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## RESEARCH PAPER

# Identifying successful outcomes and important factors to consider in upper limb amputation rehabilitation: an international web-based Delphi survey

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### Abstract

**Purpose:** To identify and gain agreement on successful outcomes of and important factors to consider in rehabilitation following upper limb absence (ULA). **Method:** Fifty-three participants consisting of multi-disciplinary rehabilitation professionals, and individuals with ULA were invited to complete a three-round modified Delphi iterative survey. Following three Delphi questionnaire rounds, participants clarified the definitions of success in three areas (prosthesis use, activities and participation and self-image). In addition, participants identified and agreed the important factors to consider in rehabilitation after ULA. **Results:** Results showed that participants reached agreement (having a SD <1) over the three rounds on 78 out of 81 rated items. Of these, 54 rated items were “accepted” as important by panel members (mean score of 4 on a five-point Likert scale). Twenty-four items were rejected. Only three rated items had not reached agreement by the third round. **Conclusions:** Clarification of successful outcomes and factors that should be taken into consideration in a patient’s rehabilitation allows a clearer evaluation of what should be the focus of rehabilitation. The findings from the Delphi study can help form the basis for a screening tool for clinicians to be able to identify areas of concern and subsequent treatment for a patient in their care.

### Keywords

Amputation, body image, prostheses, upper extremity

### History

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### ► Implications for Rehabilitation

- To date, there has been no definitive guidance on which outcomes should be assessed in amputation rehabilitation.
- This study identified the seven core domains of importance regarding the rehabilitation of individuals with ULA and created a starting point for developing a new portfolio of research that aims to address all relevant aspects of patients’ rehabilitation.
- This study reached a consensus and enabled an insight into what defines successful prosthesis use, self-image and activities and participation, and provided evidence that the current definition of prosthesis use in the literature does not sufficiently capture what RPs and individuals with ULA consider important, such as specific use of the prosthesis, as often as an individual wishes, while using it as intended.
- This study provided RPs and individuals with ULA an opportunity to communicate their opinions and knowledge anonymously regarding the important areas to consider in rehabilitation.

### Introduction

The majority of the literature on major limb absence has largely been concerned with the lower limb. Potentially, the primary reason for this is due to the relatively fewer numbers of

individuals with upper limb absence (ULA) in the community in comparison to the amount with lower limb absence (LLA). Individuals with ULA tend to be younger and to lose their limbs due to trauma, in comparison to those with LLA, who tend to be older and lose their limbs as a result of illnesses such as diabetes and vascular disease. Therefore, individuals with ULA tend to require input for a greater number of years during their lifetime and this may result in substantial costs to themselves and the health service. Thus, it is important that these individuals reach their full potential as soon as possible following rehabilitation. To facilitate this endeavor, it is essential to know what are deemed as

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successful outcomes and what factors are important to consider in rehabilitation to enable these to be achieved.

There is currently no definitive guidance on which outcomes should be measured in amputation rehabilitation and it has been recommended that amputation rehabilitation care providers should reach a consensus as to which outcome measures are to be used [1]. This will facilitate communication between centres and make possible collaboration in needed multi-centre trials [1]. However, in order to have one tool to be used in a rehabilitation setting, it is important to have one that encompasses all variables and outcomes that are of relevance to all individuals with ULA and to all members of the multi-disciplinary team. While there are existing tools such as the Disability of the Arm, Shoulders and Hand Scale [2], the Upper Extremity Functional Status module of the Orthotics and Prosthetics User Survey [3] and ABILHAND [4], most of these focus on functional outcomes. Furthermore, bringing together the most salient and important aspects of these tools is desirable.

Most of the literature concerning individuals with ULA has focused almost exclusively on the prosthesis at the expense of other aspects of rehabilitation. There are other potential outcomes that may be equally important to an individual, in particular psychological and social outcomes, such as body image disturbance or activities of importance that need to be researched. Recent publications have begun to redress this imbalance [5–8]. However, more work and greater insight is needed into these domains of ULA. It is understandable why there is this strong focus on the prosthesis, given the high cost and potential for functional gain associated with an upper limb prosthesis and therefore the need to understand the factors that promote its use. In particular, these factors are often investigated to predict “successful prosthesis use” but this term is usually loosely defined, with little or no justification for its definition. Furthermore, the definition of “successful prosthesis use” often varies across studies, which makes it difficult to compare them and to draw conclusions regarding the likely determinants of prosthesis use. In defining “prosthesis success”, some studies refer to whether the prosthesis is used at all versus outright rejection and others assess frequency of use, with greater hours of prosthesis use being considered as greater prosthesis success [9–16]. However, there is little agreement on how many hours use is “success” [10,11,14–16]. Additionally, some studies have considered that use of a cosmetic prosthesis is unsuccessful [17]. No studies have included any justification for their definition of success or an explanation for why it differs broadly across studies. Furthermore, the individuals using the prostheses have not been involved in determining what constitutes successful prosthesis use.

Additionally, within the ULA literature, the majority of studies are concerned with identifying the demographic-, physical- or amputation-related factors associated with prosthesis use and there are very few studies assessing the psychological or social factors that predict prosthesis use. In fact, this dearth of psychological and social research is evident in general in research concerning ULA. Within the LLA literature, it has been suggested that the physical aspects of disability are much less central to the adaptation process than the psychological, developmental and social environment and the resources of the individual who acquires the disability [17]. However, the psychological and social elements of limb absence are relatively understudied areas of ULA research. Since ULA is more visible and more difficult to conceal than LLA, it has the potential to have a greater impact on an individual’s body image and day to day functional activities given that only limited function is possible with an upper limb prosthesis compared to the comparatively good function a lower limb prosthesis affords [18]. Therefore, it is important to have a

greater understanding of body image disturbance and activities of importance amongst individuals with ULA; as well as understanding other factors that need to be taken into consideration during rehabilitation.

The aim of this study is to reach agreement on what should be defined as successful outcomes in three areas: “prosthesis use”, “activities and participation” and “self-image” following ULA. This study also aims to identify and gain a consensus on what factors are important to consider in rehabilitation following ULA.

## Method

### Study design

This study used a three round “Modified Delphi” technique to reach group consensus on “successful outcomes” in three areas and the most important factors to consider in rehabilitation following ULA. The aim of the Delphi technique is to reach consensus of opinion from a group of “informed individuals” in a given area. The Delphi involves sending a series of questionnaires to participants, allowing them to anonymously give their opinions and see how it aligns with others, and change it, if desired, after considering the group responses. Consensus methods such as the Delphi technique have been frequently used in health research [19–25] and amongst individuals with LLA [26]. A modified Delphi study is any study which deviates from the traditional Delphi in terms of not including an open-ended format in the first round of questionnaire distribution. It can also include as few as two questionnaire rounds. Most importantly, it still has anonymity, iteration, controlled feedback and statistical aggregation of group scores [27].

### Participants

The participant panel consisted of a heterogeneous group of participants from several disciplines involved in the rehabilitation of patients with ULA. The panel also included individuals with ULA. Patients and service users have been included in Delphi studies [25,28], and their participation has provided valuable insight and is deemed undoubtedly important [29]. To develop the initial list of participants, this study employed purposive sampling. Participants were selected on the basis of their ability to answer the research questions and were not representative of the general population [30]. Rehabilitation professionals (RPs) were identified through published literature, conference attendance and “snowballing”, where participants were encouraged to pass the questionnaire onto other eligible individuals [31].

Individuals with ULA were recruited by e-mailing relevant international support groups and requesting that they distribute the information sheet to their support group members. Private prosthetic limb fitting clinics were also contacted and asked to distribute the information sheet to their patients. In addition, individuals who attended an amputee annual conference were referred to the study. Participants were also encouraged to pass the questionnaire onto other individuals that might wish to complete the questionnaire. Due to this recruitment process, it is not possible to calculate the response rate from individuals with ULA.

The inclusion criteria for RPs to be eligible to participate in this study were that: (1) they must be either a researcher who has authored an article on upper limb amputation, prosthetics or rehabilitation that has been published in a peer reviewed journal during the past 10 years and/or (2) they must be working as part of a rehabilitation team concerned with individuals with ULA for at least three years in the past 10 years. For individuals with ULA to participate, they had to be at least one year post-amputation, be over 18 years of age, have a major ULA, and be able to read and understand written English. There is no set sample size

Table 1. Demographic information for all participants across three rounds.

Characteristics	Details	Round 1 n (%)	Round 2 n (%)	Round 3 n (%)
Total participants		73 (100)	58 (100)	53 (100)
Total group gender	Male	36 (49.1)	29 (50)	26 (49.1)
	Female	37 (50.1)	29 (50)	27 (50.9)
Total group representation	RPs	47 (64.4)	41 (70.7)	38 (71.7)
	Individuals with ULA	22 (30.1)	15 (25.9)	13 (25.5)
	RPs with ULA	4 (5.5)	2 (3.4)	2 (3.8)

for Delphi studies but a sample size of 15–30 has been recommended [32].

### Procedure

Ethical approval to conduct an international web-based Delphi study was sought and granted from *Dublin City University Ethics Committee*. There were three questionnaire rounds in total. The results from each round informed the next questionnaire round.

The first round questionnaire contained three sections. The first section contained demographic questions, with separate questions tailored specifically for RPs and individuals with ULA. Items to be rated by the panel were developed through a review of the literature on ULA, findings from repertory grid interviews [33] and qualitative research with RPs and individuals with ULA. Compilation of this data highlighted that there is disagreement in what are considered successful outcomes in some areas such as “prosthesis use”, “activities and participation” and “self-image”. Therefore, the second section in the questionnaire presented statements with the aim of reaching agreement in these areas. The literature review also highlighted that there is very little agreement on what factors are important to consider in rehabilitation of individuals with ULA. Therefore, the third section in the questionnaire sought to reach agreement on the most important factors to consider in rehabilitation. For sections 2 and 3, participants were asked to rate each item on a five-point scale for their agreement as to whether they were a “successful outcome” (second section) or important to consider in ULA rehabilitation (third section). At the end of each section, participants were given the opportunity to add to the list anything that they felt was important but had not been included.

In round 1, participants were asked to rate the items on a 1–5 Likert scale of agreement. Consensus (agreement amongst panel members) was defined prior to starting the study. Consensus on an item was reached when it had a SD of less than 1 indicating a small variation in responses from participants [34]. If the item also had a mean rating of 4 or above, it was accepted as a successful outcome.

Once an item reached agreement, participants were not asked to rate it again in the next round. If an item had a SD greater than 1, regardless of the mean score, it was considered that this statement had a wide variation in responses from participants (i.e. disagreement). Participants were asked to rate this statement again in round 2. If an item had a mean score less than 4 (but SD less than 1), it was considered that there was an agreement amongst respondents that this item was unimportant. Participants were given another opportunity in round 2 to rate this statement, however, if it was still considered unimportant in round 2, mean less than 4, this statement was fully rejected. The new items that participants suggested in round 1 were rated by participants in round 2.

The third round involved asking participants to rate any items that had not yet reached agreement in previous rounds, and those that had been rejected in the second round.

### Results

There were 73 participants in the first round of the Delphi, 58 participants in the second round and 53 participants in the third round. Of the 53 participants in the third round of the Delphi, 38 were RPs, 13 were individuals with ULA and 2 were people with ULA who were also RPs (Table 1). There were no systematic differences between those who completed all three rounds and those who dropped out at rounds 2 and 3. We have not included a detailed breakdown of demographic information for participants who were RPs with ULA due to potentially identifiable information.

Of the 38 RPs in the third round of the Delphi study, 23 were from USA, nine from UK, three from Canada, one from Australia, one from Japan and one from the Netherlands. In the third round, there were 13 OTs, 12 Prosthetists, three Engineers, four Psychologists, one Consultant in rehabilitation medicine, one Consultant in pain medicine, one Physiotherapist (1), one surgeon, one social worker and one MD. Mean years of experience in the final round was 13.3 years (SD 9.5) amongst RPs.

Of the 13 individuals with ULA in the third round, there were eight men and five women. Their mean age was 54.9 (range: 42–71) and there was a mean of 29.5 years since limb loss (range: 1–71 years). Seven individuals lost their limb due to trauma, three to cancer, two had congenital limb absence and one had an infection. Seven individuals has a below elbow limb absence, four an above elbow absence, one person through wrist and one person a shoulder disarticulation. Twelve individuals with ULA were from USA in the third round, while one was from Switzerland. Seventy-seven percent of individuals with ULA reported prosthesis use.

The results showed that by the third round, consensus (SD <1: little variation in responses) was reached on 78 of 81 rated items. Of these, 54 rated items had a mean rating of 4 or above and were accepted. Twenty-four items were rejected for having a mean score below 4. Three rated items did not reach agreement after the three rounds.

Tables 2–4 present the successful outcome domains and the associated items that were rated by participants. For prosthesis use statements, three statements were accepted, eight rejected and two did not reach agreement (Table 2). Amongst the statements for “Activities and Participation”, six were accepted, four were rejected and one did not reach agreement (Table 3). Two self-image statements were accepted and five were rejected (Table 4).

Table 5 presents the important domains and associated factors to consider in rehabilitation. It also lists the 43 items accepted and the 10 items rejected by participants.

### Discussion

To our knowledge, this is the first study to systematically gather opinions from those most informed and knowledgeable in the area of ULA, and to reach agreement on successful outcomes of and important factors to consider in rehabilitation following upper limb amputation.

This research identified and clarified what describes “success” in three areas: “prosthesis use”, “activities and

Table 2. Prosthesis use outcomes.

Successful outcome	Round 1 Mean (SD)	Round 2 Mean (SD)	Round 3 Mean (SD)	Statement status
A successful outcome is when a person uses the prosthesis as often as they wish	4.38 (0.68)			Accepted in round 1
A successful outcome is when a person uses the prosthesis as intended	4.08 (0.89)			Accepted in round 1
A successful outcome is when a person wears their prosthesis for specific activities	3.97 (0.82)	4.02 (0.61)		Accepted in round 2
A successful outcome is when a person wears their prosthesis all day every day	3.44 (1.12)	3.12 (1.08)	3.08 (1.02)	Agreement not reached by round 3
A successful outcome is when a person feels their prosthesis is part of them	4.08 (1.02)	3.83 (1.27)	3.64 (1.08)	Agreement not reached by round 3
A successful outcome is use of a prosthesis for a person's pre-amputation job or activities	3.99 (0.94)	3.79 (0.91)		Rejected in round 2
A successful outcome is use of a non-functional cosmetic prosthesis	3.08 (1.16)	3.26 (0.87)		Rejected in round 2
A successful outcome is when a person is content not to wear a prosthesis	3.42 (1.01)	2.40 (0.88)		Rejected in round 2
A successful outcome is when a person uses the prosthesis for both functional and cosmetic purposes		3.80 (0.89)	3.53 (0.93)	Rejected in round 3
A successful outcome is when a patient is satisfied with the cosmetic appearance of the prosthesis		3.88 (0.80)	3.94 (0.14)	Rejected in round 3
A successful outcome is when a person feels grateful when the prosthesis is initially delivered		2.86 (0.98)	2.62 (0.71)	Rejected in round 3
A successful outcome is when a person uses the prosthesis to feel socially accepted		3.31 (0.98)	3.04 (0.94)	Rejected in round 3

Table 3. Activities and participation outcomes.

Successful outcome	Round 1 Mean (SD)	Round 2 Mean (SD)	Round 3 Mean (SD)	Statement status
A successful outcome is a person's ability to perform their own personal care without help from other people	4.37 (0.81)			Accepted in round 1
A successful outcome is a person's ability to complete activities of daily living without help from other people	4.34 (0.82)			Accepted in round 1
A successful outcome is a person's ability to drive if they desire	4.29 (0.72)			Accepted in round 1
A successful outcome is when a person is satisfied with their functional abilities	4.51 (0.75)			Accepted in round 1
A successful outcome is when a person has returned to active employment (but may have to change jobs)	4.21 (0.65)			Accepted in round 1
A successful outcome is when a person is performing to the best of their ability	4.51 (0.71)			Accepted in round 1
The achievement of tasks set by RP		3.78 (0.73)	3.76 (0.59)	Rejected in round 2
A successful outcome is when a person uses the prosthesis to feel socially accepted		3.31 (0.98)	3.04 (0.94)	Rejected in round 2
A successful outcome is a person's ability to perform activities to the same standard as they had before the limb absence	3.52 (1.14)	3.60 (1.04)	3.38 (0.99)	Rejected in round 2
A successful outcome is a person's ability to perform activities within the same time parameters as prior to their injury	3.33 (1.00)	3.11 (0.97)		Rejected in round 2
A successful outcome is when a prosthetic user can perform an activity bi-laterally to an equal standard as a two-handed person		3.41 (1.30)	3.23 (1.17)	Agreement not reached by round 3

participation'' and ''self-image''. Statements that participants agreed described successful outcomes concerning ''prosthesis use'' included when a person ''wears a prosthesis for specific activities'', ''wears prosthesis as often as they wish'' and ''uses the prosthesis as intended''. The findings contrast with the definition that is most often used to describe successful prosthesis use in the ULA literature, that is, greater hours of use indicating greater success [10–14]. This suggests that measuring hours of

use per day, a common method of measuring successful prosthesis use in the literature, may not always be an appropriate measure of prosthesis success to be used in research or practice. The findings from the Delphi support the type of development by Gaine et al. [18] of the ''Prosthetic success score'' (constituting daily wear, patient satisfaction and function level) and Bhaskarand's [35] ''Prosthetic rehabilitation score'' (patient acceptance, prosthetic usage and function level) as alternative measures of prosthesis

Table 4. Self-image outcomes.

Successful outcome	Round 1 Mean (SD)	Round 2 Mean (SD)	Round 3 Mean (SD)	Statement status
A successful outcome is when a person reports having a positive body image (feeling attractive)	4.30 (0.81)			Accepted in round 1
A successful outcome is when a person is not feeling self-conscious when in public with a prosthesis	4.00 (0.83)			Accepted in round 1
A successful outcome is when a person is confident to show their residual limb (stump) in public	3.63 (1.0)	3.28 (1.07)	3.32 (0.75)	Rejected in round 3
A successful outcome is when a person does not feel they stand out	3.66 (0.98)	3.54 (0.60)		Rejected in round 2
A successful outcome is when a person does not mind looking at their residual limb (stump)	3.96 (0.89)	3.93 (0.95)		Rejected in round 2
A successful outcome is when a person feels that they look balanced	3.71 (0.84)	3.50 (0.73)		Rejected in round 2
A successful outcome is when a person is not feeling self-conscious when in public without a prosthesis	3.90 (0.89)	3.79 (0.85)		Rejected in round 2

success beyond the limited ‘greater hours, greater success’ notion of most studies. These ‘prosthetic scores’ [18,35] appear to be more all-encompassing measures of prosthetic success. The findings from this study are a key step in expanding the definition of prosthetic success to include individualized goals and pertinent psychological and social outcomes. Furthermore, the findings could be incorporated into a measure that evaluates subjective success of rehabilitation.

Factors to consider in the rehabilitation of ULA emerged as important across seven domains: ‘prosthesis use’, ‘activities and participation’, ‘self-image’, ‘physical factors’, ‘psychological factors’, ‘service factors’ and ‘social factors’. The category of ‘demographic factors’ which consisted of ‘age at amputation’, ‘gender’ and ‘level of education’ had all three items rejected by participants. Important factors identified in the seven domains reinforce the lessons from the field of disability studies that recommend attending to the personal, social and environmental factors that affect the life of an individual with ULA. This also reflects the domains of the International Classification of Functioning, Disability and Health [36].

The seven domains and corresponding factors that reached consensus provide for clinicians a guide to the most salient issues to attend to amongst individuals with ULA, and likely areas of concern. A review of the literature has highlighted that there is a need for a brief instrument to assess areas of concern amongst individuals with ULA, so that RPs can identify issues quickly in consultation with a patient. It would be useful to use the identified domains and factors to form a screening tool for individuals with ULA in a rehabilitation setting. The checklist would allow rapid evaluation of several areas of concern, such as disruption in activities and participation, physical issues, service issues and prosthetic issues, as well as psychological issues. This type of checklist has been found useful in other areas of healthcare [37] and is an area that warrants further research.

Identification of psychological factors of importance in the Delphi study such as ‘a patient’s feeling of control over the rehabilitation’, ‘a patient’s resilience’, ‘patient’s attitude’, ‘patient’s expectations’, ‘patient’s mood’, ‘motivation’, ‘sense of humor’ and ‘social skills’ suggest that the role these variables play in adjustment to ULA need to be assessed. Formal measurement of these variables, which have mostly not been empirically investigated in the literature, could prove informative to clinicians and add greater support for the value of promoting these psychological traits in individuals with ULA. Furthermore, it highlights the important role RPs and patients themselves believe patients play in achieving desired outcomes [38].

This research included RPs and those with ULA. It is acknowledged that there may be differences in these groups’ perspectives and motivations. However, by the final round, only three items could not reach agreement and the small attrition rates suggest that panel members were able to converge to an agreement on most items. The inclusion of both RPs and people with ULA ensured that all relevant voices were heard in this study. It is acknowledged that there was a 3 to 1 disparity between the two groups, with an over-representation of RPs compared to individuals with ULA. Although a greater number of individuals with ULA would have been desirable, their inclusion was highly valuable. It also reflects rehabilitation as a team approach and the central role of the patient in this team. The experiential knowledge of patients combined with professional knowledge provides a solid foundation for identifying meaningful outcomes and items important to consider in ULA rehabilitation. This approach is also consistent with CARF’s emphasis on promoting client-centred care [39].

### Study limitations

There are two main limitations to this study. The use of panel members from different countries and different health systems that have different priorities and funding, as well as RPs having differences in training, could have made reaching consensus difficult. However, this international Delphi resulted in a wide perspective being gathered amongst a geographically diverse group of RPs and individuals with ULA who reached consensus on all but three items. It should also be noted that difficulties in reaching consensus should not be considered as a limitation, but reflect the diversity of approaches in international rehabilitation practice. Bringing different experiences together will allow for some kind of normalization of practice for patients. Additionally, some level of attrition was expected with this research. The largest attrition rate was observed between round one and round two where 20% of round 1 participants did not complete the round 2 of the study. However, the attrition rate from round 2 to round 3 was particularly low (8.6%) and each round exceeded the recommended response rate of 70% [40].

### Conclusion

This study provided an opportunity to identify the core domains of importance regarding the rehabilitation of individuals with ULA and created a starting point for developing a new portfolio of research that aims to address all relevant aspects of patients’ rehabilitation. This study reached a consensus and enabled an

Table 5. Factors to be considered in ULA rehabilitation.

Domains	Items	Round 1 Mean (SD)	Round 2 Mean (SD)	Round 3 Mean (SD)	Statement status
Activities and participation	Achieving set goals	4.48 (0.56)			Accepted in round 1
	Engagement in activities of daily living	4.74 (0.47)			Accepted in round 1
	Engagement in leisure activities	4.55 (0.55)			Accepted in round 1
	Getting along with other people	4.10 (0.85)			Accepted in round 1
	Getting around	4.44 (0.62)			Accepted in round 1
	Perceived environmental barriers	4.16 (0.75)			Accepted in round 1
	Performing self-care	4.70 (0.55)			Accepted in round 1
	Performing social/family roles of importance (e.g. breadwinner/spouse/student/parent)	4.66 (0.53)			Accepted in round 1
	The achievement of tasks set by the individual with ULA		4.50 (0.84)		Accepted in round 2
	The achievement of tasks set by the RP		3.78 (0.73)	3.76 (0.59)	Rejected in round 3
Demographic factors	Age at amputation	3.90 (0.93)	3.85 (0.77)		Rejected in round 2
	Gender	3.34 (0.99)	3.45 (0.75)		Rejected in round 2
	Level of education	3.16 (0.83)	3.24 (0.66)		Rejected in round 2
Physical factors	Cause of limb absence (congenital or acquired)	4.01 (0.83)			Accepted in round 1
	General physical health	4.14 (0.71)			Accepted in round 1
	Level of amputation	4.44 (0.67)			Accepted in round 1
	Absence of dominant or non-dominant arm	4.26 (0.71)			Accepted in round 1
	Phantom limb pain	4.41 (0.68)			Accepted in round 1
	Phantom limb sensation	4.03 (0.80)			Accepted in round 1
	Presence/absence of certain joints	4.40 (0.60)			Accepted in round 1
	Residual limb pain	4.38 (0.64)			Accepted in round 1
	State of residual limb	4.53 (0.53)			Accepted in round 1
	Type of limb absence (bilateral or unilateral)	4.52 (0.70)			Accepted in round 1
	Time since amputation	4.15 (0.72)			Accepted in round 1
	Cause of acquired limb absence (trauma versus malignancy/disease)		3.90 (0.79)	3.89 (0.70)	Rejected in round 3
	Prosthesis use	Purpose of prosthesis use	4.47 (0.69)		
Frequency of prosthesis use		3.99 (0.86)	3.93 (0.90)		Rejected in round 2
Psychological factors	Anxiety	4.51 (0.57)			Accepted in round 1
	Coping strategies	4.64 (0.51)			Accepted in round 1
	Depression	4.59 (0.55)			Accepted in round 1
	Patient's attitude	4.66 (0.58)			Accepted in round 1
	Patient's expectations	4.77 (0.49)			Accepted in round 1
	Patient's mood	4.29 (0.66)			Accepted in round 1
	Patient's motivation	4.74 (0.47)			Accepted in round 1
	Patient's sense of humour	4.03 (0.82)			Accepted in round 1
	Pre-amputation life experiences and skills (e.g. experience of disability or limb absence in the family)	4.03 (0.87)			Accepted in round 1
	Post-traumatic stress disorder	4.48 (0.58)			Accepted in round 1
	Patient's feeling of control over the rehabilitation		4.38 (0.83)		Accepted in round 2
	Patient's resilience		4.31 (0.82)		Accepted in round 2
	The social skills of the individual with limb absence		4.03 (0.75)		Accepted in round 2
	The extent to which people compare themselves to other people who are better or worse off	3.73 (0.84)	3.41 (0.75)		Rejected in round 2
	Rehabilitation service factors	Access to services (e.g. making appointments/physical access)	4.44 (0.58)		
Satisfaction with the prosthesis		4.66 (0.53)			Accepted in round 1
Satisfaction with the rehabilitation service		4.66 (0.48)			Accepted in round 1
Cost of prosthesis			3.83 (1.01)	3.91 (0.66)	Rejected in round 3
Whether individual is entitled to compensation			3.43 (0.84)	3.11 (0.78)	Rejected in round 3
Self-image	Body image	4.41 (0.57)			Accepted in round 1
	Public self-consciousness (feeling self-conscious around other people)	4.36 (0.61)			Accepted in round 1
Social factors	Meeting another individual with limb absence	4.26 (0.75)			Accepted in round 1
	Practical support from family/friends	4.37 (0.61)			Accepted in round 1
	Reaction of family to the prosthesis	4.37 (0.70)			Accepted in round 1
	Emotional support from family/friends	4.52 (0.63)			Accepted in round 1
	Reactions from public	3.88 (0.71)	3.74 (0.61)		Rejected in round 2

insight into what defines successful prosthesis use, self-image and activities and participation, and provided evidence that the current definition of prosthesis use in the literature does not sufficiently capture what RPs and individuals with ULA consider important, such as specific use of the prosthesis, as often as an individual wishes, while using it as intended. Additionally, this study provided RPs and individuals with ULA an opportunity to communicate their opinions and knowledge anonymously regarding the important areas to consider in rehabilitation. Consumer feedback is vital to the successful development of products and services that address user wants and needs [41]. Feedback is particularly valuable in tracking user's satisfaction of new technology in upper limb prosthetics [41]. Additionally, health policy and program development needs to be based on solid research through a variety of both qualitative and quantitative methods [42]. This study provides a foundation for future outcome measures as patient specific measures that allow patients to state their individual concerns, and weight their relative importance [43]. Wright [43] argues that because we are often trying to address with treatment the concerns of individual patients, patient specific outcomes would provide us with a standardized method useful in research and clinical practice of asking patients whether they are better [42]. Our contribution of important patient specific outcomes, in conjunction with agreement from RPs is a suitable foundation for any future production of a patient specific outcome measure.

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### Declaration of interest

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