no amputee goes through the process of limb loss alone and has access to an organisation that can facilitate their needs. The mission is to provide information and access to support and resources for amputees, their families and primary care givers while promoting an inclusive community. The flagship service for Limbs 4 Life is the Amputee Peer Support Program (the "Program") which commenced in 2005 and this Program is the focus of the current research project. Prior to 2016, the Program was only available in Victoria, South Australia and Tasmania with an expansion to a National Program in early 2016.

The Program is an early intervention model and provides a vital link for individuals' pre or post amputation (and their families), for those who undergo reconstructive surgery for the purpose of prosthetic limb fittings, and for parents and carers of children living with limb deficiency (Limbs 4 Kids program). The Program works to provide a holistic "whole of family" approach including support for primary care givers and extended support networks.

To date, there has been an abundance of positive anecdotal feedback from those referring into, volunteering for, and receiving the services of, the Program. In addition, there has been a formal evaluation of the Limbs 4 Kids Program, a separate support program provided by Limbs 4 Life for children and young people with limb difference and their families (Warren N and Field R, 2017). However, the Amputee Peer Support Program has not undergone a formal evaluation. This research project did just this. It undertook a program evaluation to investigate the impact of those referring into, volunteering for, and receiving the service.

METHODS

Purpose of the evaluation

The purpose of the evaluation was to determine the impact of the Program. In doing so this will determine consistency or difference in the positive anecdotal feedback from those referring into, volunteering for, and receiving the services of, the Program.

Another purpose of the evaluation was to demonstrate that financial support for individuals who participate in the Program is justified through the reported impact on Program Participants.

Aims and objectives

This evaluation enabled referring Health Professionals, Program Volunteers and Program Participants to report on their experience with the Program and therefore determine and report on the impact of the Program, what does (facilitators) and does not (barriers) work well within the Program, as well as the cost of the Program.

Project aim

The primary aim of this evaluation was to determine the impact of the Program from the perspective of Health Professionals, Program Volunteers and Program Participants.

Objectives

- To report the impact of the Program on Program Participants.
- To report what does (facilitators) and does not (barrier) work well for referring into, volunteering for, or participating in the Program.
- To report the cost and cost-effectiveness of the Program per Program Participant.

Outputs

1) Objective 1: impact on Program Participants
    a. Output: Report on program utilisation between July 2013 and June 2018 to demonstrate the history of referral into the Program, uptake of the referral by potential Program Participants, average number of 1:1 and group sessions per Participant, and the number of Program Volunteers who commence and complete Volunteer training
    b. Outcome: Report on Program Participant self-reported impact of the Program including quality of life, fear, self-care, body image, and health service utilisation
    c. Outcome: Report on Program Volunteer perceived impact of the Program on themselves
    d. Outcome: Report on Health Professional perceived impact of the Program on themselves and on the Program Participants

2) Objective 2: Program barriers and facilitators (note that the barriers and facilitator questions were both open ended as well as framed against the Program framework to establish fidelity between the framework and the Program as it currently operates)
    a. Outcome: Report on Health Professional self-reported barriers and facilitators to referring into the Program
    b. Outcome: Report on Program Volunteer perceived barriers and facilitators to volunteering for the Program
    c. Outcome: Report on Program Participants perceived barriers and facilitators to participating in the Program

3) Objective 3: cost of the Program
    a. Output: Report on the cost of the Program per Program Participant, including the direct and indirect costs of the Program Volunteer training, administrative support, Program marketing and communication / education, Program Participant resources, hosting group Peer Support sessions as well as in-kind (opportunity) costs.
    b. Outcome: Report the cost-effectiveness of the Program by reporting the incremental cost per Program Participant per quality adjusted life year (QALY) gained through participation in the Program via an incremental cost-effectiveness ratio (ICER).

Parameters of the evaluation

In scope - formative, process and summative evaluation

Formative evaluation: designed to help shape or define the intervention (aligned to Objective 1). This phase of the evaluation was informed by the following data sets:

- The history of referral into the Program
- The number of people who commence Program Volunteer training

Process evaluation: to determine the extent to which a program is being implemented according to plan (aligned to Objectives 2 and 3). This phase of the evaluation was informed by the following data sets:

- The barriers and facilitators questions which were framed against the Program framework to establish fidelity between the framework and the Program as it currently operates to measure if the Program was implemented according to plan
- The cost of the Program per Program Participant
- The cost of the Program per Program Volunteer

Summative evaluation: assessment of the quality, outcomes and outputs of the program to report on the overall impact (aligned to Objective 1). This phase of the evaluation was informed by the following data sets:

- The impact of the Program from the perspective of referring Health Professionals, Program Volunteers and Program Participants
- The Program outputs of referral into the Program, average number of 1:1 and group sessions per Program Participant, and the number of Program Volunteers who commence Volunteer training
- The cost of the Program per Program Participant
- The cost-effectiveness of the Program by reporting the incremental cost per Program Participant per QALY gained via an ICER

Out of scope

- Randomisation of Program Participants
- Cost benefit analysis

Theory of change

The Theory of Change for the Limbs 4 Life Program is reported in Figure 1.

Theory of Change: Amputee Peer Support Program						
Development of the Program Framework	⇨	Potential Program Participants were referred into the Program	⇨	Program Participants participated in the Program	⇨	Participation in the Program had a positive impact on the Program Participants
Stage of Evaluation for the Change Process: Amputee Peer Support Program						
Formative & Process Evaluation	⇨	Formative & Process Evaluation	⇨	Formative & Process Evaluation	⇨	Summative Evaluation

Figure 1: Theory of Change for the Limbs 4 Life Amputee Peer Support Program

Research design

This research project used a program evaluation methodology. This included a combination of a questionnaire pre and post Peer Support visit for the Program Participants, as well as a once-off questionnaire for the Program Volunteers and the Health Professionals who refer into the program. Focus Groups were also conducted for the Program Participants and the Program Volunteer. The Quality of Life measures (EuroQol-5D3L and World Health Organisation BREF) are contained within the Pre and Post Program questionnaire for Program Participants (see Appendices 1-8).

For Program Participants:

As a part of "usual care" for the Limbs 4 Life Program, Program Participants completed a questionnaire Pre-Program which contained two quality of life measures. Still as a part of "usual care", the Program Participants completed a questionnaire Post-Program (6 weeks after the initial 1:1 visit from the Program Volunteer). This contained the same two quality of life measures as well as additional questions asking for feedback on their experience with the Program (see flow chart in Figure 2).

The additional step for this study was a question on the Pre and Post-Program questionnaire stating the following, and then asking for consent:

"Participation in this questionnaire is voluntary and your choice to complete the questionnaire (or not) will not impact the services you receive from Limbs 4 Life. If you complete the questionnaire, the results will be used by Limbs 4 Life for ongoing quality improvement activities. In addition to Limbs 4 Life quality improvement activities, Limbs 4

Life would like to make your questionnaire results available to Limbs 4 Life researchers to complete an evaluation of the Limbs 4 Life Program. No identifiable data will be provided to the researchers (that is, the researchers will not know you name, date of birth, address or contact details). Here is the link to the evaluation explanatory statement (hyperlink). Do you consent to making your de-identified questionnaire results available to Limb 4 Life researchers?" Y/N

The inclusion and exclusion criteria were as follows:

Program Participants of the Limbs 4 Life Program

- People were invited to participate provided they met the following criteria:
    - Referred into the Limbs 4 Life Program between March 2019 to September 2019
    - Adults aged 18 years or older
    - Person has congenital limb length discrepancy, or they have had or are likely to have an amputation
- People were excluded if they did not consent to participation

Program Volunteers of the Limbs 4 Life Program

- People were invited to participate provided they met the following criteria:
    - Volunteer for the Limbs 4 Life Program
    - Adults aged 18 years or older
- People were excluded if they did not consent to participation

Referring Health Professionals of the Limbs 4 Life Program

- People were invited to participate provided they met the following criteria:
    - Had referred a patient, on at least one occasion, into the Limbs 4 Life Program
    - Adults aged 18 years or older
- People were excluded if they did not consent to participation

Consent flow chart for Program Participants prior to Program commencement

The flow chart below (Figure 2) relates to the Program Participants who were invited to participate in the Program with respect to what is usual care versus additional for the evaluation.

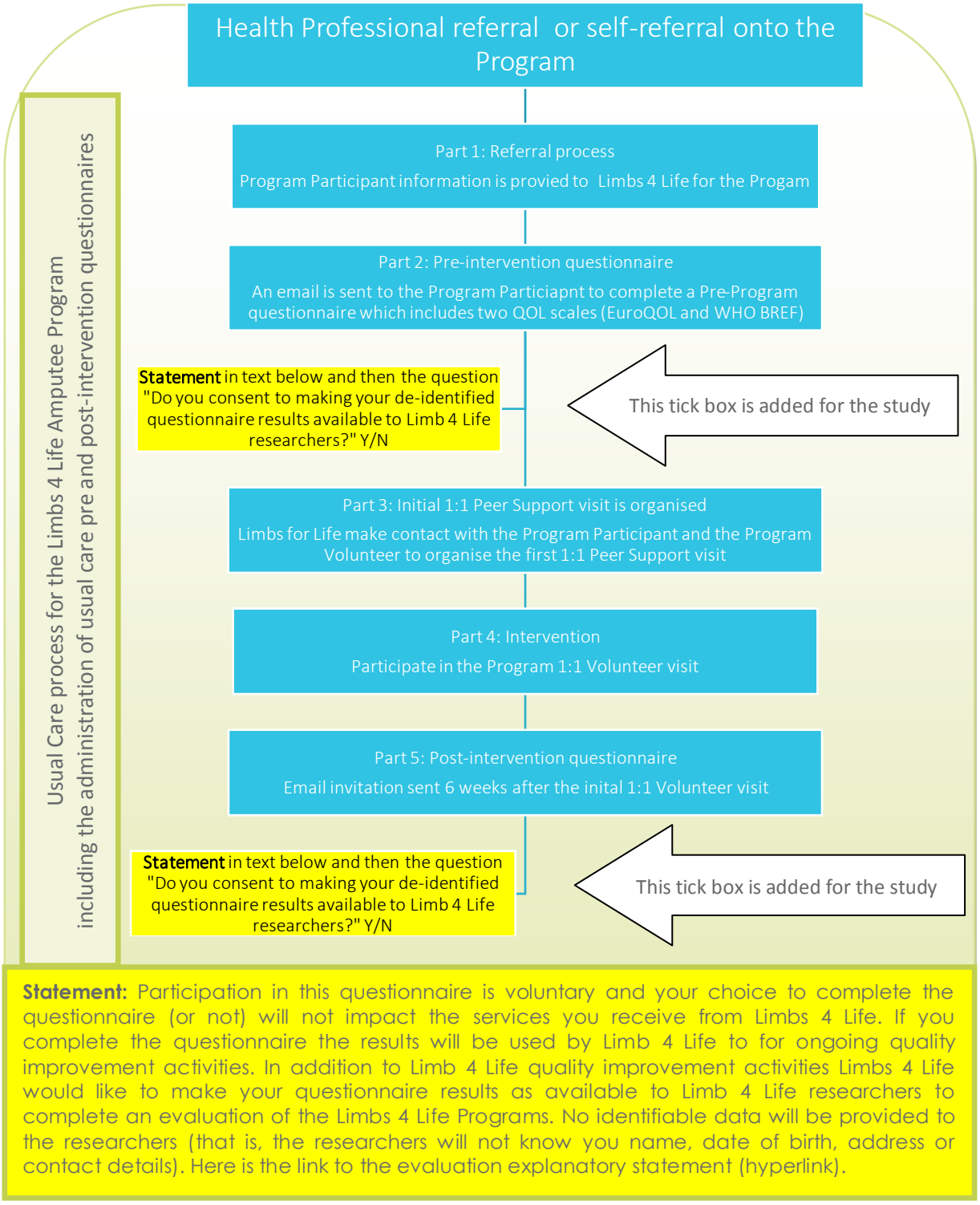

Figure 2: Consent flow chart for Program Participants prior to program commencement

Evaluation design: questionnaires

Participant recruitment

Participant recruitment is detailed in Table 1.

Table 1: Participant recruitment

	Program Participants	**Program Volunteers**	**Health Professionals**
National	March 2019 to September 2019: **Pre-Program Questionnaire:** At the point of referral the Program Participants were sent an email inviting participation in a questionnaire (n=129) **Post Program Questionnaire:** Six weeks after the initial 1:1 Peer Support visit the Program Participants were sent an email inviting participation in a questionnaire (n=129)	Early 2019: **Questionnaire:** Current Program Volunteers were sent an email inviting participation in a questionnaire (n=156)	Early 2019: **Questionnaire:** Referring Health Professionals were sent an email inviting participation in a questionnaire (n=1,450)
Victoria and South Australia	Mid 2019: **Focus group (Appendix 7)** For those who participated in the questionnaire, the final question asked Program Participants from Victoria and South Australia if they would like to participate in a focus group. The study aimed to recruit up to 12 people across two focus groups (n=12)	Mid 2019: **Focus group (Appendix 8)** For those who participated in the questionnaire, the final question asked the Program Volunteers from Victoria and South Australia if they would like to participate in a focus group. The study aimed to recruit up to 12 people across two focus groups (n=12)	

Logic model prior to Program evaluation commencement

Prior to the Program evaluation commencing, a logic model was developed to map the inputs, activities, outputs, benefits and outcomes (Table 2).

Table 2: Logic model to map the inputs, activities, outputs, benefits and outcomes

Inputs	Activities	Outputs	Benefits and Outcomes		
			Short Term	Medium Term	Long Term
Limbs 4 Life team Evaluation team Evaluation framework	Establish the evaluation team and framework Retrieve data from Limbs 4 Life regarding Program utilisation from July 2013 to June 2018	A report of the Limbs 4 Life Amputee Program from the perspective of Program Participants, Program Volunteers and referring Health Professionals	To determine the fidelity of the Program with respect to implementation consistent with the Program Framework	To report the impact of the Program on Program Participants	To demonstrate to funding bodies the value of participation and therefore justify the needs for financial support for individuals who participate in the Program
Questionnaire: Program Participants Focus group: Program Participants	Program Participants: Questionnaire to all Program Participants of the Program (National) pre and post Program participation. Focus group to Program Participants of the Program (Victoria and South Australia)	Qualitative and quantitative data from a Program Participant perspective	Understanding of the impact on the Program Participant as well as the Program Participant experience	Review and modification of the Program to improve Program Participant experience	To increase the number of Program Participants in the Program to maximise the national potential for increased QALYs
Questionnaire: Program Volunteer Focus group: Program Volunteer	Program Volunteer Questionnaire to all Program Volunteers (National) Focus group to Program Volunteers (Victoria and South Australia)	Qualitative and quantitative data from a Program Volunteer perspective	Understanding of the Program Volunteer experience	Review and modification of the Program to improve Program Volunteer experience	Growth in the number and distribution of the Program Volunteers to maximise national access to the program

Inputs	Activities	Outputs	Benefits and Outcomes		
			Short Term	Medium Term	Long Term
Questionnaire: Health Professionals	Health Professionals Questionnaire to Health Professionals who refer into the Program (National)	Qualitative and quantitative data from a Health Professionals perspective	Understanding of the Health Professional experience	Review and modification of the Program to improve Health Professional experience	To provide education to Health Professionals nationally on the Program and how to refer into the Program
Cost data	Cost data Collection of cost data from Limbs 4 Life for all direct and non-direct costs of the Program	Cost data of the Program to report cost per Program Participant. The cost-effectiveness of the Program by reporting the incremental cost per Program Participant per QALY gained via an ICER	Understanding of the direct and indirect costs as well as the cost-effectiveness of the Program	To facilitate financial planning and targeted sponsorship of the Program	To demonstrate to funding bodies the cost of participation and therefore the needs for financial support for individuals who participate in the Program

Assumptions

1. Sample size was based on a sample of convenience.
2. This only represents the perspective of referring Health Professionals, Program Volunteers and Program Participants who have interacted with the Program.
3. This is not a comparison to other programs.

Key evaluation questions

The key evaluation questions are reported in Table 3.

Table 3: Key evaluation questions

	Project evaluation question	Outcome measures	Data Source	Data Collection	Timing and Phase of Evaluation
1	What was the impact of the Program on Program Participants from the perspective of referring Health Professionals, Program Volunteers and Program Participants?	Quality of life (EuroQOL 5D3L; WHO BREF) Health service utilisation Impact of the Program: e.g. fear, self-care, body image	Questionnaire and focus groups	Questionnaires and focus groups (SF and TB)	Data collection period: March 2019 to September 2019
2	Has the Program been implemented and according to the Program Framework?	Description on fidelity between the Program and the Program Framework	Data retrieval from Limbs 4 Life as well as questionnaire and focus groups	Limbs 4 Life (data retrieval from Limbs 4 Life) Questionnaires and focus groups (SF and TB)	Data collection period: March 2019 to September 2019
3	How has the Program been utilised between July 2013 and June 2018?	Program utilisation	Data retrieval from Limbs 4 Life	Limbs 4 Life (data retrieval from Limbs 4 Life)	Data retrieval period: March 2019 to September 2019
4	What were the facilitators and barriers for referring into the Program?	Thematic analysis using the NICS (National Institute for Clinical Studies, 2006) framework	Health Professional questionnaire	Questionnaires (SF and TB)	Data collection period: March 2019 to September 2019
5	What were the facilitators and barriers for volunteering for the Program?	Thematic analysis using the NICS (National Institute for Clinical Studies, 2006) framework	Program Volunteer questionnaire and focus group	Questionnaires and focus groups (SF and TB)	Data collection period: March 2019 to September2019 Focus groups – Mid 2019
6	What were the facilitators and barriers for participating in the Program?	Thematic analysis using the NICS (National Institute for Clinical Studies, 2006) framework	Program Participant questionnaire and focus group	Questionnaires and focus groups (SF and TB)	Data collection period: March 2019 to September 2019 Focus groups – Mid 2019

	Project evaluation question	Outcome measures	Data Source	Data Collection	Timing and Phase of Evaluation
7	What were the costs of the Program per Program Participant and Program Volunteer, and the cost-effectiveness of the Program per QALY?	Cost per Program Participant ICER for cost per Program Participant per QALY gained	Data retrieval from Limbs 4 Life combined with the Program Participant self-reported outcomes via the Program Participant questionnaire	Limbs 4 Life (data retrieval from Limbs 4 Life) Questionnaires (SF and TB)	Data collection period: March 2019 to September 2019

SF and TB = Refers to researchers Sarah Foster and Tash Brusco completing the data collection for these elements

Statistical Analysis

Sample size was based on a sample of convenience for the Health Professionals, Program Volunteers and Program Participants. Quantitative data was reported with a mean and standard deviation, or as a number and percentage, as appropriate. Pre-post scores for the quality of life measures were reported using the mean difference via an independent t-test. The EuroQOL 5D3L raw scores were converted into a utility index to allow calculation of quality adjusted life years (QALYs). Significance was defined at $p<0.05$. The mean cost of participating in the Program was calculated on a per Program Participant basis, as well as on a per Program Volunteer basis. The cost of participating was reviewed in the context of QALYs gained per Program Participant, to report the cost-effectiveness of the Program by reporting the incremental cost per Program Participant per QALY gained through participation in the Program. Qualitative data was presented descriptively and as a count. The barriers and facilitators analysis reported the number of responses (content analysis) from the perspective of the Health Professionals, the Program Volunteers and the Program Participants with the responses then undergoing a thematic analysis.

Questionnaire and focus group tools

Details of the four questionnaires (1: Program Participants Pre-Program, 2: Program Participants Post-Program, 3: Program Volunteers, and 4: referring Health Professionals) and the two focus groups (1: Program Participants Post-Program, and 2: Program Volunteers) are attached to this report as separate appendices (Appendices 1-8).

Evaluation timeframe

The evaluation timeframe is reported in Table 4.

Table 4: Evaluation timeframe.

Timelines						
March 2018 to August 2018		March 2019 to September 2019		September 2019 to November 2019		December 2019
Development of the evaluation framework, establishing the team of evaluators and gaining human research ethics approval	⇨	6 months data collection from multiple data sources: referring Health Professionals, Program Volunteers and Program Participants and Limbs 4 Life administrative data	⇨	Analysis and delivery of the draft report for review by Limbs 4 Life Presentation to the Limbs 4 Life Board at the 2019 AGM (November 2019)	⇨	Delivery of final report

RESULTS

Part 1: Health Professionals

Demographics

Thirty-eight Health Professionals responded to the questionnaire (2.6%, n=38/1,450). Of those who responded, 79% (n=30) were female and the average age was 40.7 years (SD 9.67).

Health Professionals were living in Victoria (n=22, 73%), New South Wales (n=4, 14%) and South Australia (n=4, 13%), based on those who responded to the residency question (Figure 3). Thirty Health Professionals identified living in a Metropolitan region (n=30, 83%) and 6 in Rural/Regional areas (n=6, 17%), with the majority living in Metropolitan Victoria (n=19, 66%).

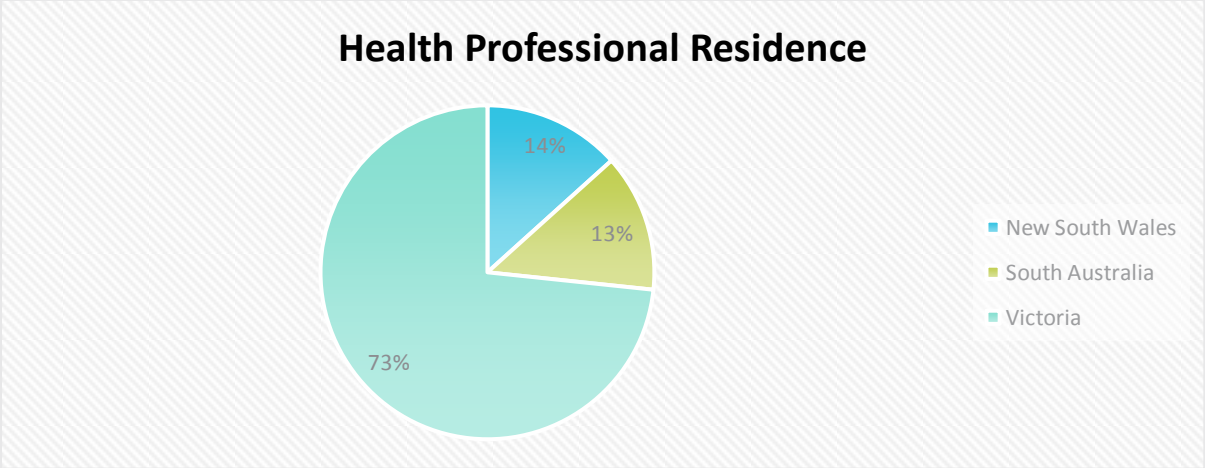

Figure 3: Health Professional Residence

The professions of the questionnaire responders were Allied Health (n=25, 66%), Nursing (n=9, 27%), Medical (n=3, 8%) and Health Service Administrator (n=1, 3%) (Figure 4). Two thirds (n=23, 62%) indicated greater than 10 years' experience in their chosen Health Profession (Figure 5).

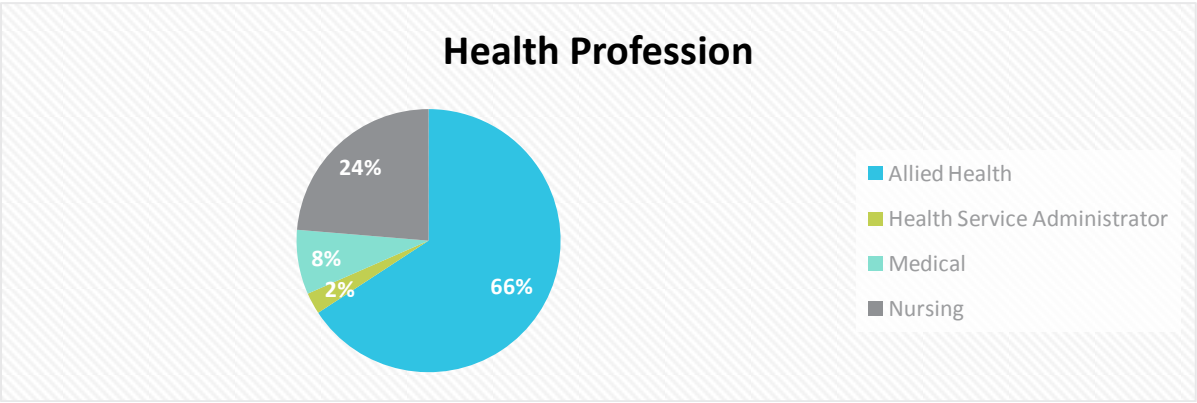

Figure 4: Health Profession

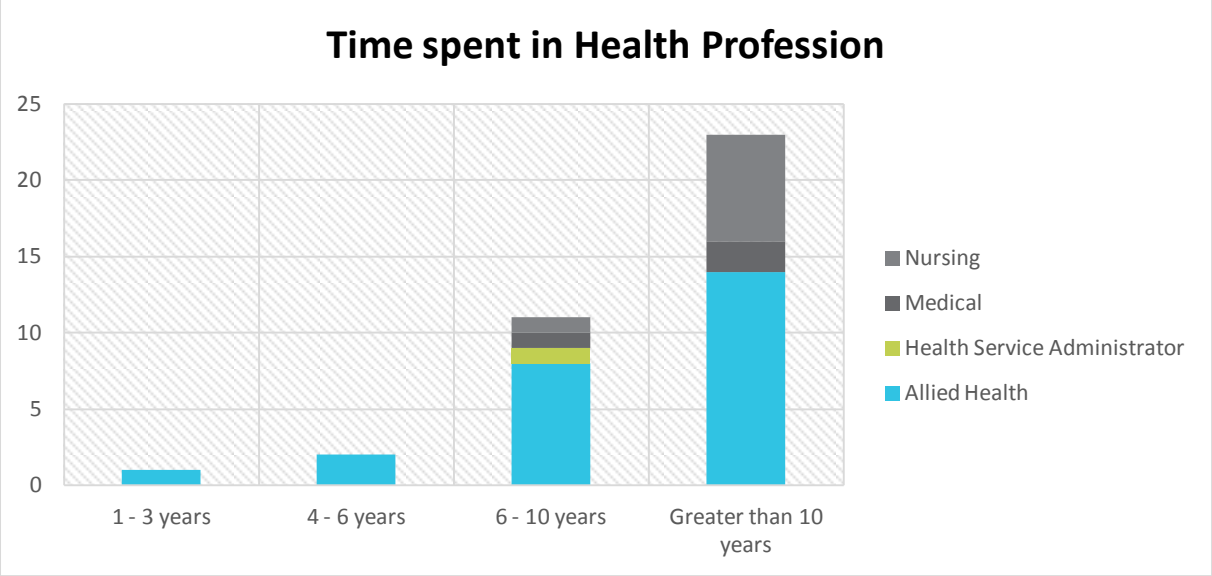

Figure 5: Time spent in Health Profession

While 39% (n=23) of respondents indicated greater than 10 years' experience working with the amputee population (Figure 6), the time spent referring into the Program was most commonly between 1-3 years (n=14, 38%) (Figure 7).

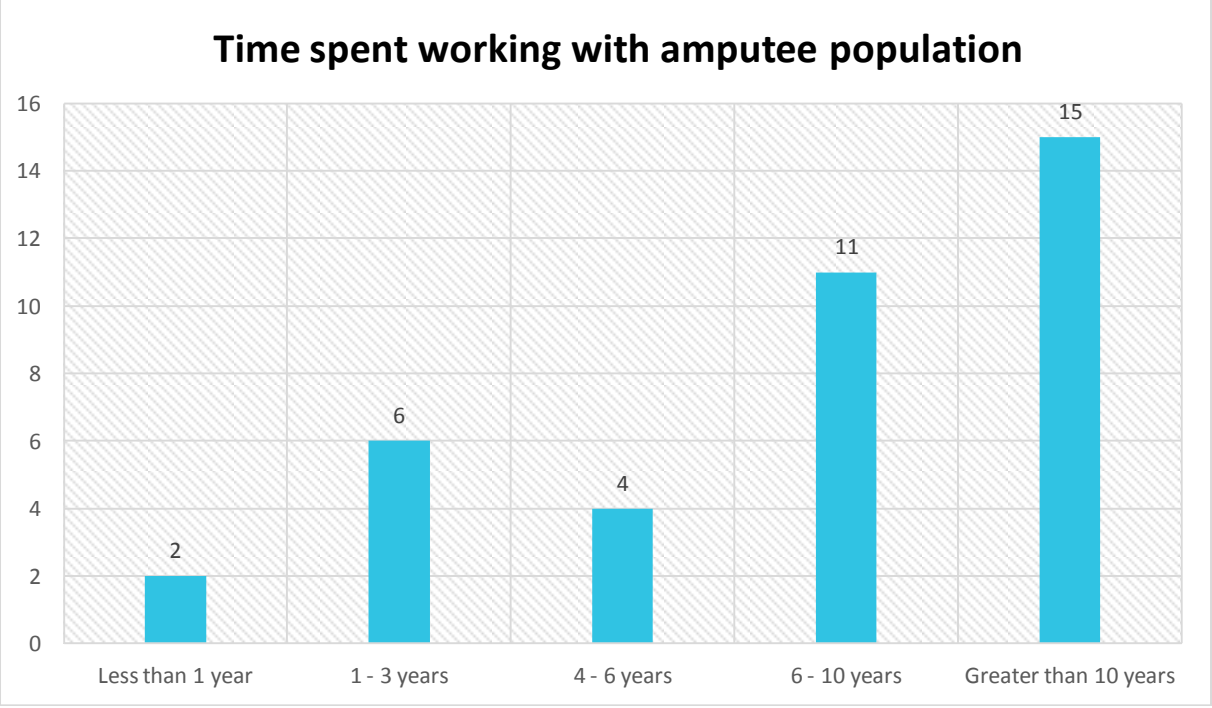

Figure 6: Time spent working with amputee population

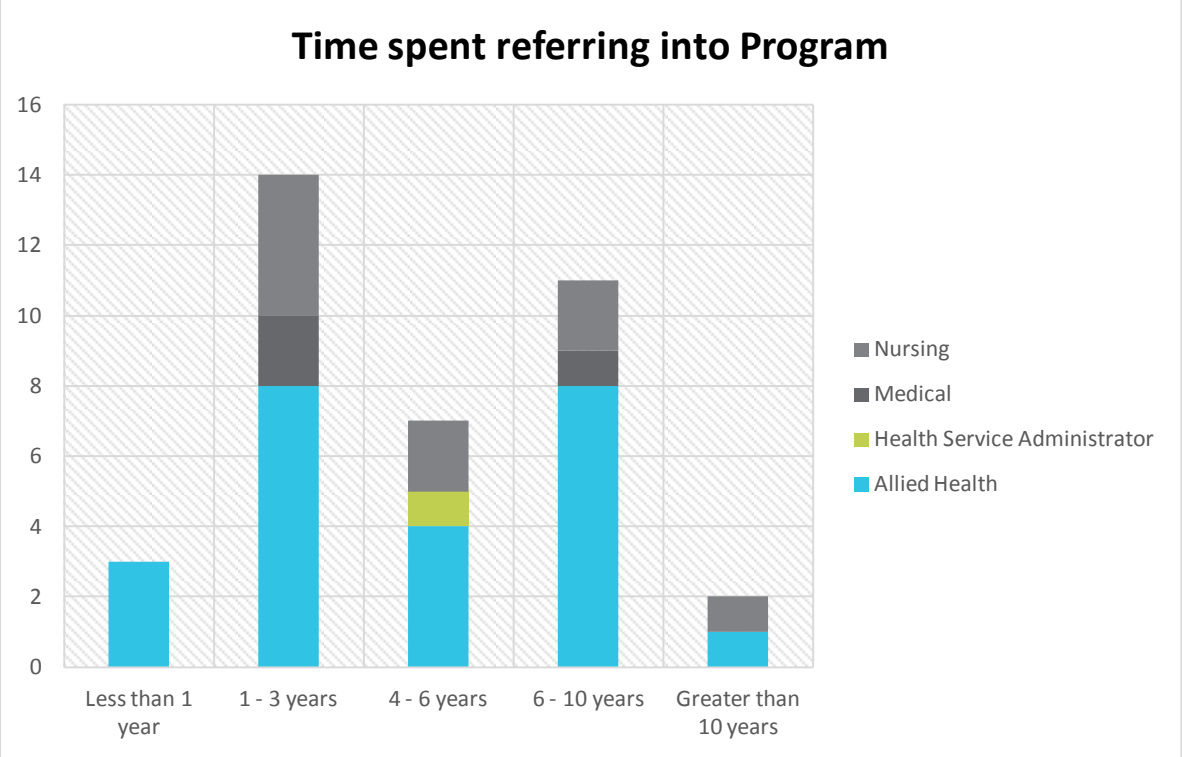

Figure 7: Time spent referring into Program

Referring into the Program was consistently done via online portal (n=18, 34%), email (n= 14, 27%) or via phone (n=13, 25%) (Figure 8), with the majority of Health Professionals having referred less than 10 patients into the Program (n=21, 55%) (Figure 9).

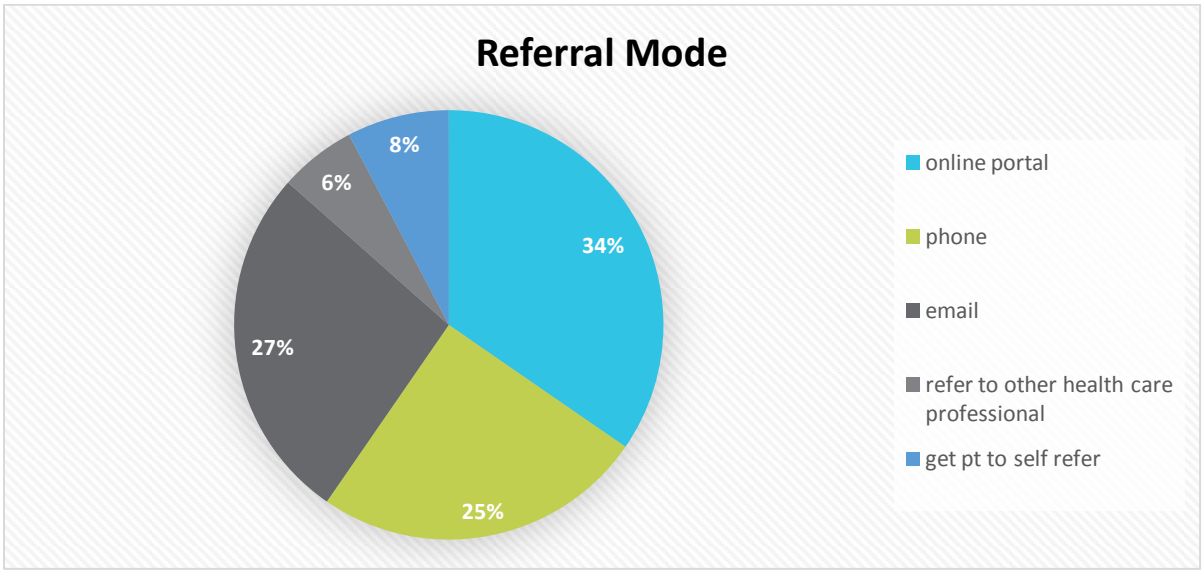

Figure 8: Referral Mode

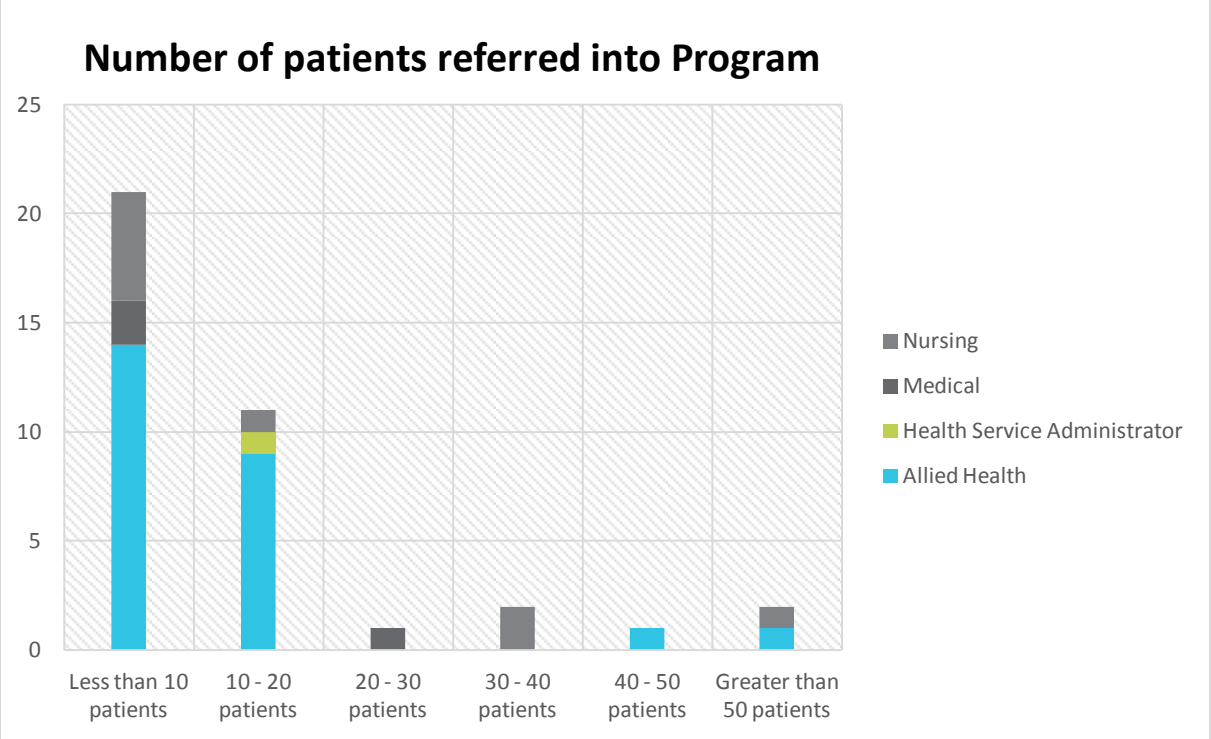

Figure 9: Number of patients referred into Program

Impact of the Amputee Peer Support Program

To understand the intended impact of the Program on the Program Participants, the Health Professionals were asked why they referred into the program. There were a total of 71 responses and the most common theme was centred on **Access** (n=39, 55%), which included sub themes of general access to the Program (n=26, 37%) and access to resources and information (n=10, 14%). The second most common theme was **Social and Emotional Wellbeing** (n= 22, 31%), which included responses detailing emotional support (n=9, 13%) and hope for the future (n=7, 10%). Specific comments from Health Professionals are presented in Text-box 1 below.

Text-box 1: Reasons for referring into the Program

Access
"Safe, efficient and a useful resource. Peers can answer the questions I can't."
"Patients struggling to come to terms with amputation or with many questions about life as an amputee. Have had good feedback from those we have referred in past. Also familiar with some of the past patients who have gone on to become peer mentors."

Social and Emotional Wellbeing
"Support and reassurance for patients"
"Mainly for new amputees who are needing further information or simply to meet someone else in a similar situation to give assurance they are not alone in their journey and looking for a little hope in a difficult situation."

Health professionals were asked to identify what impact the Program had on them, if any. There were 39 statements and **Access** (n=17, 44%) was the most common themed response with access to resources and information (n=11, 28%) predominantly mentioned. Respondents also identified **Support for Health Professionals** (n=16, 41%) was important to them and had impacted upon them (Text-box 2).

Text-box 2: Impact of Program on Health Professionals

Access
"It had been difficult to maintain a local area peer support group. It is great to be able to access this resource when required."
"A useful resource to be able to offer to patients through lived experience. Being a non-amputee person, I am not able to relate to patients through my own life and therefore find that having a peer support person helps patients with their adjustment."

Support for Health Professionals
"It has helped support the information I and my team provide to the patient."

"Great support and back up from Program that works alongside the 'medical' process of the hospital. Patients routinely remark at how helpful and supportive having a support visit was."

Health Professionals were asked to reflect on the Impact of the Program on their patients (Text-box 3). There were 42 responses, again with the most common theme being **Access** (n= 18, 43%). All Access themed responses (n=18, 100%) centred on access to information and resources, and access to the amputee community. **Social and Emotional Wellbeing** was also identified as a theme (n=14, 33%) with sub themes of emotional support and hope for the future representing 100% of responses (n=14). **Peer Support** as a standalone theme was also noted (n=8, 19%).

Text-box 3: Perceived Impact of Program on Patients

Access
"It's a fantastic initiative. I think it gives them a lot less sense of being alone. So much more powerful than being given general information by a Prosthetist. Gives patients hope."
"Feeling connected to other amputees. Feeling more informed of their options and what they face during an anxiety provoking time."

Social and Emotional Wellbeing
"Ability to show patients that others have managed to get on with their lives and return to the community in work, family, social capacities."

Peer Support
"Patients feel comfortable talking to a peer support person. They have time to talk about their own experiences as an amputee. As health professionals, we cannot describe how it feels to have an amputation so the patient tends not to discuss how they are feeling with us. When the patient chats to a peer support person, you can see a huge weight of concern released from them."

Forty-one comments were noted by Health Professionals regarding their expectations of the Program (Text-box 4). These comments identified a principle theme of providing **Peer Support** to their patients (n=26, 63%) followed by **Access** (n=9, 22%) with the sub themes of access to resources and information, and availability of Program Volunteers accounting for 100% (n=9) of these comments. Of the 37 Health Professionals who responded to this question, 35 indicated that their expectations of the Program had been met (n=35, 95%) and 2 indicated that their expectations were not met (n=2, 5%) (Text-box 4).

Text-box 4: Health Professionals expectations of the Program

Peer Support
"Support provided to clients from a first-hand experience of another amputee."
"That appropriately matched experienced amputees would be linked up with my patients, and that arrangements would be made for them to make contact/communicate with my patients. That interactions would be positive and helpful."

Access
"That a reasonably matched [person] (within bounds of available Program Volunteers) would be found to come and visit with my patient to simply give insight into their own experience and therefore give some expectations of what the new amputee might expect or encounter."
"To connect clients with resources, support and training."

Expectations met
"That appropriately matched experienced amputees would be linked up with my patients"
"To link patients with emotional supports and other people that they can relate to."

Expectations not met
"Haven't directly referred for a number of years. Think need awareness in the acute setting"

Facilitators and barriers for Health Professionals referring into the Amputee Peer Support Program

Health Professionals were asked to identify what worked well for them (Text-box 5). There were 42 extended responses that could be themed into **Support for Health Professionals** (n=18, 45%) where ease of referral was the prominent sub theme (n=10, 24%), **Access** (n=16, 38%) where direct access to the Program was the main sub theme (n=14, 33%), and **Peer Support** (n=6, 14%).

Text-box 5: What worked well for Health Professionals

Support for Health Professionals
"Easy to refer into. Very responsive to request."
"Easy communication with Limbs for Life Team. Easy to use website."

Access
"The availability of the program to refer or inform patients and other health care professionals."
"Knowing that Limbs4Life are there to help out. Their resources are fantastic and have always arrived on time whenever I have ordered something. Their resources are very practical and useful."

Peer Support
"Knowing that the responsibility to find appropriate amputee peer support people was able to be safely handed on. Also, knowing that the Program Volunteers are trained and willing."

Health professionals were asked what did not work well for them in referring into the Program and 21 comments were noted. These were themed to represent barriers concerning **Access** (n=11, 52%), with accessing Program Volunteers the main sub theme (n=6, 29%), and **Support for Health Professionals** (n=7, 33%), with ease of referral indicating issues (n=5, 24%) (Text-box 6).

Text-box 6: What did not work well for Health Professionals

Access
"Still limited local network of peer support providers so access to support via phone is perceived to not be as effective as the opportunities for face to face meetings."
"Sometimes mismatch of levels and ability or mismatch of available component to client."

Support for Health Professionals
"Some feedback or at least acknowledgement of receipt of referral plus notification that a volunteer visit has actually occurred would be greatly appreciated."
"Sometimes difficult to input patient information on behalf of patient as an external referrer (e.g. patient contact details and DOB etc…) if patients are unable to give consent (ICU admissions etc). I try to refer as early as possible to make sure that L4L are aware of the patient for planning purposes. Also, currently unable to see if a patient has already been referred."

Health Professionals were asked to discuss whether they thought the referral process was straight forward. Thirty-eight comments were noted with 84% (n=32) agreeing that the referral process was straight forward. The remaining 6 comments stated they have not referred as yet (n=3, 8%), information given to patient only (n=2, 5%) and one individual who found the referral process difficult (n=1, 3%).

There were 35 responses from Health Professionals when asked if they were easily able to access the annual Limbs 4 Life in-service at their Health Service (Text-box 7). Twenty-one people (n=21/35, 60%) indicated that they either did not know about the in-service or found it difficult to access. Twelve individuals indicated that the in-service was easy to access (n=12/35, 34%), and a "not applicable" was indicated by 2 respondents (n=2, 6%).

- Data from the Limbs 4 life Administration system indicates that, in 2019, there were 23 occasions of face to face Health Professional education provided by Limbs 4 Life staff to various Health Services nationally, with a total of 547 Health Professionals in attendance (average attendance was 24 Health Professionals per session). This indicates that only 23 Health Services requested education. This is despite all Health Professionals on the Limbs 4 Life database (n=1,450) being contacted via email at the

start of 2019 with an update on the Program and invitation to book in an education session to be provided by Limbs 4 Life staff.

Text-box 7: Accessibility of Limbs 4 Life In-service

Access - Difficult
"No, wasn't aware there was one."
"NSW not linked in at health service level."
"Perth in WA is limited in their access to Limbs-4 Life training and support."

Access - Easy
"Yes, we are close to the CBD so it was easy."
"We have recently had L4L come to our ward- now set up as a regular visit."

The South Australian Health Professionals were asked if they were aware that the Amputee Rehabilitation Guidelines in South Australia recommend that patients are referred to the Limbs 4 Life Program or another Program. Of the 4 South Australian Health Professional Participants, 50% (n=2) indicated Yes and 50 % (n=2) No.

Implementation according to the Peer Support Framework

There were three points within the Limbs 4 Life framework document that were relevant to Health Professionals and could be examined through the Health Professional questionnaire.

The framework stated that a referral may be generated through a number of pathways: online via the Limbs 4 Life website, by email or by phone. The questionnaire responses from the Health Professionals confirmed consistency in this practice (n=45/52, 87%). The remaining seven responses indicated patients were being encouraged to self-refer or referrals being directed to additional Health Professionals to complete.

The framework indicates that allied healthcare staff and medical professionals are kept informed of current programs and services, and that Limbs 4 Life offers yearly invitations to in-service sessions. Recipients of these sessions are then provided with marketing and education material. As referenced above, a large proportion (60%) indicated that they were unaware of the educational sessions or found them difficult to access.

The Framework suggests that a successful Peer Support outcome greatly depends on the ability to match each individual to a Volunteer based on several key criteria. Through the question asking about the expectations of the program by the Health Professionals, it was reported that the matching process was successful most of the time.

Part 2: Program Volunteers

The following section includes results from the questionnaire and the focus groups. For each section, the questionnaire results are presented first, followed by the focus group results. The focus group results are structured to show consistency or discrepancy with the questionnaire results, with quotes presented to substantiate these findings and expand on the questionnaire results.

Demographics

Eighty-Six Program Volunteers responded to the questionnaire (55%, n=86/156) and 33% (n=28) were female. The average age of respondents was 59.2 years (SD 13.7).

Program Volunteers were living in Victoria (n=33, 39%), South Australia (n=16, 19%), New South Wales (n=13, 15%), Western Australia (n=9, 11%), Queensland (n=6, 7%), Tasmania (n=4, 5%) and Australian Capital Territory (n= 4, 5%) (Figure 10). One respondent did not answer this question. Of the Program Volunteers who responded to living in either a metropolitan or rural / regional area, 48 identified Metropolitan (n=48, 59%) and 34 Rural/Regional areas (n=34, 41%), with the majority living in Metropolitan Victoria (n=16, 20%).

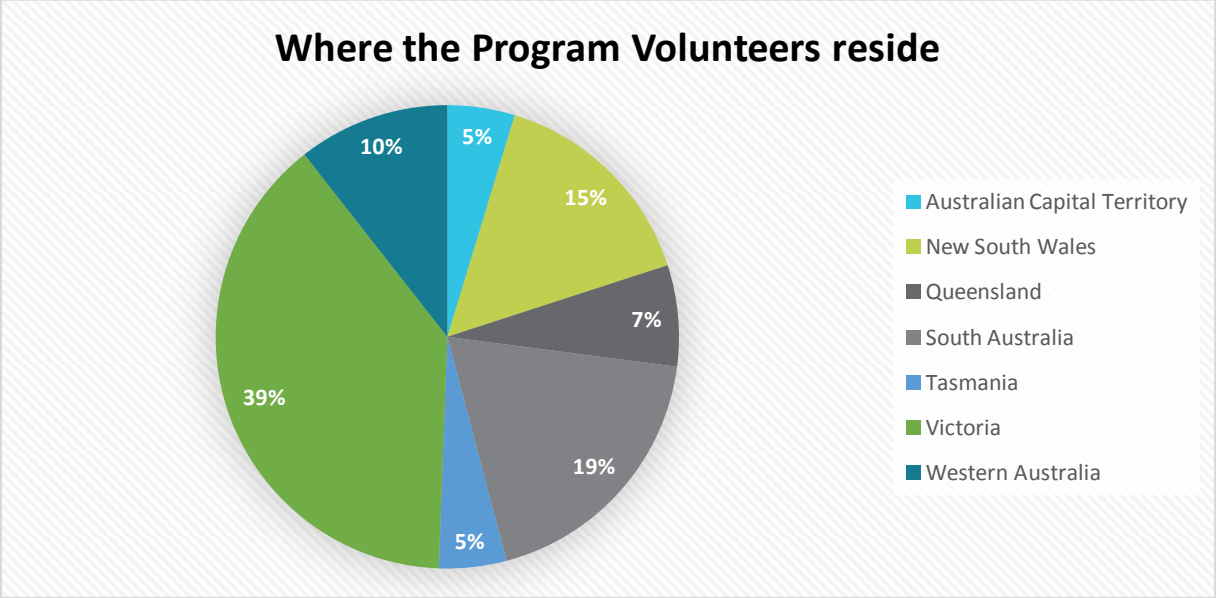

Figure 10: Where the Program Volunteers reside

The Respondents were asked to detail why they became involved as a Program Volunteer. There were 108 responses and the most common theme that evolved was **Rewarding Experience for Program Volunteers** (n=61, 56%) with sub themes of To Give Back and Rewarding for Volunteer representing all of the count. The second most common theme was **Social and Emotional Wellbeing** (n=24, 22%) with sub themes of Emotional Support (n=10, 9%) and Hope for the future (n=10, 9%) (Text-box 8).

Text-box 8: Why did you become involved as a Program Volunteer?

Rewarding Experience for Program Volunteers

"To give back to an amputee in a fairly difficult environment."

"I always wanted to give back to others. Although I received no visits from amps whilst I was recovering, it was an article in a Limbs for Life mag that motivated me. It showed I could get back into golf which I thought was a lost cause. I wanted to spread my fairly positive attitude to others as there is nothing like seeing someone else with a similar or worse disability getting on with life."

"I enjoy people. Retired, but independence regained following amputation. Wanted to return the support I'd received. Personal and professional experiences in teaching, palliative care, grief, death of a son, and aged care indicated I may have skills which could benefit others. Much admiration for indefatigable Melissa and the purpose of L4L."

Social and Emotional Wellbeing

"I wanted to help other people going through a similar experience to help make it more understandable and give them some hope of an improved life ahead."

"I have been an amputee for over 20 years and well remember that there wasn't anyone to talk to when I became an amputee which meant I was left to find my own way for some time."

The majority of respondents identified that they had been volunteering in the Program for 1-2 years (n=33, 38%) (Figure 11). Of these respondents, the majority indicated that the timeframe between their own amputation and their Program volunteering was 5 years or greater (n=35, 41%), followed by 3-4 years (n=21, 25%) (Figure 12).

- Data from the Limbs 4 life Administration system indicates that of the current 141 Program Volunteers, there is an average of 15 years (range 1 to 58 years) from time of amputation to time of commencement as a Program Volunteer, with 13 Program Volunteers (9%) commencing 1 to 2 years post amputation.

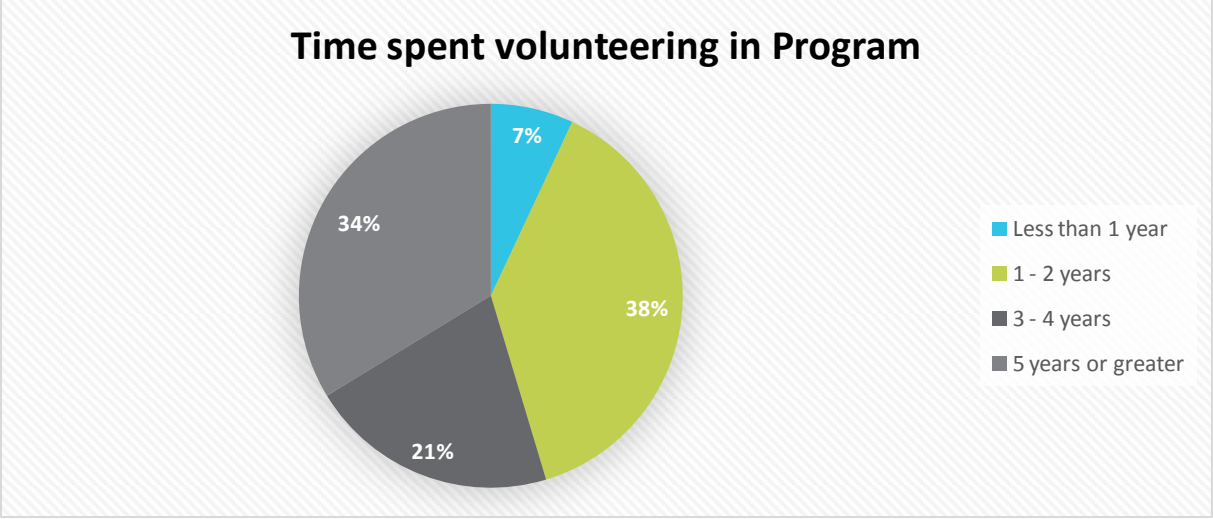

Figure 11: Time spent volunteering in Program

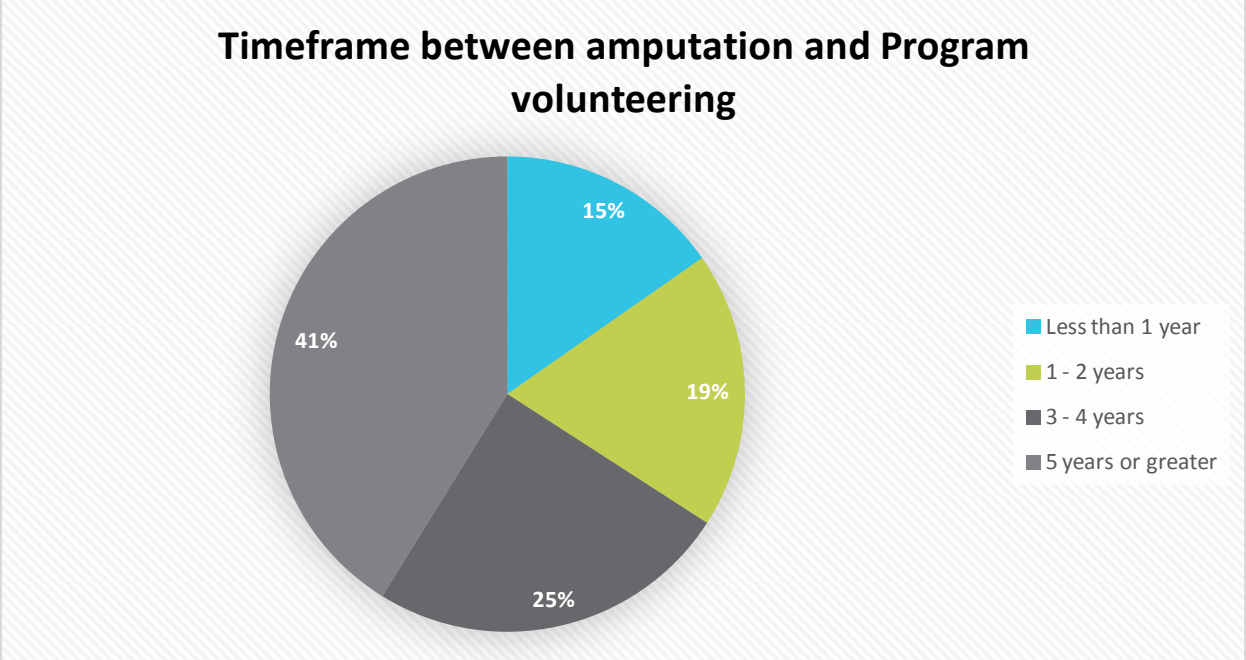

Figure 12: Timeframe between amputation and Program volunteering

The Program Volunteers were asked what types of sessions they have participated in where the responses included 1:1, group or both. The majority indicated 1:1 support sessions (n=50, 61%), followed by both (1:1 and group) (n=19, 23%), then group sessions only (n=13, 16%) (Figure 13). The preferred mode of support deliverance was face to face communication with the Program Participant (n=75, 88%), followed by phone call (n=9, 11%) and email (n=1, 1%).

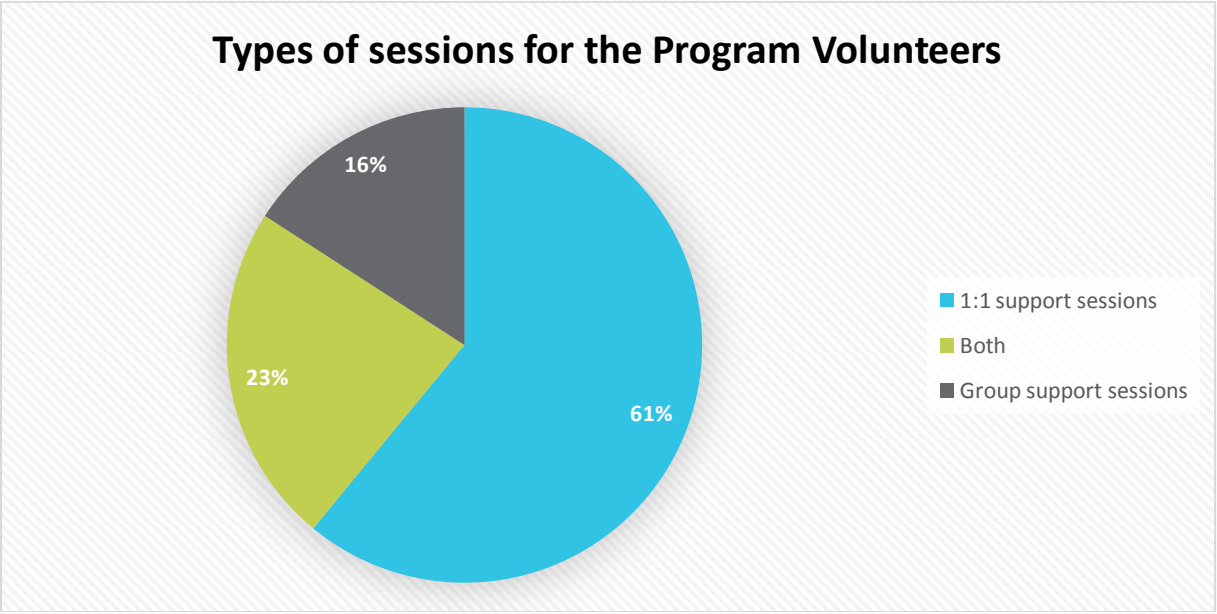

Figure 13: Types of sessions

Focus group responses

Two Focus Groups were held for the Program Volunteer cohort. One Focus Group was face to face and involved 3 Program Volunteers and the second Group was via video link and involved 4 Program Volunteers. As there was consistency in the nature of the responses, the results were analysed collectively. In total there were 6 males (n=6/7, 86%) and 1 female (n=1/7, 14%). Compared to the completed questionnaires there was a definite discrepancy in the male/female ratios with a higher ratio of males in the focus group. The average age of the Focus Group contributors was 61.9 years (SD=11.0). This remained consistent with those who had completed the questionnaire.

The Focus Group was offered to only those Program Volunteers from Victoria and South Australia. Eighty-Six percent (n=6/7) resided in Victoria and 14% (n=1/7) resided in South Australia. The sole participant from South Australia was male. Five (n=5/7, 71%) Program Volunteers lived in Metropolitan areas and Two Program Volunteers (n=2/7, 29%) lived in Regional/Rural areas. These focus group residential demographics were consistent with the demographics from the Program Volunteer questionnaires.

Of the 7 Program Volunteers in the Focus Group, 43% (n=3/7) had been volunteering for 3-4 yrs, 29% (n=2/7) for 1-2 yrs and 29% (n=2/7) for >5 yrs. These results were not representative of the questionnaire responses where the most common response was 1-2 years (38%).

All Program Volunteers (n=7/7, 100%) indicated that they only provided 1:1 support sessions. The types of sessions Program Volunteers participated in were also not representative of the questionnaire responses where 61% only provided 1:1 sessions.

Impact of the Amputee Peer Support Program

To understand the intended impact of the Program on the Program Participants, the Program Volunteers were asked what impact the Program had on them, if any. Of the 107 responses, **Rewarding Experience for Program Volunteers** was the dominant theme (n=54, 50%) with Rewarding for Program Volunteer (n=50, 48%) sub theme standing out. Responses supporting the theme of **Social and Emotional Wellbeing** was the second most common outcome (n=26, 24%) with sub theme of Emotional Support Impacting Program Volunteers (n=15, 14%) (Text-box 9).

Text-box 9: Impact of Program on Program Volunteers

Rewarding experience for Program Volunteers

"The program has given me a boost in self-esteem and pride that I am able to help new amputees in their journey."

"Volunteering is most rewarding. A feeling of satisfaction of helping a person with a similar disability or likelihood of becoming an amputee."

Social and Emotional Wellbeing

"A sense of helping other folk at a difficult time in their life. A visit with an amputee was an excellent help for me so I was happy to do likewise for other people."

"There are people out there worse off than you are. Being able to help people is a wonderful feeling. I wish that peer support was available when I had my leg amputated 40 years ago."

Program Volunteers were then asked to reflect on their expectations of the Program. There were a total of 94 responses. For the common theme supporting **Social and Emotional Wellbeing** (n=58, 62%), the majority of comments fell under the sub theme of Emotional support (n=45, 48%). **Access** (n=28, 30%) was the second most common theme with expectations of Access to the amputee community (n=15, 16%) and Access to resources (n=9, 10%) proving strong sub-themes. Eighty-One Program Volunteers responded to the question of whether their expectations of the Program were met (Text-box 10). Ninety percent (n=73) indicated that their expectations of the Program had been met and 10% (n=8) indicated that expectations were not met.

Text-box 10: Expectations of the Program

Social and Emotional Wellbeing

"To be able to assist people who are facing amputation and to show them that life is pretty good on the other side. For example - losing a limb isn't the end of the world. To answer questions I would have liked to ask someone before I had my limb amputation."

"Being able to share my own experience of becoming an amputee, showing them that they will be able regain their mobility and independence and helping them to cope with the life changing aspects of limb loss."

Access

"To be able to meet new amputees, share experiences and show that life is not over because of the loss of a limb."

"To be able to provide relevant information (documents provided by the Limbs4Life Program) re. seeking assistance etc and to share my personal experience and answer questions to the best of my knowledge and / or provide contacts of who can assist."

Focus group responses

When discussing the expectations of the Program for the Program Volunteers, the Focus Group results were consistent with the results of the questionnaire, primarily supporting the Emotional and Social Wellbeing of the individual and the Program Volunteer and being able to provide information and access to a service to individuals and their families via their lived experience.

Examples of Focus Group quotes to evidence this point include:

> "I wanted to help support people exactly like Mel had done for me, which was just be available and talk and answer questions. I was so grateful for what she'd given me, I wanted to give back when I was in a confident state. I wanted to show people there is life after amputation, and independent and self-sufficient".
>
> "To get enjoyment out of the process and give back".
>
> "Re-assuring both the families and patients that you have a whole life ahead of you. You're about to thrive".

Experience with the Amputee Peer Support Program

The Program Volunteers were asked how they were recruited into the Program. There were 85 responses with the majority (n=47, 55%) personally wanting to give back to the Program and independently offering their services. Other modes of recruitment included via Health Professional suggestion (n= 8, 9%) and via posters in clinic (n=8, 9%) (Figure 14).

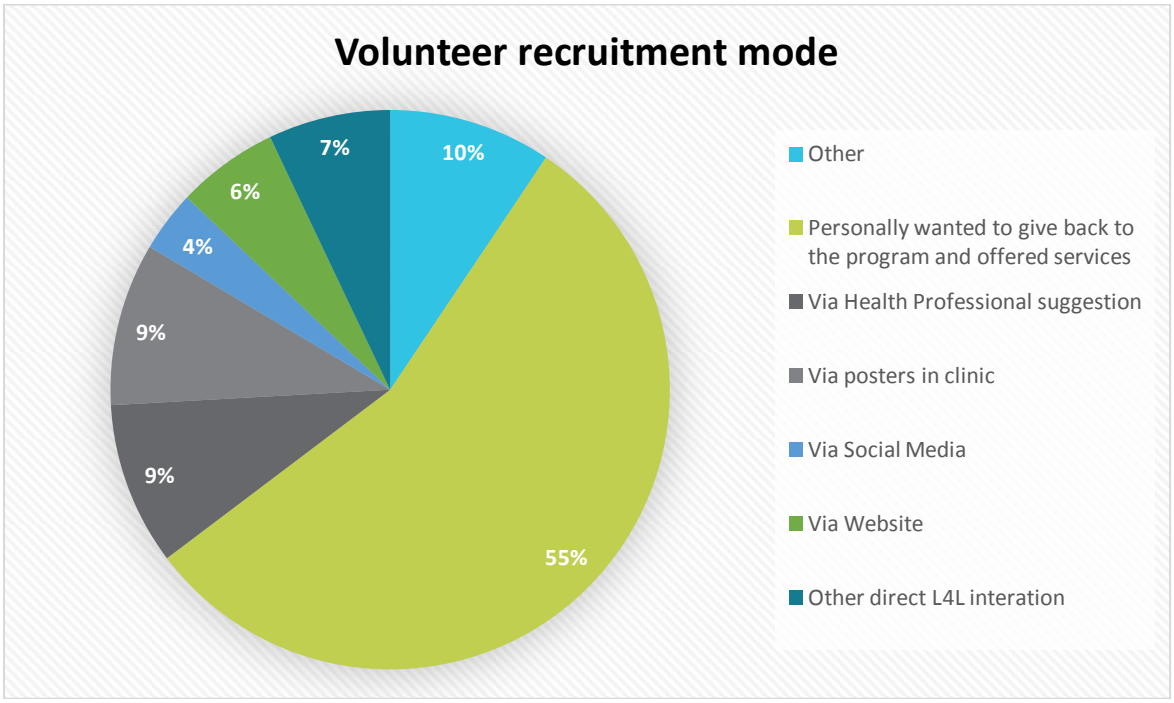

Figure 14: Volunteer recruitment mode

Ninety percent of Program Volunteers (n=73/81) indicated that participating in the Program gave them access to an organisation that understood their unique experience. Eight Program Volunteers (n=8/81, 10%) indicated that participating in the Program did not enhance their access to an organisation that understood their experience.

Ninety percent of Program Volunteers (n=73/81) believed that the matching process for Program Volunteers and Program Participants was successful. Ten percent (n=8/81) believed that the process was unsuccessful in matching important criteria between the Program Volunteer and Program Participant. Of those Program Volunteers that responded 89% (n=71/80) indicated that the matching process enhanced their experience. Nine Program Volunteers (n=9/80, 11%) did not feel that the process enhanced their experience.

Program Volunteers were asked to reflect on whether they had ever required debriefing or support following a Program Volunteer visit. Of the 83 responses, 83% (n=69) indicated that they have not required debriefing or support whereas 17% (n=14) answered yes, they had required assistance. Of those who required debriefing or support, 92% (n=12) indicated that this was provided. One Program Volunteer (1/13, 8%) felt they did not receive the required support and one Program Volunteer who previously stated they required debriefing or support did not answer the question.

The Program Volunteers were asked whether they thought the training was lacking in any areas. Of the 83 respondents, 88% (n=73) thought the training was sufficient and 12% (n=10) noted problems within the training in certain areas. The themes that arose from the 10 comments on where the Program Volunteers thought training were lacking was **Program Barriers** with a Lack of follow up (n=4, 40%) as a sub theme, **Social and Emotional Wellbeing** (n=3, 30%), particularly Emotional Wellbeing of the Program Volunteer as a sub theme, and **Access** (n=3, 30%) notably Access to resources as a sub theme (Text-box 11).

Text-box 11: Problems Identified within Program Volunteer training.

Program Barriers
"*No follow up contact after initial training.*"
"No follow up from limbs for life as to how contact with new amputee and or family went."

Social and Emotional Wellbeing
"Mental Health."

Access
"Maybe more role playing or more guidance on what you can and cannot say."

Ninety-five percent (n=79/83) of Program Volunteers agreed that the assessment to qualify as a Program Volunteer was adequate. There were 4 Program Volunteers (n=4/83, 5%) who thought that at the completion of training the assessment was insufficient.

The majority of Program Volunteers (n=78/83, 94%) felt supported as a Program Volunteer by the Program Manager. The remaining Program Volunteers (n=5/83, 6%) did not feel supported in their Volunteer role.

Focus group responses

All Program Volunteers (n=7/7, 100%) indicated that their expectations had been met, generally consistent with the results of the questionnaire.

Examples of Focus Group quotes to evidence this point include:

> "There is no way that you don't feel pleased that you've done this, and so it is gratifying to us to be able to give back".
> "I don't think I had any particular expectations except to act as a resource person, so that where people had questions, gaps in their information, that we could just answer questions…"

> "I guess my expectation of my role is that I'm there to demonstrate that there's life after amputation. It's not the doom and gloom that can sometimes be thought of. So, I go there and often will demonstrate the leg that I've got, the prosthetic that I've got and see how it works and explain that life goes on and talk about activities that one can do as amputee afterwards".

The matching process was also noted to be successful amongst the Program Volunteers (n=7/7, 100%)**.** This was representative of the questionnaire responses. Examples of Focus Group quotes to evidence this point include:

> "I think they match us up with likes, I tend to get guys who are above knee and similar age to me".

> "My personal view is it doesn't worry me at all in terms of the matching, and I don't [think there's a] problem from the amputee, the other person in terms of they're happy to talk to me as a traumatic amputee".

The Program Volunteers were asked to reflect on any interactions that hadn't gone well. Four Program Volunteers indicated that they had experienced some difficult encounters (n=4/7, 57%), however only one chose to seek support and inform Limbs 4 Life of this interaction. This result is consistent with the questionnaire responses in terms of how frequently the Program Volunteers were seeking support after conflict or a confronting experience.

A male Program Volunteer indicated that he had experienced a difficult Program Participant during a rehabilitation visit. John (not his real name) stated "I felt uncomfortable because he was being prickly. He wasn't rude, he wasn't going to stand up and start punching, but he was verbal here and there… He said his piece and I don't think there was much more I could do with that". John did not follow up with Limbs 4 Life or feel that he needed support post this interaction.

Another male Program Volunteer commented on a difficult encounter within a four-bed ward in a Metropolitan Public Hospital where privacy was not adequate and other patients were providing unwelcome commentary to the situation. This scenario was not handled well by the hospital staff according to Fred (not his real name). Fred stated "I walked out the door, went and got in my car, and I'm a big guy, don't get me wrong, I got really emotional, I felt so sorry for this guy". Fred did contact Limbs 4 Life on this occasion via email and was advised to source a private room for any further visits.

A female Program Volunteer indicated that she had at times experienced difficult encounters with Program Participants who were of a different culture. Lois (not her real name) stated "It was really difficult to support an older person, was she Greek or Italian, I can't remember, then because, partly her language, but partly because of the cultural aspect that the males, the eldest sons, had to be responsible for her." Lois found this difficult but did not feel she required Limbs 4 Life support on this occasion.

The same female Program Volunteer also stated that she had experienced multiple closely timed difficult encounters with Program Participants who were being treated in the Public Health System. Lois (not her real name) stated "Public Hospitals, I had two in a row that nearly sent me to a psychologist. I could not believe the appalling conditions and the treatment that public hospitals provide, or don't provide. They were just outrageous." Post these encounters, Lois documented her experience but did not inform Limbs 4 Life. Lois was aware that support was available, however, she was unable to recall why she did not seek it.

Facilitators and barriers for volunteering for the Amputee Peer Support Program

The Program Volunteers responded with 82 comments when asked what worked well for them within the Program. The majority of responses were themed to **Access** (n=51, 62%) with the sub theme of Access to the amputee community (n=22, 27%) and Access to resources (n=16, 20%) accounting for a significant proportion. **Social and emotional Wellbeing** also themed strongly (n=18, 22%) with Emotional Support the strongest sub theme (n=12, 15%) (Text-box 12).

Text-box 12: What worked well for Program Volunteers

Access

"Face to face contact with fellow amputees, honest discussions about expectations, pitfalls and adversities."

"We have now created a strong community of amputees, especially multiple amps. We continue to stay in touch."

Social and Emotional Wellbeing

"Being able to talk to a patient before the loss and try and alleviate their fears of both patient and family."

"The support given by other Program Volunteers and the Board and Management of Limbs 4 Life."

When asked to respond to what did not work well, the Program Volunteers provided 40 responses. The responses were spread across the themes of **Barriers to the Program** (n=16, 40%), **Social and Emotional Wellbeing** (n=12, 30%) and **Access** (n=12, 30%). Travel time and distance to Program Participants were identified as dominant Barriers to the Program sub themes (n=9, 23%) and Emotional Support (n=8, 20%) a dominant sub theme of Social and Emotional Wellbeing (Text-box 13).

Text-box 13: What did not work well for Program Volunteers.

Barriers to the Program
"Often with work commitments, distance from home for visits sometimes means a phone chat is only possible."
"I live too far away from most requests."
"Phone was difficult as it was harder to engage the person and I get nervous on the phone. It may be that I need more practice."

Social and Emotional Wellbeing
"Sometimes I felt out of my depth in the mental health aspect of things. Sometimes I couldn't relate to some trauma-related experiences because my amputation was due to vascular reasons."
"Some within the group made it all about themselves which impacted heavily on others."

Focus group responses

When discussing experiences with the Program, the Program Volunteer Focus Group responses were consistent with the results of the questionnaire in regards to what worked well for the Program Volunteers.

The themes of Access and Social and Emotional Wellbeing were highlighted amongst the Program Volunteers again. Some examples of Focus Group quotes to evidence these themes include:

> "I enjoy going out and seeing people, I've had older people to younger people and just showing that there is life after amputation. Not the end of the world."

> "Giving as much information as possible about the potential…. Clear communication, enormous support and appreciation. Thank you go an awfully long way."

> "I wanted to give back when I was in a confident state. That I'd dealt with it and able show people… that there is life after amputation and independent and self-sufficient."

> "Communicate – listen to their stories."

When discussing what hasn't worked well for the Program Volunteers during the Focus group, the responses were consistent to those of the questionnaires. Barriers to the program, including travel time, distance to the Program Participant, inability to follow up post visit and utilisation of Program Volunteer were again the most common theme. The theme of access was also represented, primarily accurate resources for the Amputee Population.

Some examples of Focus Group quotes to evidence these themes include:

> "Often they're one off sessions and I leave it up to the individual to see if they want to contact me again through Limbs 4 Life. It doesn't happen often. I don't know why. I don't know if they're happy with the way things go."

> "People in this circumstance often are concerned about financial issues. It'll often be a matter of job security and can they pay the mortgage and all sorts of things. I get asked questions about finances and the black hole of NDIS. So, I think it would be useful for Program Volunteers to be given resources maybe to answer those sorts of issues…"

> "In some ways, I'd like more interaction with people, as in more customers."

> "In fact I've only had one case in three years."

> "It may be worth considering possibly a spontaneous contact from Limbs 4 Life for these individuals to see if they're interested in a further contact, rather than relying on the individual to instigate contact."

Implementation according to the Peer Support Group Framework

The Limbs 4 Life framework is a comprehensive document and via the Program Volunteer questionnaire, we were able to comment on the following parameters.

At the completion of their training, 88% (n=73) of Program Volunteers stated that they received a first response kit, whereas 12% (n=10) claimed that they did not. The response kit is documented within the framework as a tool designed to assist them in their role and comprises of key information booklets, fact sheets and copies of the Amplified magazine from Limbs 4 Life. The kit is designed to be given to each Program Participant at a Peer Support Visit.

The Framework suggests that a successful Peer Support outcome greatly depends on the ability to match each individual to a Program Volunteer based on several key criteria. The Program Volunteers reported that the matching process was successful most of the time.

Program Volunteers were asked to identify all locations they had conducted Peer Support Visits. Of the 158 responses, the majority (n=61, 39%) were observed to have occurred during the Program Participants acute care stay followed by 28% (n=44) during the rehabilitation stay, with other meeting points seen in Figure 15. The questionnaire results are somewhat reflective of the framework requirements. Limbs 4 Life requests that if a recipient is living at home, the visit must take place in a public venue such as a café, a park or another open public space. Limbs 4 Life Program Volunteer insurance does not cover Peer Support Visits that are arranged in an individual's private home. **However, the results above indicate that 10% of visits were conducted in a private home, and this could represent a safety concern**.

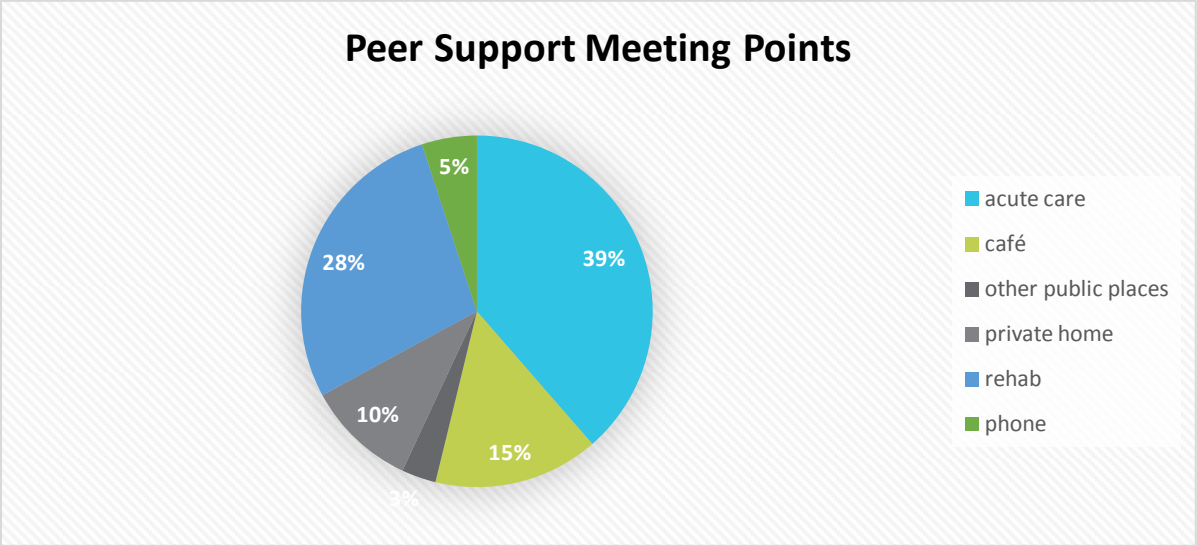

Figure 15: Peer Support Meeting Points

During these visits, 31% of Program Volunteers (n=26/84) indicated that they have provided Program Participants with their personal details whereas 69% (n=58/84) noted that had never passed on personal information. The framework document indicates that where an individual requests an additional visit the request needs to come through Limbs 4 Life rather than direct to the Program Volunteer or via a second or third party. **Organising follow up visits and contact through the Program Volunteer (not through Limbs 4 Life), could represent a safety concern.** The framework does not specifically instruct Program Volunteers not to pass on their personal details.

After completing a Peer Support visit, 43% (n=35/81) of Program Volunteers indicated that they completed a record sheet of the consultation whereas 57% (n=46/81) did not. This result is not consistent with the framework requirement. The framework indicates that upon completion of a visit Program Volunteers complete a report to the Program Manager, detailing the outcome of the visit. Any additional requests for information or additional visits are usually also reported at this time.

Program Volunteers were also asked to report on whether or not they wore a uniform during their visit. Of the 84 respondents, 57% (n=48) reported that they did wear a uniform

whereas 43% (n=36) noted that they did not, which is not consistent with the framework recommendations. The framework indicates that all Limbs 4 Life Program Volunteers wear a polo top with a Limbs 4 Life logo and a name badge so that they are easily identifiable to hospital staff. Where required, Program Volunteers also wear a Hospital Volunteer tag for security purposes.

Eighty-Two Program Volunteers provided a response to the question "Have you ever provided professional counselling, commented on medical matters or given medically related opinions to Program Participants". Eleven percent (n=9) identified yes they had provided comment to the above and 89% (n=73) stated they had not provided any counselling or comment on medical matters. This result is fairly consistent with the requirements of the framework. The framework documents that Program Volunteers are not trained counsellors and are made aware that they are not able to comment on medical advice, interfere with treatment or act like a counsellor towards people they are supporting. The majority of Program Volunteers have worked within the boundaries of the framework and shared personal experience only and directed Program Participants to their healthcare provider for any medical or health-care information required.

When asked if they had access to additional training and updates following their initial Program Volunteer training, 17% (n=14/83) indicated Yes and 83% (n=69/83) indicated no. This result is inconsistent with the Framework. The Framework indicates the following tools are available to assist the Program Volunteers in their role: briefing and debriefing support service, access to volunteer networks, additional training and updates as required.

Focus group responses

The Focus Group responses were generally consistent with the results of the questionnaire. Not all areas of the Framework were discussed and evaluated in the Focus Groups as the Framework is a comprehensive document, Focus Group sessions were time dependent and those participating were encouraged to share their experience. Where feedback was provided, we were able to make comment. The following areas were commented on.

The matching process: The Framework suggests that a successful Peer Support outcome greatly depends on the ability to match each individual to a Program Volunteer of similar age, gender, site of amputation, cause or reason for amputation, geographic location and personal interests. It may not be possible to match all criteria, however care is taken to match a Program Volunteer to a Program Participant as closely as possible. The comments listed previously are consistent with the requirements of the Peer Support Framework and also the questionnaire responses.

The meeting: The Framework clearly indicates that if the Peer Support meeting is to take place out of the hospital setting, then it must be in a public venue. All Program Volunteers were well aware of this requirement. One male Program Volunteer commented “Mel says never meet people at home, we always [take] them out.”

The Framework states that "It's the Program Volunteers' role to encourage and empower individuals to feel confident and be able to make their own decisions". For this reason, some people may request a single visit, while others may request a number of visits with the same or a different Program Volunteer if required. Where an individual requests an additional visit, the request needs to come through Limbs 4 Life rather than direct to the Program Volunteer or via a second or third party. Program Volunteers are issued with generic business cards to enable the recipient of the service to contact Limbs 4 Life should they wish to request additional information or support. The Focus Group members commented that they would like to know how the Program Participants are progressing.

> One male Program Volunteer commented that over time he has given out personal details. "Yeah. I just used to ask. I said look is it okay if I give you another call in a week or a couple of weeks to see how you're going. Here's my number."
>
> "It's very overwhelming, and it's very overwhelming when you're talking to them. As I said, if you want us to come back, we'll come back."
>
> "But you can't follow through, that's the problem, so they tell you. You need them to come back to you."

Providing medical advice to Program Participants: All Program Volunteers (n=7) in the Focus Groups stated that they had never provided medical advice to Program Participants although they had provided the "lived experience." A female Program Volunteer commented "Well that's clearly stated in the course." This is representative of the Framework.

Access to additional training or updates post initial training: The Framework indicates that additional training and updates are available as required. All Program Participants in the Focus Group (n=7) noted that they have never been offered any additional training or updates, although the following comments are noted.

> "No. No. I mean Mel and the staff were always there at the end of the phone."
>
> "I think on the phones is [enough] support."
>
> "Phone or email."

Debriefing Process: Some Program Volunteers commented on experiencing difficult encounters. These experiences and comments have been previously described in this report. The Framework states it is the role of the Program Manager to offer a debriefing process in a timely manner. The results from the Focus Group indicate that although the Program Volunteers know the service is available they have not tended to partake in it.

Acknowledgement of Valuable Contribution: All Program Volunteers were noted to feel appreciated for the contribution they are making to Limbs 4 Life and this is an aim reflected within the Framework. Some examples include.

"You're welcomed with open arms every time you come."

"I think we know that we're giving a good service. I don't need any feedback to say oh you're doing a good job or whatever. I think we all know we are doing a good job. I [would] just like – like everyone has said, like some more clients."

Re-imbursement for Program Volunteering costs: All Program Volunteers have a right to be reimbursed for their expenses as expressed in the Framework. The Focus Group Program Volunteers stated the following:

"I've never sent one in."

"My way to put back."

"Constantly, it's been offered constantly."

Part 3: Program Participants

The following section includes results from the questionnaire and the Focus Group. For each section, the questionnaire results are presented first followed by the Focus Group results. The Focus Group results are structured to show consistency or discrepancy with the questionnaire results, with quotes presented to substantiate these findings and expand on the questionnaire results.

Demographics

Questionnaire responses (Pre-Program Participant Group compared to the Post-Program Participant Group)

Due to the small response rate from a potential of 129 Program Participants, and the anonymous nature of the questionnaires, it is unknown if the Program Participants in the Pre-Program Participant Group (n=13) are the same as the Program Participants in the Post-Program Participant Group (n=12). As such, they were treated as independent groups in the analyses.

Pre-Program Participant Group: Thirteen Program Participants responded to the questionnaire prior to participating in their Peer Support visit (10%, n=13/129) and 77% (n=10) were male and 23% (n=3) were female. The average age of Program Participants was 63.1 yrs. (SD 13.8).

Forty Six percent (n=6) identified as being married/having a partner and 54% identified as being widowed/separated/divorced/single (n=7). Sixty nine percent (n=9) are recognised as not living alone and 31% (n=4) indicated living alone.

As evidenced in Figure 16, 67% (n=8) of Program Participants in the Pre-Program Participant Group were from Victoria, 25% (n=3) from NSW and 8% (n=1) from South Australia (Figure 16). Within these areas 77% (n=10) identified living in a Metropolitan region and 23% (n=3) identified living in a Rural/Regional area.

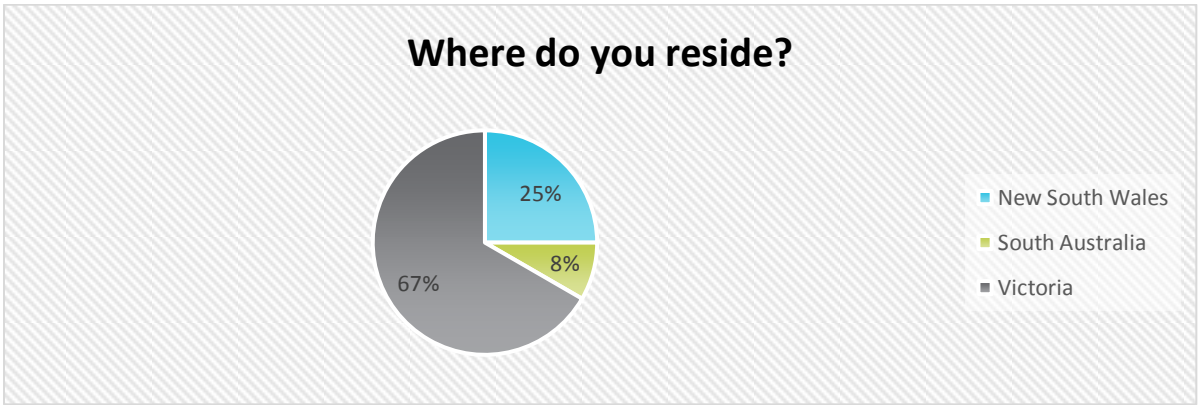

Figure 16: Residence of the Pre-Program Participant Group

At the time of completing the questionnaire, five Program Participants were residing in the community/home, 4 were in a Rehabilitation facility and 4 were in the acute care setting (Figure 17).

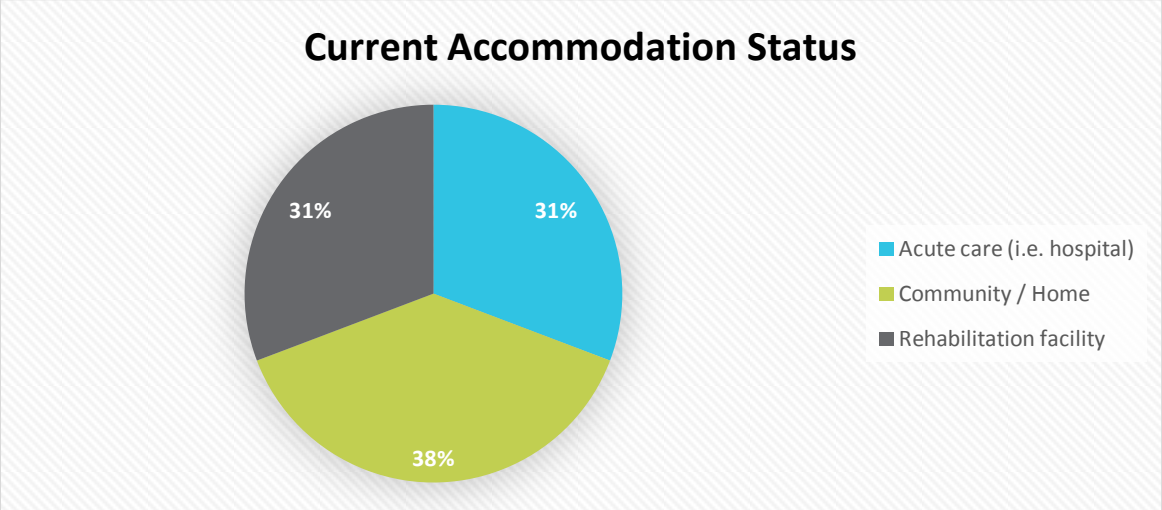

Figure 17: Current Accommodation Status

Program Participants were asked whether they self/family referred into the program or were referred via a Health Professional. Eleven (n=11/13, 85%) were referred by a Health Professional and 2 self-referred (n=2/13, 15%).

Post-Program Participant Group: Twelve Program Participants responded to the questionnaire post participating in their Peer Support visit (9.3%, n=12/129). Only 11 Program Participants answered the male / female question with males representing 73% (n=8) and females representing 27% (n=3). The average age of Program Participants was 70.2 yrs. (SD 6.3).

Sixty-four percent (n=7/11) identified as being married/having a partner and 36% identified as being widowed/separated/divorced/single (n=4/11). Seventy-five percent (n=9/12) indicated they do not live alone and 25% (n=3/12) indicated living alone.

As evidenced in Figure 18, 46% (n=5/11) of Program Participants in the Post-Program Participant Group were from Victoria, 27% (n=3/11) from NSW, 18% (n=2/11) from South Australia and 9% (n=1/11). Within these areas, 83% (n=10) identified living in a Metropolitan region and 17% (n=2) identified living in a Rural/Regional area.

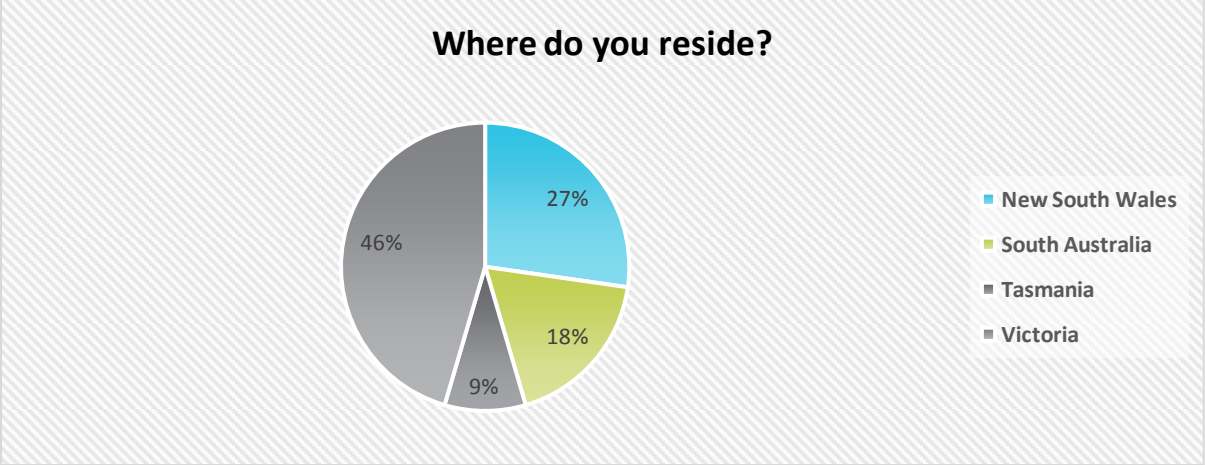

Figure 18: Residence of the Post-Program Participant Group

At the time of completing the questionnaire, the 11 Program Participants who answered the current accommodation question were all residing in the community/home (n=11/11, 100%).

Program Participants were asked whether they self/family referred into the Program or were referred via a Health Professional. Seven (n=7/11, 64%) were referred by a Health Professional and 2 self-referred (n=2/13, 15%).

The dates that the amputations occurred for these Program Participants extended from January 2018 through to August 2019. Ninety-one percent (n=10/11) indicated a lower limb amputation and 9% (n=1/11) indicated an upper limb amputation. Nine Program Participants (n=9/11, 82%) indicated that their Peer Support Visit was post their amputation and two people (n=2/11, 18%) they had indicated their Peer Support Visit was pre their amputation. Seventy-five percent (n=9/12) indicated that they attended the Peer Support Visit on their own and 3 Program Participants (n=3/12, 25%) indicated that someone else was present with them at the time.

Sixty-Seven percent of Program Participants (n=8) indicated that they have a prosthesis. The remaining 33% (n=4) did not have a prosthesis at the time of completing the questionnaire but all (n=4) indicated they would have a prosthesis in the future. The Program Participants identified they have used the following mobility devices: prosthesis (n=3/17), crutches (n=1/17), Wheel chair / scooter (n=10/17) and Walker (n=3/17) (Figure 19).

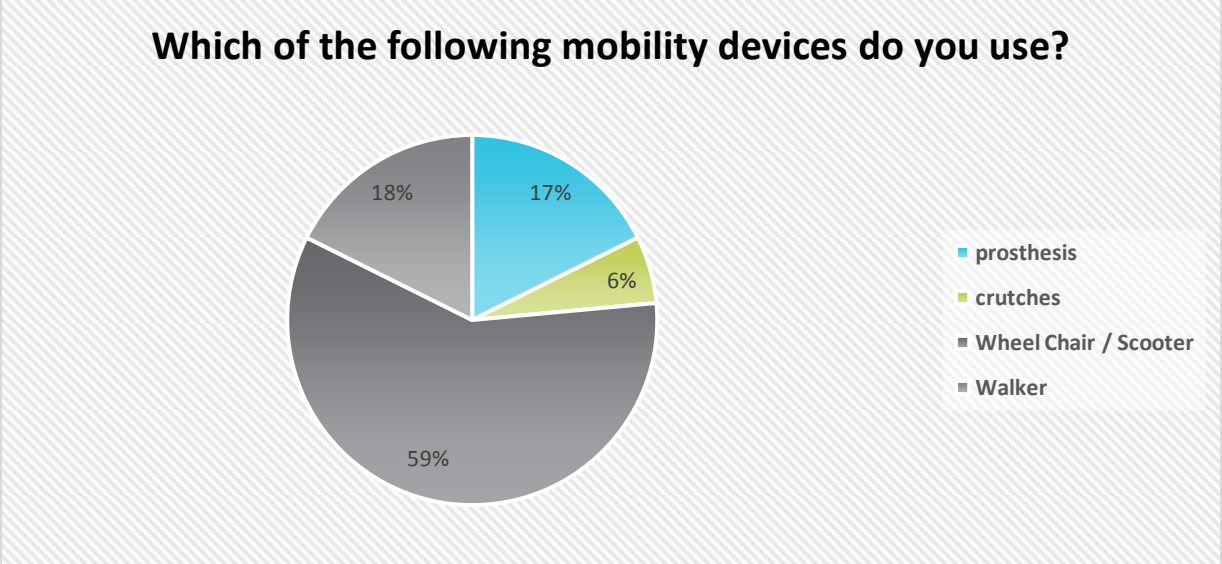

Figure 19: Mobility devices used by the Post-Program Participant Group

The majority of Program Participants (n=10/12, 83%) indicated they received one Peer Support Visit. One participant received two visits (n=1/12, 8%) and one received 4 visits (n=1/12, 8%). Ninety-two percent (n=11/12) stated they had never attended a group session while 1 individual had participated in a group session (n=1/12, 8%).

Program Participants were asked to indicate whether they are currently receiving any supports from the National Insurance Disability Scheme (NDIS) Program. One person (n=1/12, 8%) indicated they were accessing the scheme, 6 people (n=6/12, 50%) indicated they were not accessing the scheme and 5 people (n=5/12, 42%) indicated they were ineligible for the program (most commonly due to age limits). Of those who indicated they had not accessed the program, 2 stated that they would access it in the future and a further one indicated they were a TAC participant. Forty-two percent (n=5/12) indicated that they had access to other Government Disability Funding. This included Disability Support Pension (n=3), TAC (n=1) and My Aged Care (n=1).

Program Participants were asked whether participating in the Program increased their confidence through the provision of quality information, resources and community re-engagement. The most common response was 'agree' (n=5/12, 42%) (Figure 20).

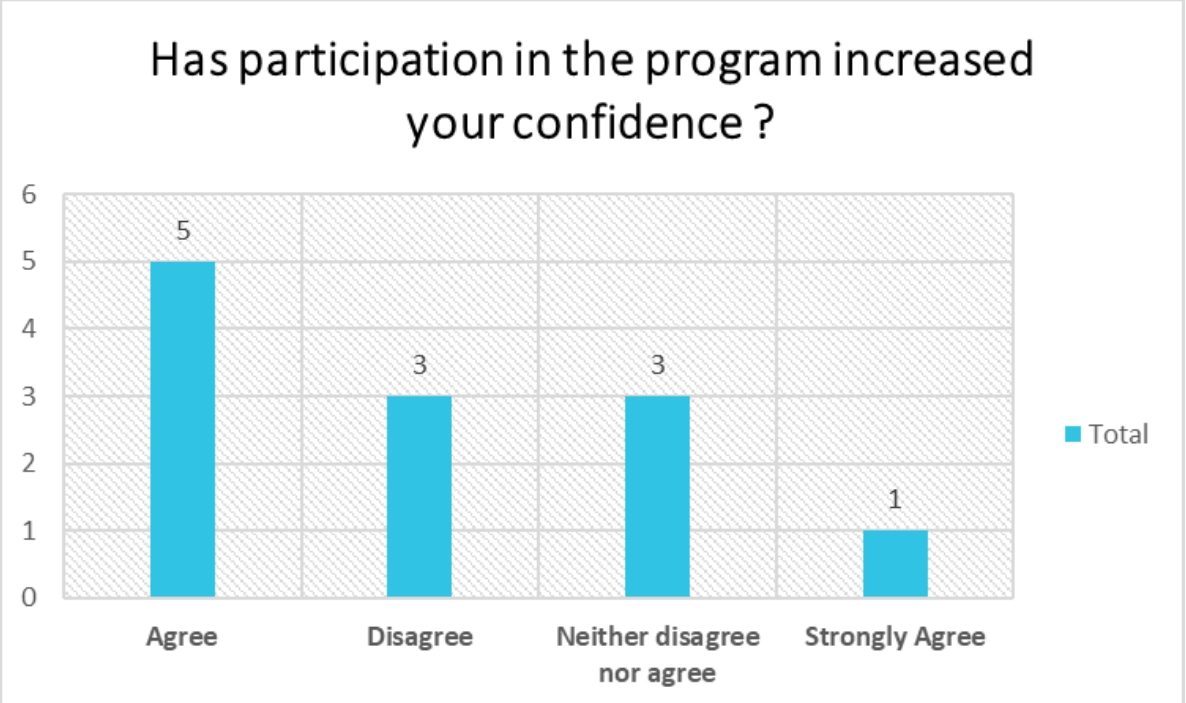

Figure 20: Increased confidence through participating in the Program

Program Participants were then asked has participation in the Program enhanced your sense of empowerment by meeting and engaging with Peers who have successfully adapted to the physical impact of limb loss. Five Program Participants (n=5/12, 42%) responded 'agree' and a further 5 (n=5/12, 42%) responded 'neither agree nor disagree' (Figure 21).

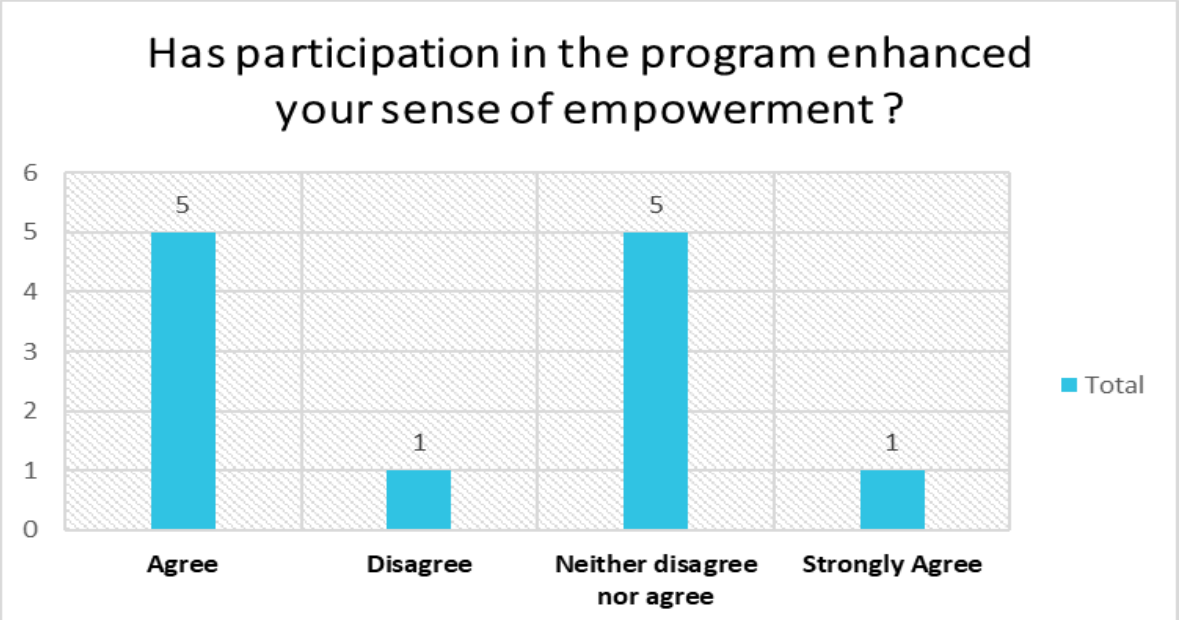

Figure 21: Sense of empowerment following a Peer Support visit

Four Program Participants (n=4/11, 36%) identified feeling "alone" prior to their interaction with a Limbs 4 Life Peer Support Program Volunteer whereas 7 Program Participants (64%) did not feel alone. After their first interaction with a Program Volunteer, 2 Program Participants (n=2/11, 18%) felt 'alone' whereas 9 Program Participants (82%) did not feel alone.

One Program Participant (n=1/12, 8%) engaged in additional NON-Limbs 4 Life services as a result of contact with the Program. Again only 1 Program Participant (n=1/12, 8%) felt that their contact with the Program reduced the need to engage in additional NON-Limbs 4 Life services.

Only 1 Program Participant (n=1/12, 8%) has attended other Limbs 4 Life social and activity programs. This event was a Sunday Luncheon. Only 5 Program Participants (n=5/11, 45%) have accessed the Limbs 4 Life website and only 3 (n=3/12, 25%) have accessed the Limbs 4 Life Facebook groups. The Limbs 4 Life Toolkit has only been accessed by 1 Program Participant (n=1/12, 8%) and only 5 Program Participants (n=5/12, 42%) felt they have been able to access support material from Limbs 4 Life.

Seventy-five percent (n=9/12) of Program Participants felt that their Program Volunteer demonstrated a listening ear and sharing of the lived experience. Five Program Participants (n=5/12, 42%) felt that participation in the Program gave them access to an organisation that understood their unique experience. Sixty-seven percent (n=8/12) of Program Participants felt that the matching process was successful and 64% (n=7/11) felt the matching process enhanced their Peer Support experience. Eighty-two percent (n=9/11) of Program Participants would recommend the Program to other people.

The expectations that Program Participants had upon joining the Program were centred primarily on gaining information, seeking support and sharing of the lived experience. An example directly from a Program Participant "To have a person having experienced what I am going through to discuss and get guidance from." These same themes emerged again when the Program Participants were asked what impact the Program had on them. An example includes "Impact has been to discuss and derive ideas from a person who has experienced similar situations as mine and understands actions he has taken to overcome issues I am dealing with." Fifty-eight percent (n=7/12) of Program Participants indicated that their expectations had been met.

When asked what worked well for the Program Participants, only 5 Program Participants delivered a response. These were not extensive responses but were again centred on the sharing of the lived experience. Two examples include "The visit from the volunteer with his life experiences." and "Receiving a number of suggestions, many quite mundane, but very useful in terms of coping with issues." When the Program Participants were asked what did not work well for them, there were only 2 comments and both of these indicated that there were no issues as evidenced by the comment "All worked to expectations."

Focus group responses

The final question of the questionnaire for the 129 Program Participants in the Post-Program Participant Group asked if they would like to participate in a Focus Group to further discuss their experience. Of the 12 Program Participants who contributed to the questionnaire, five Program Participants offered up their personal details and consented to be contacted regarding the Focus Group. All 5 Program Participants were contacted with only one positive response to participate in the Focus Group. This Focus Group hence became a sole interview. It was carried out via Video Link and is presented below as a case study.

The single Program Participant is a 75-yr. old male who lives in Metropolitan Melbourne with his wife. He self-referred into the Limbs 4 Life program after experiencing a lower limb amputation in April 2019 and locating some Limbs 4 Life literature on the ward. At present, he is learning to use his prosthesis and is mobilising around with the assistance of a wheelchair and a scooter.

Jack (not his real name) stated "The concept appealed to me because I'm sure I'm not an isolated circumstance and I thought that it might come in useful in the future." Jack has encountered one visit with a Peer Support Program Volunteer and, in his words, found the interaction to be "a sort of kinship scheme, buddy scheme." Jack initially felt that he was coping well but in hindsight regrets not having requested further contact with his Program Volunteer.

Jack was asked what his expectations of the Program were. He stated "What I was looking for was some communal input. Whether it would be via meetings or any other communication, such as we're having now… really compare notes and there really is quite a lot that one can talk about…"At present, Jack feels that his expectations have not been met. He is presently experiencing some difficulties and feels that a Limbs 4 Life Program Volunteer or representative could assist. Yet Jack is aware that it is he who has not initiated any further follow up.

Jack had a suggestion for how the Program could be improved. "I would say that… if one could get some form of major company sponsorship in one of the suppliers to the hospitals or to the orthotic program and let them take up the running in promoting Limbs 4 Life, not necessarily getting involved in any of the admin or legwork. Maybe combined with financial sponsorship from them in organizing events or something along those lines."

Jack indicated that he has not been able to access any specific funding outside of "Older Australians" which enabled him to purchase a mobility scooter. This has put additional pressure on an already stressful period.

Jack was asked if he would recommend the Program to other amputees. He stated "Most definitely. Both personally and with an ulterior motive."

Implementation according to the Amputee Peer Support Group Framework

The small sample size of the Pre and Post-Program Participant Groups and the individual case study Focus Group indicate that the responses obtained may or may not be representative of the broader amputee community. As there were minimal extended answer responses submitted it is also difficult to assess how well the Program is implemented according to the Framework. The following can be commented on though.

In line with Limbs 4 Life's statement of purpose, the Program aims to relieve the distress and isolation experienced by amputees and caregivers and assist amputees in making the transition from hospitalisation and rehabilitation back into their community via access to trained peers, access to updated resources and information and the provision of information relating to amputation/limb deficiency amongst other things. It was consistent amongst the responses received that this was achieved as the Program Participants felt that the Program Volunteers provided a listening ear (n=9/12, 75%) and the majority felt that the matching process was successful and that it enhanced their experience.

The Framework suggests that a successful Peer Support outcome greatly depends on the ability to match each Program Participant to a Program Volunteer based on several key criteria. The Program Participants reported that the matching process was successful most of the time.

The primary expectation from the Program Participants centred on the theme of providing information and support and the sharing of the lived experience. From the minimal extended responses provided above, this seems to be have been adequately achieved yet only 58% (n=7/12) indicated that their expectations of the Program had been met. However, 82% (n=9/11) would recommend the Program to others.

The case study representative provided very similar thoughts. He was hoping to share his experience with his Peer Support Program Volunteer and he felt he was successful in doing so. He has since reflected on his visit and feels he would benefit from further contact and also further community involvement.

The Framework also suggests that Limbs 4 Life runs and promotes a number of social and activity events designed specifically for amputees of all levels of ability and mobility. This was not reflected within the questionnaire responses. Only 1 participant (n=1/12, 8%) had ever attended a Limbs 4 Life social gathering.

The Limbs 4 Life website and Face book groups are yet another way that Limbs 4 Life ensure that amputees can access information. The Framework suggests that the website provides significant links and information and that the Facebook group was created in response to community demand. Interestingly the very small percentages presented for the current sample indicate that these resources are not being accessed.

Finally, at the conclusion of a Peer Support Visit, the Program Volunteer presents the Program Participant with a "First response patient kit". According to the Framework, this kit comprises of key information, fact sheets and copies of the Amplified magazine. The questionnaire responses indicated that only 1 participant (n=1/12, 8%) identified receiving such a kit and, possibly more importantly, only 5 Program Participants (n=5/12, 42%) felt they had been able to access support information at all. These results are not consistent with the aims of the Program.

As previously stated the sample size of this population and the quantity of the extended answer responses may indicate that the above analysis is not a true representation of the Amputee community, and therefore generalisability is limited.

In summary, the Facilitators and Barriers for the Health Professionals (HP), Program Volunteers (V) and Program Participants (P) were:

FACILITATORS

- The visit from the Program Volunteer with his life experiences (P),
- Positive attitude (P),
- Social and emotional wellbeing for the person (V),
- Strong community of amputees (V),
- Easy to refer (HP),
- Easy to communicate with the Limbs 4 Life team (HP),
- "Resources are fantastic" (HP),
- "Knowing the Program Volunteers are trained and willing" (HP).

BARRIERS

- None identified from the Participant (P),
- Perceived inability to have ongoing contact post 1:1 Peer Visit (P&V),
- Work commitments and distance for the visits (V),
- Out of depth with mental health concerns (V),
- Ability to see when a patient has been referred as well as receipt of referral (HP),
- Limited local networks, therefore phone visits (HP).

In summary, the Framework fidelity for the Health Professionals (HP), Program Volunteers (V) and Program Participants (P) were:

FIDELITY WITH THE FRAMEWORK

- Most Program Participants felt the Program Volunteer provided a listening ear (P),
- 90% of visits are in an appropriate location (V),
- 89% have not provided counseling / medical advice (V),
- Most Program Volunteers received a first response kit (V),
- Referral pathways (HP).

VARIATION FROM THE FRAMEWORK

- Less than half the Program Participants reported access to support information (P),
- 10% of visits are in an inappropriate location (V),
- 11% have provided counseling / medical advice (V),
- 31% of Program Volunteers have provided personal details (V),
- 17% have participated in ongoing training (V),
- Less than half completed a record sheet post visit (V),
- Over half the Program Volunteers wore a uniform on visits (V),
- Education session awareness and / or access (HP).

Part 4: Health economics

Program utilization

Between July 2013 and June 2018 (five years), there were 793 Program Participants. The average age was 58 years. Two-thirds were male (n=537). In 2013/14 (n=130) and 2014/15 (n=137), there was a similar number of Program Participants. In 2015/16 (n=176), 2016/17 (n=172) and 2017/18 (n=178), there was a consistent increase in Program Participants. The timing of this increase is consistent with the Program moving from a Victorian state-based service to a National service.

Over five years, the National spread of Program Participants was greatest in Victoria (n=457), South Australia (n=196) and New South Wales (n=79), with lesser numbers in Western Australia (n=19), Queensland (n=18), Tasmania (n=13), Australian Capital Territory (n=8) and Northern Territory (n=3). There were more metropolitan visits (n=671) compared to rural and regional visits (n=122). Most visits were in an acute hospital (n=514) or a rehabilitation hospital (n=150). The majority of visits were post amputation (n=561) with less pre-amputation (n=228) and a few for people with a limb deficiency present at birth (n=4). Most people had 1 Peer Support visit (n=715) with less having 2 visits (n=67) or more (n=11).

The Program was serviced by 256 Program Volunteers who were trained over this time.

Program costs

Program costs between July 2014 and June 2018 (five years) have been itemised in Appendix 9 where the costs have been reported for each of the five financial years. To calculate total costs, the annual costs across the five financial years have been inflated by CPI to represent a NPV in the 2018/19 financial year (AUD$2018/19).

The total cost of the Program over five years was $631,497. This is broken down into five cost buckets. 1) The direct costs of the Program Volunteer training ($199,148) such as printing, room hire, police checks, staff to provide the training, staff travel and polo shirts. 2) The indirect costs of the Program Volunteer training ($415, 134) such as marketing and communication, phone costs, insurance, IT and data base costs, capital costs and the staff costs to administer the program. 3) Directs costs for the group Programs ($3,783) such as hosting the group sessions. 4) Directs costs for the 1:1 Program ($9,522) such as reimbursement for Program Volunteer costs and handouts / resources for the Program Participants. 5) In-kind donations of goods and services (value of in-kind $3,909) such as waivered venue hire and catering costs.

The total Program cost ($631,497) can be divided by the 793 people who participated in the Program over five years, to calculate a cost of $796 per Program Participant. Alternately, the total Program cost ($631,497) can be divided by the 256 people who underwent Volunteer training for the Program over five years, to calculate a cost of $2,467 per Program Volunteer.

Program effect

Due to the small response rate from a potential of 129 Program Participants, and the anonymous nature of the questionnaires, it is unknown if the Program Participants in the Pre- Program Participant Group (n=13) are the same as the Program Participants in the Post-Program Participant Group (n=12). As such, they were treated as independent Groups in the analyses.

There was no difference reported in the quality of life outcome measures between the Pre and Post-Program Participant Groups (Table 5).

Table 5: Quality of life measures for the Pre and Post-Program Participant Groups

	Pre-Program Participant Group (n=13)	**Post-Program Participant Group (n=12)**	**Mean difference (Post minus Pre-group) (95% confidence interval, p value)**
EuroQOL 5D3L			
Utility Index (range 0-1)	0.535 (SD 0.328)	0.575 (SD 0.301)	0.040 (-0.221 to 0.302) p=0.75
Rating of overall health (range 0-100)	71.54 (SD 20.86)	68.00 (SD 14.57)	-3.54 (-19.66 to 12.58) p=0.65
WHO BREF			
"How would you rate your quality of life" (range 1-5)	3.62 (SD 0.96)	3.50 (SD 0.80)	-0.12 (-0.85 to 0.62) p=0.75
"How satisfied are you with your health" (range 1-5)	3.62 (SD 0.96)	3.17 (SD 0.84)	-0.45 (-1.19 to 0.30) p=0.23
Domain 1: Physical Health (range 0-100)	49.08 (SD 17.60)	46.58 (SD 10.53)	-2.49 (-14.62 to 9.64) p=0.68
Domain 2: Psychological (range 0-100)	51.54 (SD 15.97)	56.25 (SD 14.10)	4.7 (-7.80 to 17.22) p=0.44
Domain 3: Social Relationships (range 0-100)	61.00 (SD 27.39)	57.83 (SD 20.21)	-3.17 (-23.23 to 16.90) p=0.75
Domain 4: Environment (range 0-100)	64.08 (SD 18.32)	65.17 (SD 14.69)	1.09 (-12.61 to 14.79) p=0.87

Program cost-effectiveness

Due to "no difference" in the two quality of life outcome measures from Pre to Post-Program Participation in the Program, a cost-effectiveness analysis was not viable.

Willingness to pay

Health Professionals, Program Volunteers and Program Participants were asked to report their willingness to pay for the Program from a number of different perspectives (Figure 20; reported in AUD$2018/19). All three groups presented a similar pattern with a higher willingness to pay for the Health Service (range $113 to $450), NDIS (range $156 to $432) and Private Health Insurance (range $153 to $347); and a lower willingness to pay for the individual Program Participant (range $23 to $49). It was the Program Participants who most closely approximated the true cost of the Program per Program Participant ($796) with their willingness to pay from the perspective of the Health service ($450), NDIS ($432) and Private Health Insurance ($347).

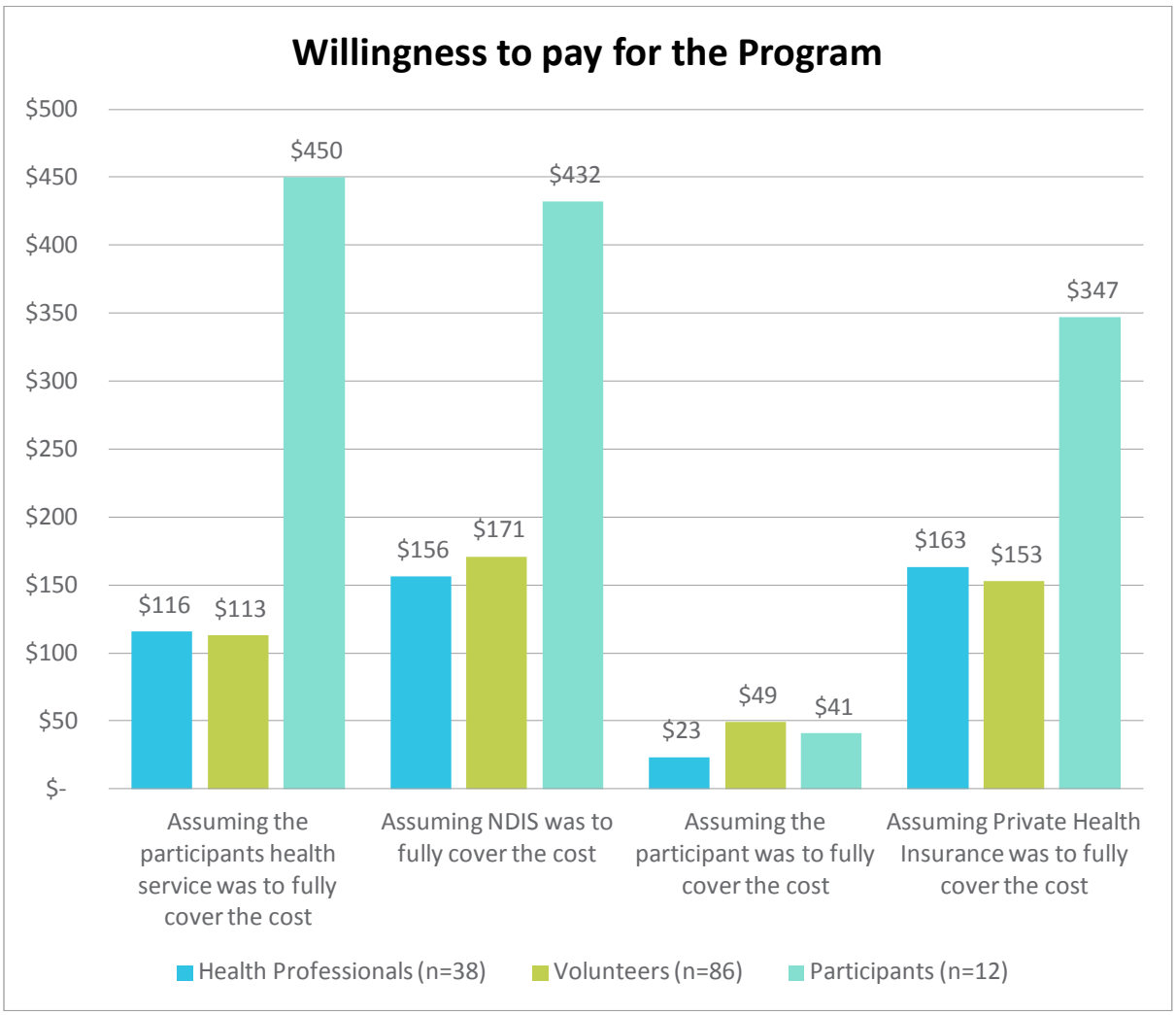

Figure 22: Willingness to pay for the Program

DISCUSSION

The current Program Evaluation investigated the Impact of the Limbs 4 Life Program from the perspective of Referring Health Professionals, Program Volunteers and Program Participants. Thirty-eight Health Professionals, 86 Program Volunteers and 25 Program Participants (13 in the Pre-Program Participant Group and 12 in the Post-Program Participant Group) from various states within Australia participated in the study by completing a questionnaire about the impact of the Program and their experience with the Program. Two Program Volunteer Focus Groups were conducted which enabled themes from the questionnaire to be further investigated and new discussion points to evolve via the lived experience of those Program Volunteers. One sole interview (case study) was carried out with a Program Participant who had recently experienced a lower limb amputation.

The Program was reported to be of significant benefit and value to all investigated parties. The themes of access to resources and information and the provision of social and emotional wellbeing were identified across all three groups as being significantly important and positively achieved. The sharing of the lived experience between a Program Volunteer and Program Participant provided a sense of belonging and connection and confirmed that the Program Volunteers were in a strong position to understand the challenges faced following an amputation. This assisted the Program Participants in coping with various challenges and possibly eased the adjustment process. The findings highlight benefits in providing peer support and suggest that such support may prove a powerful and inexpensive addition to routine care.

There is at present an abundance of anecdotal evidence in the form of case studies where peer support has positively contributed to the outcomes for patients and their families transitioning through limb loss (Reichmann and Bartman, 2018; Richardson et al., 2019; Marzen-Groller and Bartman, 2005). While physical rehabilitation is routinely provided post amputation, gaps exist with the provision of psycho-social rehabilitation (Murray and Forshaw, 2013). Peer support is a key part of psycho-social rehabilitation. The provision of peer support from those who have already made positive adjustments to amputation is recommended for all people incurring a major limb amputation (Reichmann and Bartman, 2018), however few receive this service. Peer support has the potential to inexpensively improve health outcomes and lower cost, and this requires greater research.

Amputee Peer Support Program recommendations

The Limbs 4 Life Program was evaluated against the Limbs 4 Life Program Framework. Through the questionnaires and the Focus Group results, the following recommendations are discussed. However, these recommendations need to be considered alongside the knowledge that Limbs 4 Life does not have sustainable funding for the Program, nor does it have a dedicated National Program manager (rather a team of staff who share responsibility).

> *1. Consideration could be given to ongoing contact as the Program Volunteers and Program Participants indicated a desire for ongoing 1:1 peer contact with greater support to transition to a group Limbs 4 Life Program*

Previous research suggests that the continued 1:1 contact provides hope, motivation and inspiration to both the volunteer and the participant and provides a perspective that a patient's health care team cannot offer (Richardson et al., 2019; Butcher, 2009; Marzen-Groller and Bartman, 2005).

Results indicated that Program Participants would like further follow up after their initial contact with a Limbs 4 Life Program Volunteer. Program Volunteer results also indicate that they would like to know how effective their contact was and how the Program Participant is progressing. Consideration could be given to explore if Limbs 4 Life is able to alter its framework and facilitate a Program Participant follow up phone call and seek out their interest and need in future contact with their Program Volunteer, another Program Volunteer, or for support to transition to a group Program. While facilitating a Program Participant follow up phone call may enable the Program Volunteer to access genuine feedback, it may be limited due to the multiple and significant issues and interventions at the time of the visit.

Expanding the 1:1 visits as a frequent occurrence would entail consideration that ongoing 1:1 visits may not be possible for all Program Volunteers due to time restraints and ongoing 1:1 visits may reduce the ability to respond to new people requesting the service, in addition to the additional financial and resource implications for Limbs 4 life.

The results also indicated that Program Participants wanted group interactions and social connection with other amputees on a regular basis. Ideas mentioned included sporting groups and general social gatherings. Consideration could be given to explore if Limbs 4 Life were able to facilitate greater connection between those wanting this service as Limbs 4 Life already offers many of these social initiatives, such as the Golf group, amputee Facebook group, and Program Volunteer-only Facebook group. Previous research supports interactions of this manner and suggests that it can have a positive effect on well-being and adjustment to physical health conditions, for example participants may experience feelings of peer belonging and acceptance, social acceptance, increased self-esteem, reduced isolation and community involvement through establishing relationships and connections with others (Marzen-Groller and Bartman, 2005; Embuldeniya et al., 2013; Richardson et al., 2019).

2. Consideration could be given to reinforcing current safety standards around Peer Support place of meeting and transference of personal details

Limbs 4 Life works to mitigate Program risk and indicates that the training process includes a module on Program Volunteer standards and safety practices which covers confidentiality, risk management, duty of care and dealing with difficult people. Consideration could be given to explore if Limbs 4 Life need to further emphasize and escalate the training in this area.

According to the Framework, the majority of Peer Support is provided during the acute or rehabilitation phase and, in most cases, immediately pre or post amputation surgery. If the meeting is to occur outside the health care facility, the visit must take place in a public venue such as a café or a park. Limbs 4 Life insurance does not cover Peer Support Visits that are arranged in an individual's private home and a duty of care to Program Volunteers must be maintained. As evidenced within the results, 10% of Program Volunteers have reported that they have conducted meetings in private homes.

The transference of personal details was also highlighted during the questionnaire and Focus Group phase of this study. According to the Framework document, a Program Volunteer should hand out generic Limbs 4 Life contact detail cards to Program Participants. Any future Program Participant meetings must be organised directly through Limbs 4 Life rather than direct to the Program Volunteer or via a second or third party. The results of the Program Volunteer questionnaire indicated that during visits 31% of Program Volunteers (n=26/84) have provided Program Participants with their personal details. A Program Volunteer within the Focus Group also noted that he had on multiple occasions handed out personal details or requested personal details.

It is noted within the Framework that post training Program Volunteers must complete and sign a statement declaring that they have read and understood all the policy and procedural documents provided to them. Consideration could be given to explore if Limbs 4 Life need to create an additional procedural document that states if the directives of the policies are not followed the Mentoring/Program Volunteering contract would be discontinued.

3. Consideration could be given towards the recruitment strategy for Program Volunteers to maximise the proportion who are utilised in the 1:1 Program

Program Volunteers appreciate their role and the majority participate as it provides them with a rewarding experience as well as instilling hope, emotional support and sharing of the lived experience to the Program Participants. There was great diversity across the Program Volunteers regarding on how many occasions they had been called upon to provide a service, some experiencing greater than 20 visits and some still awaiting a first visit. It was evident through this program evaluation that variation in Program Volunteer utilisation was influenced by Program Volunteer availability, Program Volunteer supply, and that not all Program Volunteers were appropriate to undertake Peer Support visits post training. Another consideration is the permanent (for example due to poor health) or short term (for example work commitments) attrition from the Program Volunteer pool. In December 2019

there were 141 registered Program Volunteers and 38 of them were unavailable for visits due to reasons such as medical issues, caring for family and travel.

Some Program Volunteers indicated that they had completed the training many years ago and, due to no or minimal interaction with Program Participants, they have failed to consolidate the skills learnt. This impacts upon the Program Volunteer emotionally and socially but also economically for Limbs 4 Life who have provided training to the individual at a cost of $2,467 per Program Volunteer. Consideration could be given to explore if Limbs 4 Life need to review their Program Volunteer training program and possibly limit intake numbers or undergo further screening prior to progression into the Program.

The Framework indicates that Limbs 4 Life rarely directly approaches individuals or actively recruits amputees to become Program Volunteers. The organisation believes that individuals should 'feel ready' within themselves to want to contribute to the Program. The framework indicates that, in most cases, a window of three years is required from the time of amputation to the time of volunteering. This recommendation is supported within the literature which suggests that it may be worthwhile for volunteers to be recruited at least two years post limb loss to ensure that the volunteer has adapted socially and emotionally to limb loss and allowing this time may increase resilience amongst the volunteer community (Richardson et al., 2019). Limbs 4 Life may need to reflect upon this recruitment requirement as the results of this study indicate that the timeframe post amputation to Program Volunteering was less than 1 year for 15% (n=13) and between 1-2 years for 19% (n=16) of the Program Volunteers. To supplement these results, data from the Limbs 4 life Administration system indicates that of the current 141 Program Volunteers, there is an average of 15 years (range 1 to 58 years) from time of amputation to time of commencement as a Program Volunteer, with 13 Program Volunteers (9%) commencing 1 to 2 years post amputation.

4. A cost recovery strategy could be considered to determine different funding models for the Program based on willingness to pay

The current evaluation explored the cost of the Program to determine the cost per Program Participant ($796). Presently this cost is borne by Limbs 4 Life through fund raising and this is a significant financial liability for such a valid service. Consideration could be given to explore different payment models. While options include payment through the Health Services, NDIS and Private Health Insurance, Limbs 4 Life does not advocate for payment from the Program Participant. These payment options may prove difficult as Health Services have been impacted by the sate-based disability service funding being transferred to the federal government to contribute to the cost of NDIS; NDIS may prove difficult due to a time lapse between the amputation (point of Peer Support visit) and when a NDIS plan is activated; and finally, in Australia there are no Private Health Insurance policies known to the research team who reimburse for the cost of peer support (personal communication with a Commonwealth Ombudsman representative in December 2019 through the website https://www.privatehealth.gov.au/).

Health Professionals, Program Volunteers and Program Participants were all asked to report their willingness to pay from these four perspectives. All three groups presented a similar

pattern, with a higher willingness to pay for the Health Service, NDIS and Private Health Insurance; and a lower willingness to pay for the Program Participant. It was the Program Participants who most closely approximated the true cost of the Program per Program Participant ($796) with their willingness to pay from the perspective of the Health Service ($450), NDIS ($432) and Private Health Insurance ($347). The findings from the willingness to pay analyses clearly place huge financial value on the service. Limbs 4 Life clearly state that no matter the actual cost, this will remain a free service to the Program Participant.

There is paucity in the literature for robust economic evaluations of peer support programs, including such programs for people following a limb amputation. This type of evaluation is essential in securing short and long term funding for programs (Peers for Progress, 2019). Other peer support services have been shown to be cost-effective, for example diabetes peer support (Peers for Progress, 2019), however it is acknowledged that economic evaluations into peer support are limited and often have methodological limitations (Bagnall et al., 2015; Simpson et al., 2014).

In the questionnaire, the South Australian Health Professionals were asked if they were aware that the Amputee Rehabilitation Guidelines in South Australia recommend that patients are referred to the Limbs 4 Life Program or another Program. Of the 4 South Australian Health Professionals, 50% (n=2) indicated Yes. Having this evidence-based recommendation in clinical guidelines is an important step towards closing the evidence-practice gap. However, consideration needs to be given towards funding this recommendation. At present, no funding consideration is provided in the Amputee Rehabilitation Guidelines in South Australia.

5. Minor points of consideration for Limbs 4 Life

The results from this research project included two additional minor points of consideration for Limbs 4 Life. The first was a request from the referring Health Professionals to receive receipt that Limbs 4 Life has received the referral. The second was to receive notification once the Peer Support visit has been completed. Feedback from the Limbs 4 Life administration team indicated that the auto-notification function from the administration database, for receipt of a referral, had not been working and that this is currently being rectified.

Future research methodological recommendations

Throughout the program evaluation there were a number of barriers to the process of implementing this research project. To counter these barriers in future Limbs 4 Life research projects / program evaluations, two methodological recommendations have been made.

i. Across 2018 and 2019, Limbs 4 Life implemented a new administration server to manage data for the organisation. The program evaluation aligned itself to this new administration server with the intent of dove-tailing the questionnaires from the program evaluation into everyday Limbs 4 Life data collection practice. Due to the complexity of the new administration server and delays in the server going live for Limbs 4 Life, the evaluation was delayed by over 6 months and data transfer from the

administration server into a usable format required significant additional time from an information technology expert. Due to these barriers it is unlikely that the questionnaires from the program evaluation will transition into everyday Limbs 4 Life data collection practice.

Recommendation: Independent research projects / program evaluations using questionnaire methodology could consider using tested administration systems which are purpose built, readily available and allow easy data transfer (such as Survey Monkey).

ii. The questionnaire response rate for the Program Participants of the Program was 10%. While there are many potential reasons for this low response rate, it is hypothesised that a questionnaire around the time of amputation and then again at 6 weeks post amputation may not be appropriate; the questionnaire may have been too long as it contained multiple sections and two quality of life questionnaires (WHO BREF and EuroQOL); and while 85% of the referrals are via the online portal, the email capture rate was low and therefore relied on Health Professionals to administer and return the questionnaire. However, for the 10% who did complete the questionnaire they completed it in full.

Recommendation: Questionnaires for Program Participants of the Program could be brief, outside of the immediate amputation period and have a robust process for delivery of the questionnaire to and from the Program Participant.

Conclusion

The Program was reported to be of significant benefit and value to Health Professionals, Program Volunteers and Program Participants. The themes of access to resources and information and the provision of social and emotional wellbeing were identified across all three groups as being significantly important and positively achieved. The sharing of the lived experience between a Program Volunteer and Program Participant provided a sense of belonging and connection and confirmed that the Program Volunteers were in a strong position to understand the challenges faced following an amputation. This assisted the Program Participants in coping with various challenges and possibly eased the adjustment process. The findings highlight benefits in providing Peer Support and suggest that such support may prove a powerful and inexpensive addition to routine care. Considerations for future iterations of the Program have been presented and these include ongoing 1:1 contact, reinforcing current safety considerations, changes to the recruitment strategy for the Program Volunteers, as well as introducing a cost recovery strategy.

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Appendix 1: Program Participants: Pre-Program Questionnaire

Q1. Do you consent to your anonymous questionnaire responses being made available to the Limbs 4 Life researchers? Yes / No
Q2. What is your age?
Q3. What is your gender? Male / Female / Other
Q4. What is your marital status? Married / Partner / Widowed / Single / Separated / Divorced
Q5. Who do you live with?
Q6. Which state or territory do you reside in?
Q7. Please indicate where you reside within your chosen state or territory? Metropolitan / Rural/Regional
Q8. How were you referred into the program? Self/Family referred or Health Practitioner referred
Q9. What is your current accommodation status? Acute care / rehabilitation facility / community (home)
Q10-15. EUROQOL - see appendix 3
Q16-24. WHOQOL - BREF - see appendix 4

Appendix 2: Program Participants: Post-Program Questionnaire.

Q1. Do you consent to your anonymous questionnaire responses being made available to the Limbs 4 Life researchers? Yes / No
Q2. What is your age?
Q3. What is your gender? Male / Female / Other
Q4. What is your marital status? Married / Partner / Widowed / Single / Separated / Divorced
Q5. Who do you live with?
Q6. Which state or territory do you reside in?
Q7. Please indicate where you reside within your chosen state or territory? Metropolitan / Rural/Regional
Q8. How were you referred into the program? Self/Family referred or Health Practitioner referred
Q9. What is your current accommodation status? Acute care / rehabilitation facility / community (home)
Q10. What was the date of your amputation (or planned future date)? If limb loss was present at birth please put down your birth date
Q11. Are you an upper limb or lower limb amputee? Upper limb / lower limb / both
Q12. Do you use a prosthesis? Yes / No. If NO - will you have a prosthesis in the future?
Q13. Which of the following mobility devices do you use? Prosthesis / crutches / WC / Scooter / Walker
Q14. Was your first peer support visit before or after your amputation? Pre / post
Q15. Did you have anyone else present with you at any of your peer visits? Yes / No
Q16. How many 1:1 peer support visits did you receive?
Q17. Have you ever attended the group support sessions? Yes / No
Q18. Are you currently receiving supports from the National Disability Insurance Scheme (NDIS) program? Yes / No / Not eligible
Q18 (2) If you answered No above do you intend to request access to the NDIS?
Q19. Besides NDIS, do you have access to other Government Disability Funding? For example, Disability Support Pension / TAC / DVA
Q20-25. EUROQOL - see appendix 3
Q26-34. WHOQOL - BREF - see appendix 4
Q35. Has participation in the program increased your confidence through the provision of quality information, resources and community re-engagement?
Strongly agree / disagree / neither agree nor disagree / agree / strongly agree
Q36. Has participation in the program enhanced your sense of empowerment by meeting and engaging with peers who have successfully adapted to the physical impact of limb loss
Strongly disagree / disagree / neither agree nor disagree / agree / strongly agree
Q37. Did you feel 'alone' prior to your first interaction with a Limbs 4 Life volunteer? Yes / No
Q38. Did you feel 'alone' after your first interaction with a Limbs 4 Life volunteer? Yes / No
Q39. What impact has the program had on you (if any)?
Q40. Did you engage in additional services (NON- Limbs 4 Life) as a result of your contact with the program? Yes / No and details
Q41. Did you feel your contact with the program reduced / limited the need to engage in additional services (NON-Limbs 4 Life)? Yes / No and details
Q42. Have you attended other Limbs 4 Life social and activity programs? Yes / No and details
Q43. Have you accessed the Limbs 4 Life website? Yes / No
Q44. Have you accessed the Limbs 4 Life Facebook groups? Yes / No
Q45. Have you accessed the Limbs 4 Life Toolkit? Yes / No
Q46. Have you been able to access support material from Limbs 4 Life? Yes / No
Q47. Did your Volunteer demonstrate a listening ear and sharing of the lived experience? Yes / No

Q48. Would you recommend the program to other people? Yes / No
Q49. What were your expectations of the program?
Q50. Were your expectations met? Yes / No
Q51. What worked well for you?
Q52. What didn't work well for you?
Q53. Did participation in the program give you access to an organisation that understands your unique experience? Yes / No
Q54. Do you think the matching process was successful (that is, you and your volunteer were well matched on important criteria)? Yes / No
Q55. Do you think the matching process enhanced the experience? Yes / No
Q56. If your health service was to fully cover the cost of participating in the program, what should they pay?
Q57.If NDIS was to fully cover the cost?
Q58. If the Participant was to fully cover the cost?
Q59. If private health insurance was to fully cover the cost?
Q60. Are you willing to participate in a 60-minute focus group to allow an in-depth discussion about your experience with the program (VIC & SA only)

Appendix 3: EuroQol – Quality of Life Measure

Health Questionnaire

English version for Australia

By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

Mobility

I have no problems in walking around	❑ PLEASE TICK
I have some problems in walking around	❑ ONE BOX
I am confined to bed	❑

Personal Care

I have no problems with personal care	❑ PLEASE TICK
I have some problems washing or dressing myself	❑ ONE BOX
I am unable to wash or dress myself	❑

Usual Activities *(e.g. work, study, housework, family or leisure activities)*

I have no problems with performing my usual activities	❑ PLEASE TICK
I have some problems with performing my usual activities	❑ ONE BOX
I am unable to perform my usual activities	❑

Pain / Discomfort

I have no pain or discomfort	❑ PLEASE TICK
I have moderate pain or discomfort	❑ ONE BOX
I have extreme pain or discomfort	❑

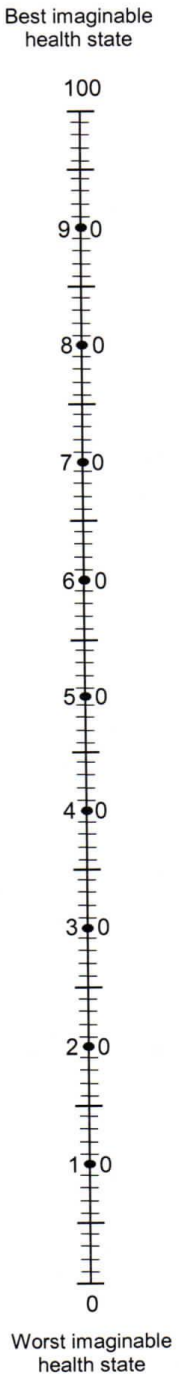
Anxiety / Depression

I am not anxious or depressed	❑ PLEASE TICK
I am moderately anxious or depressed	❑ ONE BOX
I am extremely anxious or depressed	❑

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.

Your own health state today



Appendix 4: The World Health Organisation Quality of Life (WHOQOL) – BREF

WHOQOL-BREF

The following questions ask how you feel about your quality of life, health, or other areas of your life. I will read out each question to you, along with the response options. **Please choose the answer that appears most appropriate.** If you are unsure about which response to give to a question, the first response you think of is often the best one.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last four weeks.**

		Very poor	Poor	Neither poor nor good	Good	Very good
1.	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2.	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last four weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3.	To what extent do you feel that physical pain prevents you from doing what you need to do?	5	4	3	2	1
4.	How much do you need any medical treatment to function in your daily life?	5	4	3	2	1
5.	How much do you enjoy life?	1	2	3	4	5
6.	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7.	How well are you able to concentrate?	1	2	3	4	5
8.	How safe do you feel in your daily life?	1	2	3	4	5
9.	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last four weeks.

		Not at all	A little	Moderately	Mostly	Completely
10.	Do you have enough energy for everyday life?	1	2	3	4	5
11.	Are you able to accept your bodily appearance?	1	2	3	4	5
12.	Have you enough money to meet your needs?	1	2	3	4	5
13.	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14.	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15.	How well are you able to get around?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16.	How satisfied are you with your sleep?	1	2	3	4	5
17.	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18.	How satisfied are you with your capacity for work?	1	2	3	4	5
19.	How satisfied are you with yourself?	1	2	3	4	5

20.	How satisfied are you with your personal relationships?	1	2	3	4	5
21.	How satisfied are you with your sex life?	1	2	3	4	5
22.	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23.	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24.	How satisfied are you with your access to health services?	1	2	3	4	5
25.	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last four weeks.

		Never	Seldom	Quite often	Very often	Always
26.	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	5	4	3	2	1

Appendix 5: Program Volunteer Questionnaire

Q1. Do you consent to your anonymous questionnaire responses being made available to the Limbs 4 Life researchers? Yes / No
Q2. What is your age?
Q3. What is your gender? Male / Female / Other
Q4. Which state or territory do you reside in?
Q5. Please indicate where you reside within your chosen state or territory? Metropolitan / Rural/Regional
Q6. What was the duration of time between your amputation and your volunteering in the program? Please indicate in years. <1 / 1-2 / 3-4 / >5
Q7. How long have you been involved in the program as a volunteer? Please indicate in years. <1/1-2/3-4/>5
Q8. What was your chosen mode of providing the 1:1 volunteer sessions? Please indicate all appropriate responses. Face to face / phone / other
Q9. What type of peer support sessions did you participate in? 1:1 sessions / group sessions / both
Q10. What impact has the program had on you (if any)?
Q11. What were your expectations of the program?
Q12. Were your expectations met? Yes / No
Q13. What worked well for you?
Q14. What didn't work well for you?
Q15. Did participation in the program give you access to an organisation that understands your unique experience? Yes / No
Q16. Do you think the matching process was successful (that is, were you and your participant well matched on important criteria)? Yes / No
Q17. Do you think the matching process enhanced your experience? Yes / No
Q18. Why did you become involved as a Volunteer?
Q19. How were you recruited as a Volunteer? Personally wanted to give back to the program and offered services / via posters in clinic / via Health Professional suggestion / via website / via social media / other
Q20. Have you ever required debriefing / support following a visit as a volunteer? Yes / No. If yes - did you receive the required support?
Q21. Do you feel the training was lacking in any area? Yes / No. If yes please explain.
Q22. At the completion of the training, do you think the assessment to qualify as a volunteer was adequate? Yes / No
Q23. Do you feel supported as a volunteer by the program manager? Yes / No
Q24. Were you provided with a first response kit at the completion of your training? Yes / No
Q25. Do you complete a record sheet after each visit with the Program Participants? Yes / No
Q26. Do you wear a uniform? Yes / No
Q27. At what locations have you met a participant for a 1:1 visit? Please indicate all appropriate responses? Acute / rehabilitation / park / café / private home / other
Q28. Have you ever provided professional counselling, commented on medical matters or given medically related opinions to Program Participants? Yes / No
Q29. Have you ever provided a participant with your personal details? Yes / No
Q30. Have you had access to additional training and updates following your initial volunteer training?
Q31. If the participant's health service was to fully cover the cost of participating in the program, what should they pay?
Q32.If NDIS was to fully cover the cost?
Q33. If the Participant was to fully cover the cost?
Q34. If private health insurance was to fully cover the cost?
Q35. Are you willing to participate in a 60-minute focus group to allow an in-depth discussion about your experience with the program (VIC & SA only)

Appendix 6: Health Professional Questionnaire

Q1. Do you consent to your anonymous questionnaire responses being made available to the Limbs 4 Life researchers? Yes / No
Q2. What is your age?
Q3. What is your gender? Male / Female / Other
Q4. Which state or territory do you reside in?
Q5. Please indicate where you reside within your chosen state or territory? Metropolitan / Rural/Regional
Q6. What is your Health Profession? Medical / Nursing / Allied Health / other
Q7. How long have you been working in your health profession? Please indicate in years. <1 / 1-3 / 4-6 / 6-10 / >10
Q8. How long have you been working with the Amputee Population? <1 / 1-3 / 4-6 / 6-10 / >10
Q9. How long have you been referring into the Limbs 4 Life Amputee Program? <1 / 1-3 / 4-6 / 6-10 / >10
Q10. How do you refer into the program? Please indicate all appropriate responses. Email / online portal / phone / other
Q11. Approximately how many patients have you referred into the program? ,10 / 10-20 / 20-30 / 30-40 / 40-50 / >50
Q12. What are your reasons for referring into the program?
Q13. As a Health Professional what impact has the program had on you (if any)?
Q14. As a Health Professional what impact do you think the program had on your patients (if any)?
Q15. What were your expectations of the program?
Q16. Were your expectations met? Yes / No
Q17. As a Health Professional what worked well for you?
Q18. As a Health Professional what didn't work well for you?
Q19. Was the referral process straight forward? Please discuss your answer/
Q20. Were you able to easily access the annual Limbs 4 Life in-service at your local health service? Please discuss your response.
Q21. If the participant's health service was to fully cover the cost of participating in the program, what should they pay?
Q22.If NDIS was to fully cover the cost?
Q23. If the Participant was to fully cover the cost?
Q24. If private health insurance was to fully cover the cost?
Q25. South Australian Health Professionals only: Are you aware that the Amputee Rehabilitation Guidelines in SA recommend that patients are referred to the Limbs 4 Life Program or another Program? Yes / No

Appendix 7: Post-Program Participant Focus Group

Post-Program Participant Focus Group (Victoria and South Australia)

The focus groups will be facilitated by one investigator with note taking by a second investigator. In addition, the focus groups will be recorded and transcribed verbatim for analysis of the focus group content.

Section of the focus group	Comments
Introduction and consent	It is explained that participation is voluntary and prior to commencing all Program Participants have given informed consent to participate.
Demographics	It is explained that the demographic information will be presented for the group, not individuals and that individuals will remain de-identified. Demographic data to be collected: • Age group • Gender • Site of amputation • Rural or metropolitan residence (State / Territory will be known) • Current accommodation (acute hospital, rehabilitation hospital, community)
Questions and topics for discussion	• As a program participant, what was your expectation of the Program? • Was your expectation met? • What worked well for you? • What did not work well for you? • What could be done to improve the program? • What impact did the program have on you? • Experience with access to government funding for amputee related needs and support (e.g. NDIS and Amputee Support Funding) • Would you recommend this program to other people? • Additional topics will be informed by the feedback that has emerged from the program participant questionnaires
Wrap up of the session	Program Participants are thanked for their time and for participating in the focus group

Appendix 8: Program Volunteer Focus Group

Program Volunteer focus groups (Victoria and South Australia)

The focus groups will be facilitated by one investigator with note taking by a second investigator. In addition, the focus groups will be recorded and transcribed verbatim for analysis of the focus group content.

Section of the focus group	Comments
Introduction and consent	It is explained that participation is voluntary and prior to commencing all Program Participants have given informed consent to participate.
Demographics	It is explained that the demographic information will be presented for the group, not individuals and that individuals will remain de-identified. Demographic data to be collected: • Length of time as a volunteer in the program • Age group • Gender • Site of amputation • Rural or metropolitan residence (State / Territory will be known)
Questions and topics for discussion	• As a volunteer, what was your expectation of the Program? • Was your expectation met? • What worked well for you? • What did not work well for you? • Ease of access to reimbursement for volunteer costs? • Did the training program ensure you were well prepared you to be a volunteer? • Are you aware of the limitations and your own needs to avoid situations that are unsafe / uncomfortable? • Have you ever provided professional counselling, commented on medical matters or given medically related opinions to Program Participants? • Have you ever had to deal with an issue raised regarding mental health or suicide? If so, how confident were you in dealing with the situation? • Have you had access to additional training and updates following your initial volunteer training? • Do you get acknowledgement from Limbs 4 Life for your valuable contribution? • Additional topics will be informed by the feedback that has emerged from the program volunteer questionnaires
Wrap up of the session	Program Volunteers are thanked for their time and for participating in the focus group

Appendix 9: Costs for the Program 2013/14 to 2017/18 (inflated to NPV 2018/19)

			2013/14	2014/15	2015/16	2016/17	2017/18	Total (each year inflated by CPI for a 2018/19 NPV)
Direct costs of volunteer training program	Hosting the Volunteer training sessions CATERING	Number of units (number of training sessions)	5	4	3	8	5	
		Cost per unit	Variable	Variable	Variable	Variable	Variable	
		Total cost	$864	$1,185	$950	$2,338	$1,066	$6,714
	Additional printed support for the Program Volunteers	Number of units		1	1			
		Description		Health literacy Guide ($2860) Local Support Group manual ($1286) Volunteer business cards ($178).	Training manual ($9.30 x 42) & kit bags ($1.39 x 42) guide ($2.53 x 42)			
		Cost per unit		Variable	Variable			
		Total cost		$4,324	$555			$5,203
	Hosting the Volunteer training sessions ROOM HIRE	Number of units (number of training sessions)	5	4	3	6	5	
		Cost per unit	Variable	Variable	Variable	Variable	Variable	
		Total cost	$403	$250	$250	$1,715	$1,015	$3,778
	Postage to the Program Volunteers	Number of units (number of Program Volunteers)	1	1	1	1	1	
		Description	Postage	Postage	Postage	Postage	Postage	
		Cost per unit	$6,655	$7,053	$10,622	$11,637	$11,500	
		Total cost	$6,655	$7,053	$10,622	$11,637	$11,500	$49,725
	Printing	Number of units (number of Program Volunteers)	1	1	1	1	1	
		Description	Printing	Printing	Printing	Printing	Printing	
		Cost per unit	$14,148	$13,845	$28,879	$15,475	$13,700	
		Total cost	$14,148	$13,845	$28,879	$15,475	$13,700	$90,611

			2013/14	2014/15	2015/16	2016/17	2017/18	Total (each year inflated by CPI for a 2018/19 NPV)
	Police checks	Number of units (number of Program Volunteers)	25	35	42	61	49	
		Description	Police checks	Police checks	Police checks	Police checks	Police checks	
		Cost per unit	$16	$16	$16	$12	$19	
		Total cost	$388	$543	$651	$720	$950	$3,399
	Limbs 4 Life staff providing the training	Number of units (number of Program Volunteers)	1		1	1		
		Description	General training costs		General training costs	General training costs		
		Cost per unit	$2,276		$5,606	$8,046		
		Total cost	$2,276		$5,606	$8,046		$16,739
	Polo shirts	Number of units (number of Program Volunteers)	47	35	42	83	49	
		Description	Polo shirts	Polo shirts	Polo shirts	Polo shirts	Polo shirts	
		Cost per unit	$18	$17	$17	$17	$17	
		Total cost	$846	$589	$706	$1,396	$824	$4,578
	General volunteer expenses	Number of units (number of Program Volunteers)	1	1	1	1	1	
		Description	General	General	General	General	General	
		Cost per unit	$2,829	$550	$1,796	$720	$750	
		Total cost	$2,829	$550	$1,796	$720	$750	$7,060
	Resources for the Program Volunteers	Number of units (number of Program Volunteers)	47	35	42	83	49	
		Description	Group handbook	Group handbook	Group handbook	Group handbook	Group handbook	
		Cost per unit	$6	$6	$6	$6	$6	
		Total cost	$259	$193	$193	$457	$270	$1,436
	Resources for the Program Volunteers	Number of units (number of Program Volunteers)	47	35	42	83	49	
		Description	Volunteer handbook	Volunteer handbook	Volunteer handbook	Volunteer handbook	Volunteer handbook	
		Cost per unit	$7	$8	$8	$8	$8	
		Total cost	$306	$296	$296	$702	$415	$2,110
	Travel including airfares,	Number of units				7	4	

			2013/14	2014/15	2015/16	2016/17	2017/18	Total (each year inflated by CPI for a 2018/19 NPV)
	accommodation and airport transfers.	Total cost				$5,000	$1,650	$6,863
	Other costs associated with the Volunteer training program	Number of units		1			Lanyard IDs n=49 Program Volunteers at $2.51 each	
		Cost per unit		$756			$123	$932
In-direct costs of volunteer training program	Marketing and Communication - Program flyers	Number of units	2,240	2,240	2,240	5,110	5,110	
		Cost per unit	$0.19	$0.19	$0.19	$0.19	$0.19	
		Total cost	$426	$426	$426	$971	$971	$3,359
	Marketing and Communication - Peer support posters	Number of units	64	64	64	146	146	
		Cost per unit	$1	$1	$1	$1	$1	
		Total cost	$64	$64	$64	$146	$146	$505
	Phone	Number of units	1	1	1	1	1	
		Cost per unit	$3,872	$3,516	$3,946	$4,620	$3,900	
		Total cost	$3,872	$3,516	$3,946	$4,620	$3,900	$20,876
	Insurance	Number of units	1	1	1	1	1	
		Cost per unit	$2,800	$2,587	$2,811	$2,822	$2,580	
		Total cost	$2,800	$2,587	$2,811	$2,822	$2,580	$14,316
	Database	Number of units	1	1		1	1	
		Cost per unit	$1,080	$2,281		$877	$1,700	
		Total cost	$1,080	$2,281		$877	$1,700	$6,242
	IT Systems/website	Number of units	1	1			Online Peer Support referral poster and postage n=146	
		Cost per unit	$2,200	$740			$3	

			2013/14	2014/15	2015/16	2016/17	2017/18	Total (each year inflated by CPI for a 2018/19 NPV)
		Total cost	$2,200	$740			$387	$3,567
	Personally - Admin Support, CEO, Program Manager	Number of units	Susanne Riddington	Susanne Riddington	Fay Keegan/ Kylie Franson ($32000) Mel Noonan ($35000)	Fay Keegan/ Kylie Franson ($32000) Mel Noonan ($35000)	Mel Noonan/Kylie Franson	
		Cost per unit	$35,000	$35,000	$67,000	$75,000	$75,000	$300,116
	Capital costs (rent)	Number of units	1	1	1	1	1	
		Cost per unit	$7,500	$9,833	$9,564	$14,659	$21,862	$66,153
Direct cost for the peer support sessions - GROUP	1 Hosting the group sessions (room hire, refreshments, etc)	Number of units (number of group sessions)	AGM/Peer Support Awards, venue hire (318), catering (734)	Melbourne 'amputees in motion' project n=50				
		Cost per unit	$1,052	$300				$1,460
	2 Hosting the group sessions (room hire, refreshments, etc)	Number of units (number of group sessions)		Brisbane n=35				
		Cost per unit		$0				$0
	3 Hosting the group sessions (room hire, refreshments, etc)	Number of units (number of group sessions)		NSW forum n=65 cost of airfare and accommodation				
		Cost per unit		$855				$913
	4 Hosting the group sessions (room hire, refreshments, etc)	Number of units (number of group sessions)		Adelaide forum n=40				
		Cost per unit		$771				$823
	5 Hosting the group sessions (room hire, refreshments, etc)	Number of units (number of group sessions)		Golf Xmas even n=25 (balls x $10.00 per person, coach $150.00 x 2 hours				
		Cost per unit		$550				$587
	Reimburse-ment of volunteer costs	Number of units (number of Program Volunteers)						
		Cost per unit						$0
Direct cost	Reimbursem	Number of	20	1				

			2013/14	2014/15	2015/16	2016/17	2017/18	Total (each year inflated by CPI for a 2018/19 NPV)
for the peer support sessions - 1:1	ent of volunteer costs - fuel costs	units (number of Program Volunteers)						
		Cost per unit	$50	$105				
		Total cost	$1,000	$105				$1,196
	Handouts and written resources for the Program Participants - patient kits	Number of units (number of Program Participants)	130	137	176	172	178	
		Cost per unit	$10	$10	$10	$10	$10	
		Total cost	$1,245	$1,312	$1,312	$1,694	$1,753	$7,677
	Other	Number of units		$137				
		Description		Images ($265) Pens ($1.10 each x 137) Stress balls ($1.03 x 137) fact sheets ($0.26 x 137) Info cards ($0.08 x137)				
		Cost per unit		Variable				
		Total cost		$608				$649
In kind: either products (IT, equipment, printing, etc) or services (people time)	1	Describe the product or service	Adelaide Peer training venue hire, pro bono	Brisbane group session n=35 venue hire/catering	Adelaide volunteer training session - in kind venue hire	Venue hire x 2	Catering	
		Cost	$100	$1,000	$300	$330	$300	$2,140
	2	Describe the product or service		NSW forum n=65 venue hire/catering			Venue hire	
		Cost		$500			$165	$701
	3	Describe the product or service		Adelaide forum n=40 venue/ catering				
		Cost		$500				$534
	4	Describe the product or service		Golf Xmas event n=25 venue				
		Cost		$500				$534